Healthcare Information Management and Systems: ….with less fears and tears!

Dr Roderick Neame[?]

Background

The past few decades have seen extensive changes in politics and healthcare. For much of the world healthcare is a service centrally managed by government, and therefore intimately associated with politics. The worldwide communications revolution has made the community more aware of the art of the possible in healthcare and less tolerant of illness, resulting in rapidly rising demands for and expectations of healthcare services.

For the most part the healthcare system has not re-invented itself, unlike many other sectors: it has in many places remained managed with sophistication little greater than that of a backyard business, with all the inefficiency and ineffectiveness that this often entails. Increased service demands, coupled with outmoded and inept management have led to costs escalating faster than the public purse can readily afford.

It is self-evident that information management and systems must come to play a major part in the future management and delivery of healthcare services: there is extensive talk of electronic patient records and paperless hospitals. However there is also an extensive catalogue of expensive IT failures in healthcare. These notes aim to highlight some of the issues, and some approaches to their resolution.

Change Drivers

The basic principles of the healthcare system are to maximise the health status of a population, at the same time to minimise unnecessary morbidity and premature mortality, all within an envelope of achieving the best value for money.

The main forces driving the ongoing revolution in the healthcare system to achieve these principles are predominantly aimed at achieving:

1. resource allocation to services/providers on the basis of patient throughput
2. efficient service production being recognised and rewarded
3. effectiveness in managing (down) costs of care being rewarded
4. better quality of care and outcomes
5. enhanced accountability, and detection and elimination of fraud
6. reduced demand for services, especially those that are expensive and risky
7. empowerment of patients in terms of access, choice, preferences and control

[?] **Dr Roderick Neame**, MA,PhD,MB,BChir is Managing Director and Chief Executive Officer of **Health Information Consulting** Ltd, Homestall House, Homestall Lane, Faversham, Kent ME13 8UT, England Fax: +44 (0)870 7627176 Email:roddyneame@hic-ltd.com

8. sufficient information being gathered to support the above, as well as:
   analyses of incidences, trends, best quality practices, cost-effective protocols
   forward planning of healthcare investments
   economic modelling and forecasting of fiscal performance
   setting healthcare policies and priorities thereby determining resource allocation

From the point of view of both management and clinical practice, these goals are self-evidently and eminently sensible. However in many environments these principles threaten the entire structure and establishment of the existing healthcare system, and therefore may be quite unwelcome.

These operational goals of the healthcare sector can only be achieved by gathering appropriate information: without information there is no way of determining whether progress is being made, nor to compare performance between institutions and with external benchmarks of performance. Therefore appropriate development of information management and systems must appear at the forefront of planning for these outcomes.

Information Management in Healthcare – what and why?

Understanding why we need health information management systems is the first step in gaining a more informed perspective on these systems. Let us consider what is or should be recorded in relation to healthcare events and encounters, and why. This then defines to a significant extent the data flows that are required to support the healthcare system.

Health Records

Recording information about care events serves a number of important purposes:

1. Patient Care: serving the immediate and future care of the patient – supporting the ongoing process of care, especially where that care is shared between a team drawn from community, primary, secondary and tertiary care services, often together with social services, and increasingly often crossing the boundaries between enterprises; future care of the patient – future events are very frequently more quickly and accurately diagnosed by reference to past care events, and future care is planned better in the full knowledge of past history;
2. Management and administration: running the business – supporting the goals of improving productivity, efficiency and effectiveness, and improving value for money (and profitability, where that is permissible); ensuring that claims for payment can be supported by records; ensuring that insurance payments due are paid; monitoring workloads, throughputs; assuring quality; meeting legal and mandatory requirements for numerous purposes, including for government and international organisations (eg WHO), containment of serious infectious diseases (public health)
3. Developing new knowledge: undertaking analysis and research into procedures, new technologies, practices, therapies, protocols of care; gathering evidence for dissemination to providers and patients; predicting trends and using these data to plan ahead, identify priorities for investment and resource allocation etc

All of these are reasons why the capture of key elements of care encounters can be of vital importance.

Health Communications

In terms of communications, there are three distinct generic flows of information in the healthcare system, relating to pretty much the same domains - (i) clinical care, (ii) administration and management, (iii) education and decision support.

(i) Information and Clinical Care

Contemporary patient care increasingly involves flexible use of facilities, plant and personnel. This flexibility involves better integration of provider teams, with better access to shared information to achieve care continuity, cost-effectiveness and quality outcomes. More information must be moved more quickly between care providers to support this process – hence the vital importance of communications and telemedicine. In the wider perspective, more information from these myriad of care encounters must be collected and analysed to support the accumulation of evidence and the formulation of best quality practices and cost-effective care protocols.

(ii) Administration and Management

The same flexibility discussed above requires better integration of care programs and services across enterprises. Proper management requires gathering of data to support the drive towards effectiveness and efficiency as well as to claim for services provided and to allocate human and other resources to achieve the best overall performance. Statutory requirements often impose a burden of reporting by care organisations to central government. There may additionally be a requirement to manage collection of funds from the community in the form of an insurance premium of some sort, and/or differing entitlements to benefits based on the level of these contributions. The trend is towards increasing requirements for more detailed and timely information often in coded formats.

(iii) Education and Decision Support

Dissemination of accurate, up-to-date and relevant information to patients, providers and administrators is vital to improve overall performance of the system. It can contribute to prevention and patient's accepting responsibility for their own healthcare; fostering appropriate utilisation of available resources, facilities and services; monitoring services efficiency and quality, and overall care effectiveness. Ultimately it is through these measures that it becomes possible to improve quality and cost-effectiveness, to enhance community health status and to contain demand for services.

What is the Problem?

Earlier in this paper I mentioned the 'catalogue of expensive failures': unfortunately this list continues to grow. We carry significant 'baggage', a history of technology solutions in the health sector that have failed to function correctly or to deliver the expected benefits, or which have run hopelessly over budget. Perhaps the most important perspective on this is that rarely do the purchasers of a system know exactly what they want. It may be possible with a lot of hard work to specify the functions that it must deliver, and to guess at the transaction volumes it must handle: but even if this is done, it is almost impossible to specify such critical aspects as the man-machine interface, the 'look and feel' of the system, factors which are vitally important in determining whether or not it will be used.

Most systems are designed and developed by technologists who have little understanding of the unique needs of the healthcare system, the realities of the workplace, nor of what it is that these systems must be designed to achieve. But few healthcare professionals have shown themselves willing to become involved with the process of information management and computerisation. One can argue that in broad terms the healthcare system deserves what it has got. The healthcare and information management cultures are far apart, understand each other little, have difficulty appreciating the strengths and limitations of what the other does and do not share a common understanding or language. Bad experiences in the past have increased the tendency of health professionals and managers to distance themselves from new computerisation projects.

From the technology perspective everything required to address the problems and meet the needs of the healthcare system exists. At the semantic level we continue to be confounded by issues of medical terminology, classification, coding and data sets. At the functional level the risks (eg of failures of integrity, availability, confidentiality) seem often to receive inadequate attention. At the operational level, many systems are neither intuitive nor easy to use. And at the personnel level we continue to struggle with the complex of issues surrounding adoption of new technology and processes.

Then there is the cost. To put costs in perspective, it is worth noting that the UK Audit Commission in 1995 estimated the overall cost of (paper-based) information management in district general hospitals at in the region of 20-25% of recurrent budget. Replacing this functionality across an entire healthcare system is inevitably going to involve significant capital outlay. However getting it wrong constitutes an expensive and disastrous mistake.

Finally we come to the issue of 'experts'. True experts in this field are few and far between. Most are technocrats whose experience, such as it is, comes from automation in unrelated fields – for example industrial automation or financial management. Healthcare IS different: it is information intensive, relying on assembly and manipulation of an enormous breadth of information (the medical dictionary runs to perhaps as many as 500,000 terms and concepts). It has different imperatives, where 'minor' system errors or failures in business terms may result in human tragedy in the health sector, and will certainly lead to a political backlash.

So – how do we get it right?

There is no magical formula – rather a number of pointers which alone may not guarantee success, but certainly seem to contribute towards it.

Identifying the problem

The intense focus on the specific issues that are confronted by the client organisation – often government – may be such as to preclude consideration of the legitimate needs of other inter-related stakeholders in the health sector, notably other public institutions, the patients and the health professionals. There is a need to look to the 'big picture' or else the solution risks becoming an island marooned in a flow of information that all passes it by. There is a need to identify and deliver benefits for all stakeholders; or else the solution is unlikely to be accepted since the investment

required to 'learn' the system outweighs the potential benefits to be gained from using it.

Specifying a Solution

Essentially there two ways of specifying a solution: by describe the required functionality and performance required, including capacity to communicate with other systems; or by defining in detail the technology, hardware, software, databases etc to be used. The latter produces a document typically 50-100 pages long: the former a document perhaps one tenth of that. The latter restricts the supplier to specific technology (which may be out of date even when specified, let alone when delivered): the former allows the supplier to be creative in using leading edge technologies and re-using previously developed modules and code. Further, some aspects of a solution defy ready specification – for example the look and feel of an application, the screen layout, graphical design, intuitiveness etc.

Given the timeframes likely to pertain to an official procurement, the former approach (functional specification) is likely to be the most appropriate to the needs (but see also 'relating to the supplier' and 'managing the development' below).

Factoring in Security and Confidentiality

Experience shows that the fast rising tide of community concern about security, and especially about personal information privacy, is a major force that cannot safely be ignored. Extensive computerisation, widespread networking, dedicated 'hackers' and improved hacking tools, coupled with many well-publicised security breaches have created a fraught environment. Security cannot be tacked on as an after-thought to a development: it must be designed in as a fundamental requirement of any system. However widespread mis-understanding of what constitutes security, and particularly confidentiality, has contributed to the particularly poor addressing of this issue. International privacy principles have been widely accepted for almost two decades, and stringent legislation based on these has been sweeping across the world in the wake of one breach after another. The trend will not stop, and adoption of the highest ethical principles in this respect will always pay dividends.

Relating to the Supplier

Just as there are two ways of specifying a solution (above) there are two ways of dealing with a supplier: one essentially creates a potentially adversarial arrangement; the other endeavours to foster a creative business partnership (normally based around a functional specification). The former tends to minimise communications, fosters the hiding of potential problems, and usually includes no progress checks. When the solution is delivered it may or may not meet the needs as they were specified, but typically no longer meets the needs of the user community, whose expectations may have moved on in the time since the solutions was specified. The next phase is a wrangle over accountability for the shortcomings, or over the costs of changes to try to deliver a product that does meet the needs. The latter arrangement of a business partnership tends to foster an environment of open collaboration between supplier and purchaser, and encourages the use of rapid application prototyping (RAP) – an iterative approach to finding a solution that is acceptable in look and feel, as well as in functionality to the user community. Problems are brought out rather than hidden away, and progress is continually monitored.

Off-the-shelf, bespoke, or modified software

There is an apparently irresistible temptation to re-invent the wheel in developing solutions for healthcare needs. Many solutions exist, and work: there is much less risk in adopting one of these, and adapting it where necessary, than in developing an entirely new solution (which may differ little from what others have done before).

Development Process

Most solutions will involve a bespoke component, tailoring a generic solution to fit a specific niche requirement. The benefits of using a RAP approach to solution development and implementation have already been mentioned above. The discipline of using RAP throws up numerous limitations and opportunities as the development proceeds, and therefore typically results in a process of incremental change, even before the solution has been delivered. To the auditor or accountant this is often difficult to accept as a process: to the realist this interaction and resultant 'slide' in specifications is not only healthy and productive, but also vital to the success of the project. It does, however, bring in the need for an approach to management and control of change to be incorporated in the contractual arrangements. RAP has an added advantage in terms of expectation management. The expectations of the user community tend to escalate over time, so that what is finally delivered after a long interval falls far short of what was expected: at the same time the developers expectations often truncate over time, minimising the functionality they incorporate in the solution. The RAP process continually brings back those expectations on both sides to an agreed set of functions.

Systems Integration

Once again there are two ways to tackle the issue of creating 'integrated' systems. One approach is technical, and involves building specific interfaces to enable one application to interoperate with another (hard-integration). The other is to design the integration at the information (as opposed to the technical) level, passing messages between systems as best fit the needs, and can be developed consistent with the evolution of a clinical intranet environment. The former is doomed to failure in a short period of time, if, indeed, it can be made to work at all: however it is often the preferred option for the technologist, who in all likelihood will be unable to understand the information itself. Every time any element of either of the hard-integrated applications is changed (for example a simple upgrade, or changed coding table), the interfaces must be rebuilt. Hard-integration involves the development of approximately the square of the number of systems to be linked, so as number of linked systems rise, so the approach becomes untenable.

Systems integration brings into focus two other key issues – standards and, as a sub-set of that, data coding.

Standards

Standards have been defined for many aspects of information systems, both technical and semantic. At the technical level, standards exist that enable hardware to be linked together into effective networks: these are now widely accepted. Semantic standard, such as for terminology and coding are less widely accepted, but no less important. Functional integration of information can only take place where there is general agreement on what terms mean ('data dictionary'), which data elements are required for specific purposes (data sets) and on how they should be represented (classification

and coding). Coding in healthcare is of central importance – especially given the large number of unique entities that must be represented (say 500,000). Many healthcare coding systems exist, each developed for one specific purpose: few can be used successfully for more than that one purpose. This is another area where there seems to be an irresistible human urge to develop a new one: developing coding systems is complex, costly and not for amateurs: using such a home-made system means that the data you capture cannot normally be compared or exchanged with anyone else, unless they also adopt your coding system.

Project Control and Management

In most instances a project of this type will be out-sourced to a private company. This is a high risk process, even if the proposals above relating to project specification and so on have been adopted. It is a common experience that contracting out IT work often ends up in dispute or litigation. The reasons are essentially that the contractor is too often left largely unsupervised. Where a practical or strategic decision has to be made, the contractor may refer it to the client: however in the absence of a clear steer from the client, the contractors make the decision themselves in order to press ahead with the work. This approach runs the risk that the project runs entirely off the rails, and, at the end, delivers nothing useful although in audit terms everything has been done 'by the rule book'.

The client must always ensure that they have sufficient knowledge and understanding of the project aims and the technology and solution being developed and implemented to be able to give clear instructions to the contractors, and to review in detail what they are doing. This expertise may be in-house or through a consultancy arrangement. In the absence of this oversight, it should not come as a surprise when what is ultimately delivered fits neither the needs nor the environment that are required of the solution. The development process (following) proposed is designed to mesh in with just such a 'hands-on' approach to project control.

Managing the end-users

Reviews have shown that the same applications implemented in very similar environments may be quite different in terms of their success. A key determinant is the attitude of the users to the system, and their response to the process whereby it was introduced. Nothing is easier than for a health professional effectively to sabotage a software application: to make it work well often takes determination and creativity. Project management must ensure that a positive 'can do' attitude exists or is fostered amongst the staff: they can often be persuaded to 'buy-into' the solution by colleagues who act as 'champions' of the system. The key to achieving this acceptance is the strategic management of the process. Wide discussion of goals and benefits, the sharing of a common vision of the 'big picture' of where the development is going, 'open door' and active listening policies, and early involvement in specifying and selecting the preferred solution are all vital elements of the people management process. The use of RAP can be an important contributor to the success of the development.

Evolution

One thing is certain about every information system: that there will be a need for it to undergo change during its lifetime. It is essential, therefore, that the architectural design is sufficiently flexible for example to permit embedded coding systems to be

replaced, upgraded or extended, or for data sets and flows to be changed as circumstances require, or for a connection to be established with another system. Not only must the system support such change, but also changes must be manageable in a timely, cost-effective and preferably vendor-independent way.

Conclusion

The process of developing a computerised information management system to support the needs of an organisation or sector is admittedly difficult. Critical is the need for recognising the 'big picture' and projecting the entirety of the environment into which this piece must fit, rather than undertaking a development as if it were an 'island'. Aspects of an intended solution will be in places vague or ambiguous and in some respects lacking – the specification inevitably will be incomplete, even where it is described solely in terms of functionality (not technology). The client needs are continually evolving both by the nature of the environment, but also because the process of specifying a system is educational in itself and brings with it new insights into process and possibilities. The technology is advancing rapidly, rendering specifications out of date often even before agreement to commence work has been reached.

A scenario as uncertain as this does not lend itself readily to 'externalisation' – contracting it to an outside group runs the real risk of loss of control, and of having a solution delivered that comes in many respects as a surprise, may be all but useless and is often already obsolete in terms of technology. There must be a mechanism for ensuring on-going client involvement with the development of the solution: the client must have access to considerable subject area expertise, intimate knowledge of the evolving solution and a mechanism for exerting influence over it. This is likely to work best where there is a business partnership between client and solution provider, and a commitment to iterative development based on rapid prototyping.

Communications, not long ago little more than a nice-to-have add-on are now arguably the core of all modern systems developments. Integration with other systems is vital for achieving functionality and for future enhancement. Understanding this in terms of integration of information, rather than technical integration through building interfaces, is absolutely critical. This requires consideration of representations, classification and coding schemes, agreement of dictionaries, data sets and formats, and of the requirements for different types of messages.

And a final word about risk management and security. Once again the world is in a state of rapid change. Security, and especially personal information privacy, was not long ago a feature that was nice-to-have but too hard to think out and deliver: if considered at all it was at best tacked on hastily at the end of a development, having little integrity or power to protect. Now failure to address this issue up-front is the single show-stopper that can lead to outright rejection of a system by both patients and health professionals, as well as risking that the solution becomes prematurely obsolete due to failure to meet incipient and evolving legislation.

