An anarchistic view of sharing information

Dr John Bryden
Independent public health and health information consultant.

More information can be obtained from http://www.ibmpcug.co.uk/~healthit

John can be contacted at: jsbry@healthinfo.win-uk.net

If a near to retirement doctor is asked to be a last minute stand-in at a nursing conference then it’s a wonderful opportunity to try to be an anarchist.

A potted CV has to show why I am taking this stance:

- summer vacations as a nursing orderly - would that all future doctors were so brought up;
- orthopaedics with Accident and Emergency work;
- three years as a family doctor in Govan - Rab C Nesbit country;
- since then 25 years in public health and medical management.

The UK NHS goes through cycles. We now have NHS Trusts. In 1971 in England and Wales you had local Hospital Management Committees, in Scotland we had Boards of Management. Although the organisational structure is different twixt such Trusts and pre 1974 managements, the institutions covered are very similar. I joined one of these in 1971, in Paisley, where its Royal Alexandra Infirmary serviced a population of a quarter of a million. We supported the clinical care of these patients with a management team of four:- one administrator, one finance officer, a chief nurse and myself as the medical superintendent. Compare and contrast that with today's management staffing.

Information for management

From 1974 as the senior doctor for one of the Scottish Health Boards, I was fortunate to help shape within its health information consortium many information ideas such as the first Scottish hospital Patient Administration System and the first Community Health Index of our Board's population - even from the late seventies we were able to download information to the then embryonic GP systems.

I do believe in a National Health Service with good supportive management. I do not believe in its being over-managed. I do believe in health information systems.
The Nursing Specialist Group, allied with its fellow specialist groups in the British Computer Society Health Information Specialist Groups (HISG) sponsored the Medical Informatics Europe congress in Glasgow in 1990. Its theme was 'Health-Added Value from Information'. I think that this concept is very important for your debate. I believe we should only use information systems when they add value to health.

Take for example a Community Health Index - very good for paying GPs. But is it of any real value unless we use it for other targets such as cervical screening? Or baby and other immunisation (although one does wonder how effective that has been when one hears the saga of how difficult it was to identify the children already immunised in the national campaign that was current at the time of the conference); or in finding hidden diabetics; or getting into say the ethically controversial topic of looking for those missed out from family planning schemes. I think that if you have a Community Health Index you should use it to Add Health Value into some of these issues.

**Adding value to patient care**

Do we get health added value from the Patient Administration System (PAS)? Is it just to help the medical records officers? I think we do add such value:

- we find notes more quickly, you hear apocryphal stories of how long it takes to get notes;
- finding available beds - at the moment, highly significant.

Or is it the very simple extra, subject to confidentiality, of supporting the telephonists? They have the unenviable 'oh of tracing the whereabouts of patients. Relatives are very understandably upset if the telephonist does not know the whereabouts of their nearest and dearest. These are some very simple examples of Health Added Value arising from the seemingly mundane PAS.

I am not completely convinced that our information systems need to be led by finance, contract or resource allocation goals. In Scotland, at the time of giving this paper, we had an interesting situation of an American hospital, part-funded by Enterprise Zone funding (that comes from taxes), apparently aiming at wealthy clientele from around Southern Europe and the Middle-East. I was fortunate in having a look at their information systems. Their principal information system is entirely about care of patients. As most of the patients come in on fixed price contracts they have no need for a direct relationship between patient care information and billing. This seems to be one lesson from America which is worth watching.

I think there is value in the central abstraction of high quality data from the clinical scene, to be used, subject to confidentiality control, centrally for either management or, equally important, for the epidemiology for the provision of health services. Case-mix is an important subject. I am interested in aspects other than medical and diagnosis casemix. There is also the question of case-mix and equity. How do you find out some interesting figures for routine prostatectomy in the south side of Glasgow. The prostatectomy rate per head of the population, age standardised, is three times that in Eastwood as it is in Pollock, two miles away. The social class in Eastwood is 'above one'. The social class in Pollock is 'below five'. Now the data for such an enquiry comes from the Scottish Hospitals' Morbidity recording - an exercise
that has been going on from the mid sixties. It comes from soft medical data coded by hard-working and long-suffering clerical staff. At times it is very much despised by the limited number of clinicians who have put much time and effort into detailed clinical coding. Nevertheless in this particular example there is little chance of error - prostatectomy is something you cannot miss on a case sheet. This central use of aggregated data starts staff asking why are the folk in Eastwood having so many more prostatectomies than Pollock? There is no evidence that they need it more than in Pollock. You can do the same thing with hip replacements and so on.

**A new model**

I have been trying to find an analogy for where I think the power should come from in health information. I started thinking of car ferries and their thrust from propellers. But ferries are not very safe for an analogy. I then thought of the space shuttle, hurled into orbit. Once it is propelled into orbit, leaving the big engines behind, eventually it begins its return back to earth powered by a multiplicity of small jet engines, all pointing in different directions. Each produces very powerful movement. If it is coordinated it moves the spacecraft towards chosen goals. The proposed system is illustrated below.
I am now convinced that that is how the power of health information systems should really arise. We have already got it in the community. We have a multiplicity of GP systems. They may only be collecting prescribing information but they offer latent collective power. That is the way I hope we might be moving in hospital systems.

Preparing for sharing

In Hong Kong I was asked to give a paper on 25 years of health information in Scotland - what was the message? I am afraid it was not a very happy text. It was in brief - put not your trust in governments, or in software manufacturers. That was three years ago and I have not changed my mind.

Ray Rogers, in his paper, has given a three year timetable for the detailed work on his clinical system project. Even at that it will be a very tight time scale. Anne Casey has explained the size of Read Version 3. John Kirby highlighted the problems in the
relationships between the realities of clinical care and the clinical recording. Between
the live patient, or for that matter the dead patient, and the codified data there needs to
be slick, robust, time-saving software that helps the clinician, be it nurse or doctor, to
quickly capture the clinical care. No matter how much education there is, we will still
have a constantly changing staff: doctors changing every three months on rotating
contracts, who must also be helped to capture information. So it needs to be simple.

As I mentioned earlier, I was working with cardiac surgeons. We felt that with the
clinicians we had well specified for this huge EEC/GAT procurement. Yet, with one
of the best contractors around with a first rate underlying data-base, we found it very
difficult to mimic the clinical process and yet at the same time give us all the things
the clinician needs. We need in real time, even while the consultant is in outpatients,
to calculate the risk of death from cardiac surgery. Patients are not necessarily keen
to know about such a hard fact. Almost always this is sought by the nearest and
dearest who accompanies them. To he able to get such a risk statistic in real time
while the surgeon is there, and not take 25 minutes to capture the data when there are
only 5 to 10 minutes for the consultation, is not easy. That is only one example from
a major, but numerically very small field. Remember that a cardiac surgeon working
flat out only does about six operations a week. Think of Ear Nose and Throat work
and its huge numbers, or of ophthalmology.

Ray Rogers’ goal is attractive. It is a must if you accept my philosophy of the clinical
information being the engines. From my recent experience I feel, for the UK, we will
be very lucky if we manage by the turn of the century to have a generic approach. I
wonder if it will ever be generic. I think it will probably be some standard, hopefully
of the highest common factor.

Since 1980 I have been suggesting we have some sort of broad band or high quality
information pathway. This now can be a reality. Initially I put the PAS in the middle
as the driving force of the system. It is not that I now diminish its importance the
identification of the patients and the topics in quality control, in Maureen Goodman's
paper, are important. It is just that I now see the strength coming from a series of
different, well tailored, clinical information engines. These give my jet propulsion to
the spaceship. I have tried to show these in the very complex drawing with this paper
in the green cross-hatched balloons. But a lot of computer systems, with not much
tagged on, would not be of use. So we need to add on the sources of the information:
nursing stations to acquire information; ward clerks; secretaries, consultants, house
officers, theatres and so on. You can then add in the GP telecommunications. Then
you can tap for management and epidemiology information.

We have turned some of this into practice in the cardiac surgery project. It is called
MACSS (Medical Audit in Cardiac Surgery in Scotland). The software engine on the
top, data-base in the middle and an output engine, plugged into the information
corridor, with links to the engine for pc stations (nurses, ward or consultant), one in
the outpatient room, the secretaries are on word processing and PAS, several printers,
the PAS itself and pre-operative rehabilitation. This small team of three: a dietician, a
nurse and a physiotherapist help patients to lose weight and prepare for surgery. In
the cardiac ITU in Edinburgh it was hoped to have a nursing module that will slickly
pick up changes in what would have been written information - not information
coming off the monitors.
Anne Casey, in her paper, talked of sub-sets of Read Terms. For example, if the nursing team were working with the cardiac surgery team they would have access to the cardiac surgery software, or if it was a colposcopy group the nurse would be looking at the colposcopy subset.

It is not that I would abandon central systems. It is the top-down philosophy. This should be abandoned. We need to turn inside-out our approach: to focus and build up from well designed clinical information systems.

**Discussion**

**Denise Barnett** Editor ITIN.

I was very interested in your suggestion of the multiple engines all pushing in different directions and being co-ordinated. Where do you see that co-ordination coming from if we are taking a really patient-centred view?

**Dr Bryden**

In a hospital system I think it should come from the hospital directorates: by some agreed rules that bring them together. Most hospitals have a high quality information officer, and his or her strength should be in co-ordination. How do you obtain coordination in which systems you will buy. I have been through a huge EC procurement; we spent months visiting sites all around the UK. There really does not seem to me to be a wide-enough choice. You cannot say here are five systems, and this one has the best discount and so on. As a result at this point in time you certainly will have a multiplicity of engines. They may not couple up at all.

Although I am talking of anarchy: of a lot of different systems; there has to be some philosophy that pulls them all together. In Greater Glasgow, we had a philosophy that did not come from any health professionals. It was that we should have a standard clinical information systems. So we went out and bought one, with no consultation with any of the health professionals. We had done the same thing with word processing. The word processing had been very successful, you can train everyone to use it. It was good value for money. But that same approach to a clinical information system failed, it had its own version of Read and ICD9. If you keyed into that system the word 'Pagets' it would find Paget's disease of the nipple but not Paget's disease of bone. The firm had done their own sub-set of ICD9!

I think it will be nearer to the turn of the century for the solution.

**Anne Casey** Great Ormond Street and the Centre for Coding and Classification.

I think we have missed the boat! We have in our hospital hundreds of clinical information systems. Every department has their own system, one they have developed to meet their needs, whether it is for audit, tracking patients, for research or a combination of those. The systems are being used by clinical staff. In the meantime we have messed about thinking shall we have a HIS, shall we have a central engine, we have a PAS that does not connect to anything. These people have gone out and done it.
What are we going to do now? They have all their data, what they want in their little, narrow area. Nobody is sharing anything. I think this occurs throughout the country. How do we develop this engine in the middle that pulls all this stuff together? They have gone further ahead than we have.

**Dr Bryden**

I think the first thing, and that is what your paper related, was to have a common coding base underneath it. It has to be Read, with all its complexities and its size.

The firm we are working with for the cardiac surgery has used Read codes. In fact Jame's Read's work was originally based on this firm's software, so this firm when they go to a new site, do a lot of pseudo-Read coding and then follow it up with a mapping exercise. I think that is how you bring these things together. There has to be commonality of the coding and a commonality of definitions. Then you interface them to the information corridor. You may have to pay quite a bit of money for the interfacing engine. But that is the way to bring them in, then you get the benefits: the secretaries no longer have to type in stuff to the PAS and then in to the clinical information systems. It becomes just one amount of typing.

By bringing all the directorates together you do not waste all the work that has already been done. Some of these systems are very, very good. A lot of thought has gone into clinical systems