



**AN ORIGINAL ARTICLE BY PROFESSOR DENIS PROTTI**

**A rare treat! We have an original article by Prof Denis Protti, Professor, Health Information Science at University of Victoria, British Columbia, Canada, written especially for this Record Access Collaborative edition.**

Professor Protti has vast international experience of systems, attitudes and approaches to the electronic health record. He recently came to the UK to both investigate approaches here and to lecture.

We would welcome comments and debate on the issues raised.

**The Health Information Bank: Revisiting Bill Dodd's Idea of 10 Years Ago**

Denis J. Protti  
Professor, Health Informatics  
University of Victoria, CANADA

**Introduction**

Ten years ago a Scottish GP, Dr. Bill Dodd's wrote a two page paper in the British Journal of Health Computing entitled "An independent 'Health Information Bank' could solve data security issues." It was a ground breaking piece of thinking and has since been picked up by others over the years. Though some of the terminology used then (e.g. Electronic Patient Record) has been dropped from the English vocabulary, the essence of the paper will still resonate with many readers.

Very recently, Gold and Ball argued that there is no unified, functioning system currently exists for the exchange of comprehensive health-care information across the wide spectrum of health-care networks in the United States. Regional health information organizations (RHIOs) and a national health information network (NHIN) have been proposed as vital building blocks in providing such a system, but these face many challenges, including delineation and implementation of accepted standards for health-care data, accurate patient identification and record matching, and the definition of incentives for accelerated deployment of health information technology. Their paper suggests an alternative option, the Health Record Banking (HRB) system. Emulating commercial banking, this approach uses health-record banks to serve the need for immediately accessible and secure data for diverse stakeholders. It provides a means for financial independence for these banks and a mechanism for fostering medical research.

This particular offering is an abridged version of a more detailed paper which Dr. Dodd wrote in 1999 at the request of the Scotland Department of Health. This shortened version of the 1999 Dodd paper is intended to stimulate discussion and debate on the merits of his idea. It should be noted that the Dodd idea was long before “the Spine” was conceived and created. Although Dodd’s Bank concept would offer far more services, some might see it as essentially the current Spine and hence subject to all the same concerns.

### **Background (written by Bill Dodd in 1999)**

Money is information and, in the developed world, this money information is usually managed in the networks and computer databases of banks. Even the coinage and notes have no intrinsic value but provide tokens to give some flexibility and convenience mainly for small-scale local transactions. With the globalisation of banking you can pay for a meal in Stockbridge or Shanghai or rent a boat in the Bahamas or get local currency wherever you are, using the same plastic token. You can check your bank account and carry out many banking transactions using home banking facilities wherever you can link a computer to a telephone line and you can get the current status of your account from tens of thousands of cash points scattered across the country. Electronic banking has made handling money easy and convenient for the customers and the vast majority of the population now have access to banking facilities.

On the other hand most information about a patient’s health is handled in the way that banking was practised a generation ago with locally held records and paper-based transfers and records of transactions. While a patient can legally demand to see his/her record or receive a copy, in practice this can be difficult and access to information in the record is usually through a health professional. Although personal health information is usually more complex than personal financial information the problems are similar. The need for availability, accuracy, privacy, confidentiality and security is essential for both. Electronic banking became possible when these problems had been solved. This paper suggests that the analogy of banking can provide a model for developing health information services in the modern world and that the “currency” of the bank would be the patient’s Electronic Health Record (EHR).

Over the past decade, interest has grown in developing a widely applicable electronic patient record and as a consequence concerns about patient privacy, confidentiality and security of health records have surfaced as important issues. Developments in data protection especially arising from the EC Directive but also from the UK Data Protection Office were perceived as placing serious constraints on the use of clinical data in health service management and in epidemiological research such as cancer registration. Much of the thinking on patient empowerment implied the use by the patient of information in the record judiciously and effectively but:

- For some years patients had been given the right of access to their health records (Data Protection Act 1984 and Access to Health Records Act 1991) but in practice access was so cumbersome and poorly explained that only a minority exercised the right. The Data Protection Act 1998 has replaced these two Acts and gives patients similar rights but the prospect of the majority of patients exercising these rights is no greater.
- Ownership of records was hotly disputed. Some said that the Secretary of State owned them, some the Health Authority, some the clinician in charge and some even suggested that the patient might own the record (or at least the content). We were often told about the value of health records but no one was given the mechanisms to maximise the benefit of this asset.
- Trials of the use of patient records held on smart cards were undertaken with varying success. While the patient usually had access to the information on the card, in most cases it became clear that the information was for the health professionals and the patients were passive vehicles to transport the record from one health professional to another.

- The life to death record was claimed to be an ideal that we should aim for but it raised some serious data protection issues, for example, retention of information beyond its relevance: is an uncomplicated abortion relevant ten or twenty years after the event; on the other hand, is childhood tuberculosis, managed before streptomycin, relevant after more than half a century?
- Patient based clinical information was increasingly needed by researchers and by commerce but this produced ethical issues that became increasingly difficult to unravel. This was highlighted at the start of the decade by the ethical problems produced by the provision of free computer systems to GPs in exchange for anonymised information about patient's health and disease.
- There were serious anxieties about the potential abuse of too easily available patient information in large databases and through linking databases. During the decade these anxieties were expressed in conflict between the Department of Health and the BMA about confidentiality and security of patient information which led to the establishment of the Caldicott Committee.

During this conflict, it became clear that many of these and other significant problems could be solved if the patient was given responsibility for their own information so that health professionals were not required to make decisions about disclosure of information by proxy for their patients. It was suggested that patients could take responsibility for their records if an institution was created where patients could have their health record deposited for safe keeping; where they could add to it when appropriate or when they wished; where they could get regular or ad hoc statements of the contents of their record; where they could control how the record is used and where the record contents could be used securely for mutual benefit. In other words the institution would be a health information bank.

### **The concept of the Bank**

The purpose of the bank would be to manage personal health information on behalf of a patient and provide other related services. The bank would hold an *extract* or *summary* of the patient's record securely and make it available when required according to the patient's needs and wishes. The record would also have pointers to where full information about a specific event or episode was held. Hospitals, practices and staff in the community would continue to produce the detailed records needed for them to manage the episodes of illness for which they are responsible. They would send the customary referral and discharge letters.

#### ***The core services***

The bank, and so the patient, would facilitate and control the sharing of the wider 'birth to death' longitudinal health record – it would be the Electronic Health Record (EHR) while the detailed records maintained by the health professionals would be the Electronic Patient Records (EPR).<sup>1</sup> For example the transfer of information between GP practices when patients change would be unnecessary since the patient could authorise the new practice to have access to the health information in the bank. Only limited past history would be needed in a referral letter. It is sometimes difficult for the doctor making the referral to decide what is relevant from the consultant's point of view and, with the bank; consultants would have access to a comprehensive summary of the patient's health information.

#### ***The added value services***

The main purpose of the bank would be to manage the health information for the patient. However, since the relationship between the bank and customer would be based on trust, other services could be offered which

---

<sup>1</sup> This appears at variance with the definition of EHR in the English Strategy *Information for Health* that places the EHR within the Primary Care Sector. This apparent inconsistency can be resolved by agreeing that the Bank would be part of the Primary Care Sector though not necessarily within the NHS.

could build on this trust for the patients' benefit and to support the work of the NHS. Key services associated with the health record and provided early in the development of the Bank might include:

- It could provide to patients personalised health education material and personalised information about their diagnoses and treatment in terms that they could understand. It could help patients make contact with relevant condition-specific patient support groups. It could also inform patients about reliable Web sites and email discussion groups relevant to their problems
- It could provide anonymised, aggregated information for research, education, audit, clinical governance, management and commerce with the explicit, informed consent of the patient via a Health Information Agency (see below).
- It could administer chronic disease registers such as cancer and diabetes and, collaborating with the clinical services, provide support to patients such as recall reminders and maintaining the regular review data. From this it could provide epidemiological services based on anonymised, aggregated information to the public health and research communities via the Health Information Agency (see below).
- It could support screening and other disease prevention programmes from the patient's point of view including reminders and results management. This would be in parallel with the operational systems to improve uptake and reduce the number lost to follow-up.
- It could provide the patient with factual information about the clinicians and institutions that might be involved in their care.

Other services that would benefit patients at present being developed by the NHS or other agencies but which could with benefit be transferred to the bank might include:

- It could administer the unique patient numbering system for the NHS and provide all patient-customers with a swipe card or 'smart card' with their name and unique number (but not other identifying information that could be used to verify identity centrally and would be difficult to maintain). As part of this activity, the bank could replace the NHS Number Strategic Tracing Service providing the information needed by the NHS while protecting the patients' legitimate interests.
- It could provide to its customers many of the functions of NHS Direct with the call centre staff having direct access to the summary patient record and other supporting information in the bank with the explicit consent of the patient. The contact and the advice would be entered automatically into the patient's record in the bank. Other administrative functions such as making appointments could be transferred to more appropriate NHS call centres.
- It could help in the case of disputes between patients and clinicians and, in particular, it could 'broker' between doctor and patient, a patient's request for a second opinion. The information held in the bank, possibly enhanced by direct patient input, could be used to support access to "virtual hospitals" or "virtual second-opinions" from distant centres via telemedicine mediated through the bank.
- It could also provide basic advice to patients on medicolegal issues

The bank would be available 24 hours a day to allow emergency access. Access to patient information would be through the unique number and PIN and/or other access controls. First Direct or other home banking operations where most access is by telephone provides a model. As an additional check, the health professional being given access to the information would also need to be identified as an appropriate recipient with their own access code and PIN.

The bank would also handle all requests for health information from third parties such as employers and insurance companies. The patient would know what information was being given and would be able to amend or correct misleading information or request the withholding of information which was irrelevant to the purpose. The bank would be responsible for ensuring "fairness" for the third party and the patient.

Two other supporting organisations would be needed to allow the bank to provide maximum benefit and to be trusted by its customers and sponsors.

### ***The Health Information Agency***

This would be a centre for promoting the use of health information and for improving health records. The Audit Commission report "Setting the Record Straight" recommended such a centre and the European AIM project PROREC is working to set up centres to promote health records in each of the EU countries. The agency would have two main functions.

- It would contain an Office of Health Information, similar to Oftel in telecommunications, which would supervise the bank's activities and specify and enforce appropriate ethical standards with regard to confidentiality and security.
- It would facilitate and supervise the ethical use of health information supplied by the bank for health management, research, education and audit.

The Agency would provide a statistical service to the NHS and to Government and would be the channel through which patient-based information would be provided to researchers. Almost all the information handled by and transferred through the Agency would be anonymised and aggregated and any raw data would be destroyed after use. In some circumstances, named data is essential for research. This would need the agreement of the Office of Health Information, the agreement of the Bank as the agent of the patient and the informed consent of the patient that would be sought by the Bank.

### ***The Health Information Corporation***

This Corporation would deal with the commercial exploitation of the anonymised and aggregated data from the bank. This would be used mainly for market research and pharmaceutical research. The key would be that none of the information handled by the Corporation would be personally identifiable, the information would be provided with the patient's informed consent and the Health Information Agency and particularly Office of Health Information would guarantee ethical usage. All the information handled by and transferred through the Corporation would have an agreed "shelf-life" and would be destroyed when this had expired.

This approach would be a major step to improving the quality of the healthcare and enabling patient empowerment. It would protect and advance the interests of the patient while enhancing patient care and enabling epidemiological and other research and legitimate commercial use of the information within the proper constraints of security and data protection.

### **The Bank in Practice**

While the concept of the Bank has been discussed for a number of years, political, organisational and technical barriers have prevented it from being a practical proposition. Recent changes have radically changed the situation. Politically, emphasis has moved from competition in the NHS to co-operation to achieve the aims of the New NHS. The English and Scottish Information Strategies identify a number of services which the Bank is well placed to provide. Organisationally, the restructuring of Trusts, the developments in General Practice especially the Local Health Care Co-operatives and the out of hours services, the introduction of NHS Direct, the implementation of the Information Strategy, the introduction of the National unique patient number, all pose problems and present opportunities to which the Bank is uniquely placed to respond. Technically, the developments in networks and particularly of the Internet over the last five years and the wide acceptance of an SGML/XML document paradigm in health records have, to a large extent, proved the technical concepts which were suggested in the early discussions about the Bank.

## ***Organisation***

This proposal represents a major industrial undertaking which would need substantial government and other funding and the support of leading commercial concerns. On the other hand, it has the potential for major improvements in quality of health care and large efficiency savings in other parts of the NHS. Managing health information is not related directly to the core business of the NHS which is to preserve health, prevent disease and cure or alleviate illness and NHS resources are likely to be over-stretched in implementing the other facets of the information strategies. If another body could undertake the management of the EHR and the related services efficiently and effectively, the prospect of having resources, particularly manpower, to implement the strategies would be greatly improved. It is suggested that the Bank could be such a body. If the NHS would have problems in setting up such an organisation, the problems of passing it to the private sector are probably greater with potential conflicts of shareholders interests and patients rights.

Many of the problems could be diminished if the Bank were a not-for-profit organisation set up to promote and protect the interest of its customers rather like a trustee savings bank. Since the Bank would deal with patient-based information, this information could relate to NHS and non-NHS transactions such as private health care or health problems outside the UK. The customer must feel that their information is safe and the organisation's first duty must be to protect their interests. The organisation would be governed by a Board of Trustees representing all the stakeholders – patients and patients organisation, the NHS executive, managers, clinicians, the private health sector, the Health Information Agency (particularly the Office of Health Information) and the Health Information Corporation.

The relationship between the patient and the bank would be prescribed in a form of agreement that would explain clearly how they (the patient) could use the bank's services and the rules of the bank governing security and confidentiality. It would explain how the information could be used including a section covering consent to the use of their information either as identifiable information in a few research situations when explicit consent would be sought or, normally, in an anonymised, aggregated form used for the purposes outlined above in the paragraphs on the Health Information Bank, the Health Information Agency and the Health Information Corporation and supervised by the Office of Health Information. The information would be patient-centred and would come from all services that provided care to the patient whether in the public or private sector.

The Health Information Agency would be a government body to supervise the bank, protect the interests of the NHS and to maximise the benefit arising from the information obtained from the bank. The Health Information Corporation would be a commercial organisation to market the health information bought ethically from the Bank. Reliable, comprehensive and timely information could have a substantial market valuable for planning and research in the pharmaceutical and other parts of the health care industry.

While the paper refers to "bank" in the singular, there is no reason why there should not be several banks competing for customers on the level of service provided. It would be highly desirable that a patient use only one bank at a time but change could be relatively easy and each bank should be compelled to transfer all the information about the patient on request. Competition would not necessarily be a bad thing since it would avoid a single monolithic database containing all the information about the whole population

## ***Electronic Health Record***

The English *Information for Health* Strategy draws a distinction between the Electronic Patient Record and the Electronic Health Record which are defined as:

“*Electronic Patient Record (EPR)* describes the record of the periodic care provided mainly by one institution. Typically this will relate to the healthcare provided to a patient by an acute hospital, for example, specialist units or mental health NHS Trusts.

The term *Electronic Health Record (EHR)* is used to describe the concept of a longitudinal record of patient’s health and healthcare – from cradle to grave. It combines both the information about patient contacts with primary healthcare as well as subsets of information associated with the outcomes of periodic care held in the EPRs.

The Strategy puts the view that EHR is basically the Primary Care Record while EPR is about the episodic care given typically by acute hospitals. NHS developments make this difficult to sustain. With the rise of big partnerships, out-of-hours services and NHS Direct, specialist nurses and nurse practitioners, Primary Care is losing much of the continuity which was a feature in the past. Special efforts would be needed to create the longitudinal multiprofessional record needed for the EHR. It is also difficult to envisage a nation-wide, 24 hours a day, 365 days a year service for every patient based on Primary Care as it is currently organised.

An alternative view is that EPR is for the health professionals to use to support their day-by-day practice and EHR is for the patient to have a record of significant health events over his/her lifetime. They have two distinct and different purposes and should be provided by organisations designed specifically to meet these purposes.

The information held in the Bank could be:

a) Patient Information

- i) Identifying information - name and unique number
- ii) Demographic information. This would be detailed and provided by the patient at the time of registering with the Bank and would be updated as required. It could be used for validation of identity and for record linkage by the bank if the unique number was lost or not available. Unidentifiable extracts could also be use for clinical, epidemiological and market research if approved by Office of Health Information.

The system managing the patient information component of the record could form the basis in the Bank for the administration of the NHS number and the NHS Number Strategic Tracing Service if they were delegated to it.

b) Clinical information

- i) Critical Information - allergies, blood group, certain critical diagnoses and medication which would influence any other treatment etc.
- ii) Problem (diagnosis) list of all SIGNIFICANT illnesses, including name, address and contact number of responsible clinicians and contact number of institution where the record is held.
- iii) Copies of standardised discharge/transfer letters linked where possible to problems in the problem list
- iv) List of current medication (from GP/Pharmacy link and from discharge letters) with an archive of past medications both being problem-oriented where possible.
- v) Significant health information e.g. immunisations, health hazards etc.
- vi) Other health-related information specifically requested by the patient.

Taken together, this would give a manageable and useful health summary. Most of the information could be collected and transferred electronically and automatically but until all health care services are adequately

computerised, paper collection and transfer should be possible. In the interests of security the identifying and clinical information would be held separately and linked possibly by the new NHS number or more probably by a code generated within the computer.

While it is expected that most health care organisations would co-operate, the Data Protection Act should ensure that the information is made available to the bank at the patient's request even if there is some initial reluctance on the part of the health care establishment. The information could come from either the patient or from the doctor (e.g. the GP) using a paper form or by direct transfer from the healthcare enterprise rather like the idea of a direct debit where a single authorisation covers a series of transactions that are processed automatically.

### ***Technology***

The technologies needed to underpin the activities of the bank are no longer experimental or exotic but are widely used in commerce and industry. Enormous volumes of information are now moving across both public and private networks and the storage capacity of computers is growing almost exponentially. At the start of the century, and for more than a generation after, motor cars were for the expert mechanic or the enthusiast. As the market matured the power of the car in transport passed to the people and knowledge of the internal combustion engine and transmission systems were no longer a prerequisite of car ownership. In the same way for more than a generation computing was presented as the domain of the industry experts and the nerds and the anoraks. The development of the PC, powerful computer games, the Digital Revolution and the sweeping success of Internet technology has shown that the power of the computer and communication technology is for everyone: the industry is now mature. The Bank can be an agent to put this power in the hands of the people to help them take increasing responsibility for their health. The underlying technology in the bank, academy and corporation would be SGML/XML based document management while the analytical functions could be provided by linked relational databases.

It is often suggested that smartcards carried by patients and containing their record summary would meet the needs for an EHR. Difficulties associated with smartcards as a vehicle for the EHR include problems of universal access, responsibility for updating and maintenance, summarising to prevent information overload. The bank would give a more flexible and comprehensive approach to the EHR and provide solutions to more general problems that beset patients when they seek health care.

The bank would enable information to be future-proofed in a way that would be difficult in any other system since the responsibility for the technology beyond the telephone access would be the responsibility of the bank.

### ***Security and Data Protection Legislation***

The bank would comply with all the relevant legislation and NHS standards and guidance on security and confidentiality. Compliance would be checked rigorously by the Office of Health Information.

Patient identifying information and clinical information should be held separately in the Bank and linkage even by bank staff would be strictly controlled. Linkage would only be made with the request or consent of the patient together with a request for linkage from an identified clinician both validated by PINs. In an emergency a mechanism to allow linkage without patient consent would be available but this would be subject to close scrutiny on a case by case basis by the Office of Health Information which would also be able to scrutinise all linkage transactions and to impose penalties for any infringement.

Three levels of security could be offered

- Regular
- Gold card
- Platinum card

These would differ in level of security offered or required and the types of service offered. The regular service would fully meet the needs of most people. The gold card service would be available for those with clinical conditions which merit special consideration or whose social status (e.g. politicians or pop stars) might make them wish to pay for greater levels of data security and confidentiality. The platinum card would be available for those whose social position made them believe that they needed extraordinary levels of confidentiality. These services would differ in cost so that charges would reflect the additional cost of providing the additional service.

The Health Information Agency could undertake the role of being a "trusted third party" for encryption in healthcare.

### ***Funding***

Funding would come from a number of sources:

- from the NHS for services that would otherwise be provided by the NHS. For example GP to GP transfer of information when a patient changes practice can be managed efficiently by the Bank
- from the Agency for information to be used for research, management, clinical governance, audit and education (at cost)
- from the Corporation for information to be used commercially
- from the private sector for information to be used for private healthcare, insurance and employment
- from the patient for exceptional services.

### ***The way forward***

The first step would be to commission a study to explore the practicality of the proposal, to prepare a plan for implementation and to draw up a business case quantifying the costs and benefits and to consider options. If the project looked feasible, the next step would be to set up a pilot in a region or in a specialty where patients are likely to benefit from the Bank, such as diabetes. If this is successful, it is likely that the best strategy would be to implement incrementally across the country. During these studies it will be important to recognise the links with other policies such as telemedicine and EPR and EHR development.

### **Conclusion**

In closing, is it possible that Bill Dodd's Bank could indeed possibly to a conventional financial bank?

As Ward reported, it was very recently announced that the Tennessee-based Medical Banking Project plans to unveil a computer-based platform that would allow banks to share medical record information and offer standards to manage that process. They intend to link the banking system into health care so the health care world doesn't have to invest in technology and processes that banks already have spent on heavily. Proponents of the project note that banks already have worked to ensure the security of data and that consumers typically trust banks.

Deborah Peel, a psychiatrist in Texas and chair of Patient Privacy Rights, said that her group supports legislation that soon will be introduced in Congress to create health data banks in which consumers could store copies of their medical records and control who accesses their records.

More food for thought?

**References (chronologically listed)**

Dodd B. An independent 'Health Information Bank' could solve data security issues. BJHC. Volume 14, Number 8. Oct 97

Ramasaroop P, Ball MJ. The "Bank of Health" – A Model for More Useful Patient Health Records. MD Computing. July/August 2000.

Bloor R. Personal data stores to protect key data. Computer Weekly. Sep 9, 2003.

Anonymous. Bills Authorize Health Data 'Banks'. Health Data Management. June 28, 2006.

Ball M and Golf J. Banking on Health: Personal Records and Information Exchange. Journal of Healthcare Information Management. Vol. 20, No. 2, 2006

Yasnoff W. Health Record Banking: A Practical Approach to the National Health Information Infrastructure. June 21, 2006. <http://williamyasnoff.com/?p=26>

Bazzoli F. Medical Banking Project to focus on personal health records. Healthcare IT News. 01/15/07.

Gold J and Ball M. The Health Record Banking imperative: A conceptual model. IBM SYSTEMS JOURNAL. VOL 46, NO 1, 2007.

Ward G. Project melds health-care, banking information: Backers say idea could slash costs of medical care. Tennessean.com. Wednesday, 05/09/07.  
<http://www.tennessean.com/apps/pbcs.dll/article?AID=/20070509/BUSINESS01/705090409>