Future of Health Informatics: a unified database

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1. Introduction

The development of medical interventions and services is based on clinical data. These interventions are a response to ill-health. For health care services to prevent ill-health in the first place different types of information are required in order to understand the process of disease development. This distinction has often been likened to the dynamics of a swiftly flowing river where intervention is downstream activity, i.e. continuously jumping in the river and saving drowning people and preventative is upstream activity, i.e. understanding how and why people are drowning. Most health service research is downstream, therefore, does not add insight into our understanding of upstream dynamics (Thunhurst, 1982). In addition to downstream (clinical) information, appropriate upstream (non-clinical) information is required to inform the process of health service policy development.

The massive and rapid progress in technology promised a bright future for informatics in terms of not only data management but also generating knowledge from data. Unfortunately, within the computing/technology and informatics community, technological progress, in terms of products and gadgets, is often referred to as "solutions" which has made informatics technology led rather than human behaviour led. The question that arises is whether health care systems are keeping up with what technological advancements can offer in order to meet the complex dynamics of human behaviour in terms of public health needs (Shahtahmasebi, 2008).

While technological capabilities (gadgets) are referred to as solutions it is argued that solutions must be developed in the context of an identifiable problem. In other words, a solution that is developed ahead of a problem (i.e. before a problem is identified) if applied is not likely to be a perfect solution and may lead to unforeseen additional problems. The purpose of this paper is to conceptualise a human behavior-led technological application for health informatics. In doing so, we argue that health informatics is more than about learning and teaching how to use new technologies. Furthermore, we discuss that, over and above data collection and storage, the role of informatics is to inform.

2. Background

Like any other business, the health sector relies heavily on information for its operations; from government allocation and distribution of resources, to health care service development and interventional programmes. Morbidity and mortality statistics have been used for these purposes. Data items such as age, sex, post code, diagnosis, treatment, patient's outcome, and cause of death are routinely collected and are available through patients' records.

As health care systems have become more and more complex, and in order to respond to all the ill-health needs of its population, some scholars began to equate resources with the rising demand and inequalities in health. Health statisticians and health professionals need to refocus, to investigate the largely unmapped terrain upstream (Thunhurst, 1982), particularly in solving the problem of differential class experiences of health (Butterworth et al., 2009; Holstein et al., 2009; Wagstaff, 2002).

In an earlier paper, Shahtahmasebi (Shahtahmasebi, 2006) argued that despite the attempts to research and map upstream, health services still rely heavily on downstream research, thus building up information systems consisting of data collected after the event i.e. incidence of an illness which necessitated a consultation with a health service professional.

Vast improvements in ICT have enabled large volumes of digital information from medical images to large databases/spreadsheets to be shared through high speed broadband modems. In New Zealand, data sharing appears to be patchy and dependent upon health care provider's information systems and networks (Whetton, 2005). For example, some patients' hospital records such as x-rays or specialists consultation notes may be

visible to the patients' primary care providers (GP) depending on the area, and district health board. A recent study confirms the incompatibility of information systems across the health sector (McKenna, 2009).

On the other hand, health outcomes have been linked to other social, educational and economic outcomes (Butterworth et al., 2009; Holstein et al., 2009; Shahtahmasebi, 2004; Shahtahmasebi, 2006; Shahtahmasebi et al., 1992; Wagstaff, 2002). In the context of government policy the UK government acknowledged the link between socio-economic factors (Department of Health, 2011), e.g. employment status, and health outcomes in the UK's mental health strategy. It is reasonable to expect that the process of health care planning should be informed by information from other processes such as social, education, economy and politics. Whilst these processes have set up their own information systems to routinely collect data, however, these information systems do not communicate with each other. The question is then how does a policy statement that declares a causal relationship between poverty and mental health outcomes be translated into relevant and appropriate policy actions?

Although technology is sufficiently advanced to create a unified database most of the efforts in translating *access* to information has concentrated on access to clinical information. For example, the apparent recommendation and development of e-records by various governments such as the UK, Australia, USA, New Zealand and Canada will ultimately lead to e-health (Whetton, 2005).

In the UK e-records are already in use and a campaign is being carried out by the respective agencies to win public opinion through (i) emphasising the advantages of e-records over current information systems, (ii) by providing the public with a choice as whether or not they would like to have an e-record, and (iii) by reassuring the public about security measures to maintain their privacy (see www.nhscarerecords.nhs.uk).

In New Zealand, the government has begun public consultations about the introduction of "Shared Care Records" (SCR) http://www.sharedcareplan.co.nz/. The SCR may be a type of electronic patient's record initially starting with people with long-term conditions and mothers and new born babies. Both the UK's e-records and New Zealand's SCRs collect important clinical information that may be accessed by all the stakeholders involved in the provision of care of an individual. The creation of e-records, where important information such as medication history, diagnoses, and allergies are stored for common access is still a *downstream* philosophy and a reinvention of the wheel.

3. Discussion

It is argued that the rapid rise in the status of health informatics has coincided with rapid advances in computer and telecommunication technologies. Therefore, in this paper we will not dwell upon the issues that are directly relevant to the development of the technology, but instead focus on the issues that are relevant to the utilisation of the technology. It seems that there are two major issues remaining: the appropriate and innovative applications of ICT, and information itself.

Technological advancements have led to an increasing number of ICT applications within the health sector from automated patient monitoring systems to the storage and retrieval of patients' records, virtual lecture theatres, and the application of artificial intelligence (AI) in intelligent information systems e.g. see Buchan (Buchan et al., 2009). It is not surprising that a joint universities report in New Zealand (Kerr, 2006) reported that the New Zealand Government health information strategy was to increase the utilisation of ICTs to improve health care delivery but the strategy appeared to ignore the implications for the skill-based workforce that is needed to implement the strategy. One of the report's recommendations was for the Government to invest more in health informatics education.

As suggested earlier, most educational establishments in New Zealand offer postgraduate diplomas in health informatics e.g. see http://www.hien.otago.ac.nz/index.php?cat=about&page=home. However, these diplomas are designed to bring students up to speed with the ICT applications currently in use in the health sector so that they can play a role in their respective organisations or enable them to seek employment in the health informatics industry. Yet again, a downstream philosophy.

Beyond the basics of record keeping, the applications of health informatics have extended to patient care e.g. automated patient monitoring systems; distant care delivery e.g. telemedicine; education and training e.g. telemedicine; virtual classroom (Gregory & Tynan, 2009; Honey et al., 2009); management e.g. hospital records; medical warning systems (MWS), and so on. One of the main issues is that information systems are not connected and do not communicate with each other (http://www.healthnavigator.org.nz/centre-for-clinical-excellence/national-shared-care-plan-programme/).

To resolve the issue of non-compatibility, recent decades have witnessed some central strategic planning and implementation of e-records, e.g. in the UK (www.nhscarerecords.nhs.uk) and "Shared Care Record" (SCR) in New Zealand http://www.sharedcareplan.co.nz/. These ideas are marketed in terms of usefulness of access to patients' records anywhere and anytime and by health professionals who are involved with the care of a patient. The e-records provide a summary of important patient's (clinical) data such as allergies, diagnoses and medication history.

These activities and utilisation of "solutions" are clinical based and are only appropriate for the administration of medical interventions. Clinical data does not lend itself to study 'health' and inform health care planning. A study of international comparison of health care systems (Davis et al., 2010) suggests a good but varying degree of international utilisation of ICT in the health sector but raises the question whether data from e-records may necessarily produce quality information to inform, in particular, primary health care service development. Therefore, these information systems should be referred to as ill-health or patient or clinical informatics rather than health informatics.

In the past, a number of databases such as the census and a geographical information system (GIS) e.g. see (Bensley et al., 1994; Shahtahmasebi, 1997; Shahtahmasebi, 2001; Shahtahmasebi, 2008) have been linked with patients' records to study the effect of socio-economic factors on health outcomes. Buchan (Buchan et al., 2009) proposes a model to improve access to health data from a variety of sources. Nevertheless, such practice is still dependent on data after the event, non-linked longitudinal aggregated data and only provides a snapshot of socio-economic characteristics of residential areas. There is very little in health records to inform our understanding of disease development – information which is necessary to plan an effective health care system.

3.1 Information

International comparisons (Davis et al., 2010) suggests that New Zealand is the biggest relative spender on administration and insurance – but is also one of the best users of information technology computerisation: 'in New Zealand it is easier to phone the GPs clinic, they are the best at getting information between clinics, hospitals and patients in good time, sending reminders out about cancer checks, and other mechanisms co-ordinating services across different parts of the system are among the best.' Clearly, digitising data and automating the administration of health care using information systems has some benefits in providing timely health care services. However, health care information systems require more than administrative data if they are to improve access to information by health care professionals, and, to inform the process of health care planning in order to reduce morbidity and mortality and to improve quality of life (Birnbaum & Birnbaum, 2004; Cassidy et al., 2004; Maharajh & Abdool, 2005; Merrick et al., 2005; Shahtahmasebi, 2004; Shahtahmasebi, 2006; Ventegodt et al., 2006; Ventegodt et al., 2003). Despite a complex ill-health informatics, as the report also suggests (Davis et al., 2010), New Zealand's preventative health care and outcomes are relatively poor e.g. chronic conditions such as high blood pressure, high mortality rates (that can be prevented), and high infant deaths.

Recently, attention has focused on electronic patients' records (e-records). This is in line with the concept of computerisation of data for administrative purposes e.g. administering clinical care. For example the UK's health e-records will initially maintain summary care records containing important patient details such as test results, diagnoses, allergies, prescription and medication history (www.nhscarerecords.nhs.uk). Over time these records may be updated every time a patient uses any health care services. A summary record is created once an individual has given consent and this record will be accessible by any health professional who is directly involved in providing care for the individual. The usefulness of such an e-record system is pointed out (www.nhscarerecords.nhs.uk) in terms of access to information 'at the point of delivery' and generally in situations where the care provider is not the patient's own GP: when a patient is away in another part of the country, in accidents and emergency departments or when ambulance services are called out.

Similarly, the New Zealand government is introducing the "Shared Care Record" (SCR) http://www.sharedcareplan.co.nz/. The emphasis is on patients' access and, to some extent, ownership of their own data. This approach will raise more problems than it pertains to solve. For example, the system could potentially allow patients to password protect data items on the SCRs. Such behaviour will defeat the objectives for why shared records are being introduced, i.e. improved care through the health care professional's access to important patient data at the point of delivery of care.

Once again the idea of e-records may appear innovative and in line with improving access to information, however, in the light of the high utilisation of ICT and the computerisation of information systems, e-records may be seen as a re-invention of the wheel. In other words most patient records are already available in a digitised format in a database and (ignoring the economics of it) e-records provide another storage facility with the promise of more access conditional upon patient's consent.

The main issue is to decide whether we want a 'health' informatics system or a series of 'ill-health' database systems. The former can be conceptualised and realised with only a fraction of the costs associated with e-records. For example, during pregnancy and child birth and subsequent child development the system appears to be amassing *life history* data on individuals, albeit in a fragmented and multi-medium format. These data are potentially *health informatics* and have been ignored for decades. Similarly, in the community and primary care sector nursing data is still fragmented and does not lend itself to be shared in a fast and efficient way, and, does not inform our understanding of the process of disease development. Nursing informatics can contribute to the

development of a unified database and also benefit from it to inform the process of nursing care policy development.

3.2 Conceptualising a Unified Database

Table 1 provides an example of routinely collected data that, if complete, can provide upstream data. Together, the data collection systems have the potential to provide life event histories for any individual. The major issue here is that these data collection systems are not linked and do not communicate with each other. It is possible that data collection systems are often purpose-built and designed independently. Nevertheless, most data systems will have a common unique individual identifier(s) that can be used to link data systems together. In an ideal world databases would have been part of the same design and by default would have been linked so that upstream data may inform the planning of downstream activities (clinical interventions). Whilst, we do not live in an ideal world, given the vast advancement in hardware and software technology, we can conceptualise a unified database.

Table 1 – an example of available data systems and routinely collected data

Data exist because of incidents of ill health		Data exists because of reporting checks and monitoring	
Ill-health data systems	**Data Items**	**"Qualitative" Health data systems**	**Data Items**
Patients records	e.g. unique identifier, personal details, diagnosis, treatment, referrals, …	Midwifery records	e.g. unique identifier, personal details, baby's nutrition, weight, height, problems and issues,…
Hospital records	e.g. unique identifier, personal details, diagnosis, treatment, hospital identifier, specialists, referrals, …	Nursing records	e.g. unique identifier, personal details, nutrition, weight, prenatal and postnatal monitors, problems and issues,…
GP records	e.g. unique identifier, personal details, diagnosis, treatment, referrals, …	Monitoring records	e.g. Screening records (e.g. breast and cervical), routine check-ups (e.g. heart),…
Mortality records	e.g. unique identifier, personal details, cause(s) of death,…	Other records	e.g. Education records, Justice/police records, social and employment records,...

As shown in Fig. 1, a virtual mega database may be conceptualised to provide access to life history events including health, morbidity (hospital records) and mortality records for professional practice, and, anonymised and aggregated life histories for research. I do not propose to re-invent the wheel by insisting on another physical database such as e-records. The unified database could be a set of communication software protocols acting as secure gateways to other databases, or, it can be a virtual database which is populated from other databases via communications software protocol. As suggested earlier, health and social outcome data and life event histories are already available but from different sources and in different formats. The technical issues in this scenario will relate to the architectural design of the database (or interface) and populating it with anonymised life history records.

Of course the records will have to be linked perhaps via a unique identifier code such as a National Insurance number or social security number. It is also possible to conceptualise a unified database in terms of access to anonymised life histories which are linked by a unique identifier. The basic structure of a unified database will be a 'hub' that is enabled to communicate with other available databases and run queries on them. The hub will be software interfaced to perform basic as well as complex time series statistical modelling. In both scenarios, the ability to communicate in real time will need to be considered in order to help health care professionals make informed decisions.

One of the major benefits of a unified database, in the context of downstream activities, will be to resolve the communication problems often claimed by care service agencies when a tragedy such as death due to suicide or

child abuse occurs. Because, concerns raised by a care service provider (e.g. hospital) will be immediately flagged up and seen by another (e.g. social services, police).
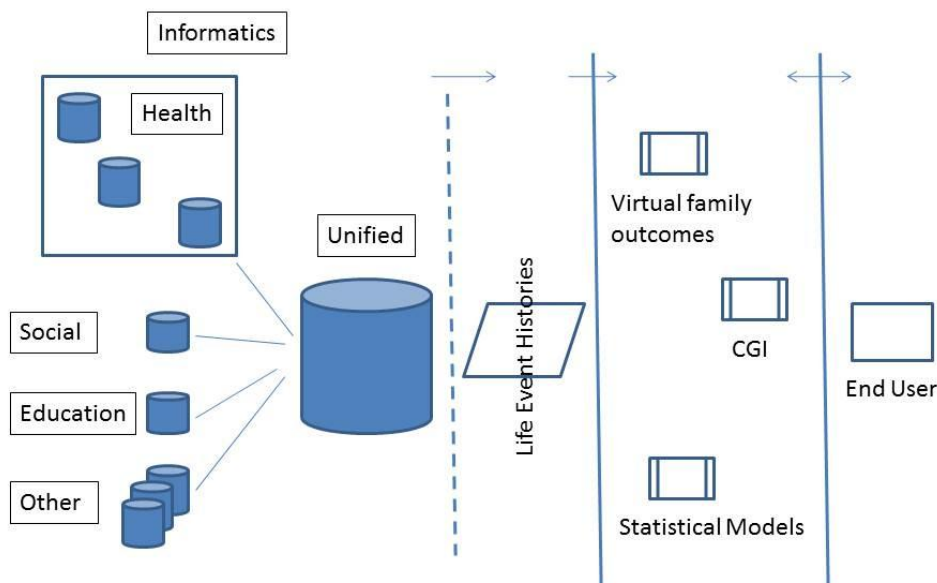

Figure 1. A conceptual model of a unified (health) informatics

Obviously, there are many issues that are relevant for the design and architecture of a database, such as ethics (privacy and confidentiality), resources, stakeholders and access, will need to be identified and resolved. Clearly, issues appropriate to creating a unified database such as design, ethics and so on are large scale research projects in their own right.

3.3 Barriers to Adoption of Technologies

Although, society responds well to technological gadgets and is enthusiastic about technology, its application in public administration is resource intensive, politicised and is challenged with legal and ethical issues including privacy and confidentiality. In the UK, during 1993-4, a proposal for the analysis of hospital records to utilise the added data item 'social class' did not proceed because the data item 'social class' had not been populated with relevant values. The extraordinary high missing values is not surprising as an exploratory analysis of such records suggested that professionals, on average, reported statutory minimum clinical data requirement. In an evaluation study of the English e-records system (Greenhalgh et al., 2010) a lack of compliance with reporting on all the data items, ethical considerations, skills gap, experience and knowledge of the systems in use, shortage of resources, immediate and free access to an informatics station, are some of the issues raised as barriers to full utilisation of the e-records.

The shift towards a technology-based culture may also be reinforcing the barriers to the utilisation of new informatics systems. For example, at the Health Informatics New Zealand (HINZ) Conference 2010, speakers and delegates commonly described the available technologies such as smart pens, smart pads, e-health and mobile technology as *solutions*. In other words, we can now define, or, perhaps create a problem/market for which there exists a 'solution' in the form of a device. By the same token, the fact that we have lots of 'solutions' suggests that the advancing technology is no longer an issue but its applications are.

However, most 'solutions' appear to address clinical administration e.g. improved and fast access to patients' records, reduction in human error, and accounting. Given the extent of the technological advancement in hardware and software we ought to have, at some point, asked ourselves why stop with 'solutions' for administrative aspects of health care while there are questions that can be investigated? In other words, technological solutions must be human behaviour-led (evidence-based) and not the other way round. This approach can also assist to overcome some of the barriers in the full utilisation of technology.

On the other hand, under a human behaviour-led approach barriers can be conceptualised as *opportunities* in developing more socially acceptable 'solutions', see Fig. 1. The inclusion of human and social parameters in the process of developing informatics systems at the concept stage will enhance the decision making process and its outcomes, see Fig. 2. Indeed, conceptualisation considers the barriers as part of the solution by assuming they are processes in their own right. Thus barriers become multi-disciplinary research projects to inform the process of defining a unified database and its functions.
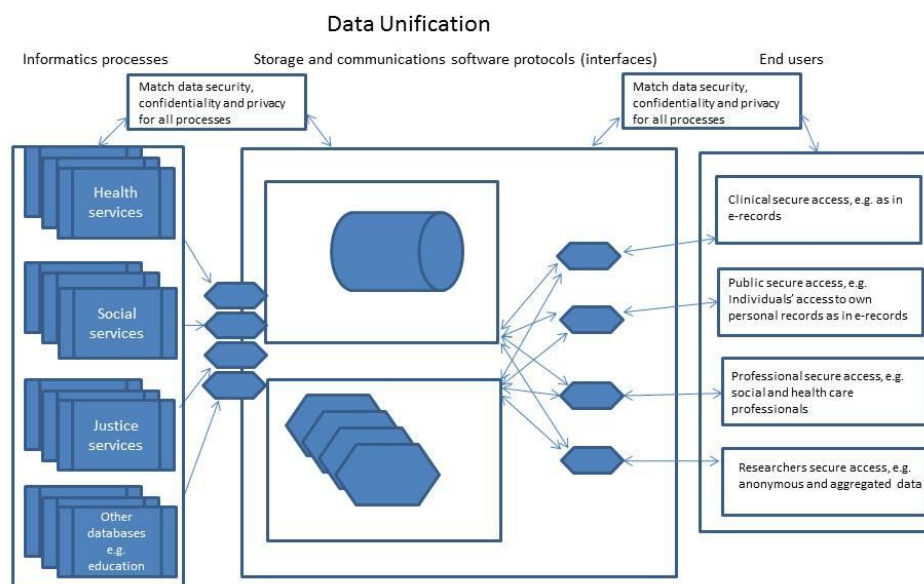

Figure 2. Conceptualising the informatics processes

4. Concluding Comments

Ironically, the problems and issues discussed in this paper, including failing to prevent tragedies because different care agencies fail to communicate, were supposed to be resolved through major IT strategies both at a government and agency level. The various strategies may have actually contributed to more complexities while addressing the digitisation of data. Due to market forces health care providers may have opted for the IT systems that meet their IT strategy for their budget, e.g. value for money. A unified IT strategy approach would have been far better so that all care agencies would be invited to subscribe to the same purpose-build and designed data collection system. This approach would have reduced variability and facilitated communication between systems.

In recent years, the under utilisation of technology has been echoed by others (Buchan et al., 2009; Davis et al., 2010). While, Buchan et al (Buchan et al., 2009) suggests methods of increasing access to data in addition to those from patients records, they propose the utilisation of technology for a unified modelling approach. Buchan et al (Buchan et al., 2009) do not discuss the limitations of such an approach, for example their unified modelling approach lacks a statistical modelling approach which allows the selection of a parsimonious model from which inference may be made. Statistical data reduction techniques often used with large data sets are not suitable for inferential purposes (Aitkin, 1979; Shahtahmasebi & Berridge, 2010). Unification of the various information systems could potentially provide large scale life event histories. Modelling such data requires the understanding of substantive theories underpinning human behaviour such as temporal dependencies which will support the application of appropriate modelling approaches (Shahtahmasebi & Berridge, 2010).

Other computerised models (e.g. see (Gustafson et al., 2002)) claim computers remove barriers to accessing information with particular application for those 'underserved' such as minorities and the elderly. In practice barriers remain in place until such a time that a policy is developed to (i) enable a distinction between data and information is explicitly made, (ii) enable equal super-fast access to data by all, and (iii) account for the subsequent consequences of that access to data has on human behaviour (Shahtahmasebi, 2008). The latter has

already manifested as self-treatment which could lead to adverse health effects through poor judgement, uncritical use of the internet, a lack of medication compliance, a lack of consultation with a GP or a medical professional (De Bolle et al., 2008; Stevenson et al., 2003). Quality information when critically assessed empowers individuals and may indeed lead to an informed decision. While access to uncritical data may lead to poor decisions and adversely affect health.

In a changing environment (e.g. the impact of global warming on health care services) coupled with the dynamics of human behaviour, our information needs may be best served by a unified database that is not only responsive to clinical needs but also responds to the needs of the community and primary health care as well as research. Whereas, the deployment of a system such as e-records, may improve access to important patient information which may improve clinical decision making and potentially lead to a more effective delivery of care. But, the utilisation of e-records only occurs after the event of an illness and with the patient's consent. Unfortunately, this appears to be the extent of e-records. Therefore, e-records do not inform our understanding of the process of disease development.

The real issue is how better e-records will perform than the current relatively low cost system that allows patients to wear a tag with their particular chronic condition, or, questions and answers at the time of delivery of care. Moreover, cases where e-records are updated overtime are simply a replication of the current patient data collection, albeit, in a different medium. In other words, do the outcomes in health care delivery, in an evidence-based decision making environment, justify the millions of dollars spent on hardware to maintain minimum datasets that are already available?

The current (ill-)health informatics systems including e-records and e-health are a downstream philosophy and do nothing to provide further insight into health and the development of ill-health. On the other hand access to a unified database may inform the process of understanding the long-term effects of a behaviour, e.g. maternal smoking or medication (Ventegodt & Merrick, 2003a; Ventegodt & Merrick, 2003b), on an individuals' health so that health care services may become responsive.

Finally, the health informatics community must come to grips with what is meant by health information (Shahtahmasebi, 2008), particularly in a climate where there is increasing interest in reaching consumers and patients directly through ICT (Eysenbach, 2000).

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