Chapter 2
The Information Paradox: Researching Health Service Information Systems Development

Said Shahtahmasebi
The Good Life Research Centre Trust, New Zealand & University of Kentucky, USA

ABSTRACT
This paper is based on a 2008 chapter (Shahtahmasebi, 2008) exploring the availability of information for public health policy purposes which argued its ineffectiveness to add insight and inform the process of policy development. Processes are dynamic by nature which politicians and professionals often neglect in addressing public health issues. The Chapter argued that whilst information is a major currency within health systems a lack of understanding of what constitutes information has disguised available data as small change. Since 2008, against a backdrop of reorganisations, restructuring, buzzwords, and coupled with the rapid advancement in technology the issues remain the same but are somewhat more complicated due to the feedback effect of dynamic processes. For example, a curious persistence of various governments with electronic health records has done nothing to address the gap in “information” or incompatibility in the information systems developed and managed by various care agencies. Furthermore, changing information to “intelligence” (e.g. Public Health Intelligence Units) or “observatories” to carry out similar tasks of reporting health outcomes using the same routine data will not solve the problem. This paper proposes a re-evaluation of the author’s focus on informatics and suggests a move away from a technological “solution” based approach to a human behaviour-led approach that utilises the full potential of technologies to address important issues. To this end, this paper proposes a conceptual model to improve access, over and above clinical data, to health data.

INTRODUCTION
Data is the main currency within any organisation, especially within health services around the world. However, currency gains value when it informs the process of policy and service development that is appropriate, efficient, effective, and value for money.

For the purpose of administration, health services routinely collect monitoring and clinical data. Such data helps to forecast and plan population-based interventions, e.g. secondary care services that may be
required such as the number of hospital beds, number of operations, number of health professionals, for
the following financial year. In other words, this data refers to morbidity and mortality after the event, to
add insight into the process of morbidity or disease development decision makers often rely on funded
projects and research studies.

Until recently data collection was paper-based and as such the method was designed to suit the medium
on which data were recorded. Rapid advancement in technology substantially improved the collection
and access to digitised data with a much increased capacity for data storage. Information technology (IT)
opened up whole new horizons to be creative with data and enhance its value as a currency.

However, practice suggests that creativity may only be limited to the technology. For example, Pa-
gliari (Pagliari et al., 2007) explains that “HealthSpace (www.healthspace.nhs.uk/) is a secure online
personal health organiser available to all patients in England. The system was initially launched in 2003
to store health notes generated by patients.” The system collects and stores administrative and clinical
data selection and booking of hospital appointments; storage and charting of health indicators such as
blood pressure, peak flow, or weight; a calendar with the option to generate email reminders; a database
of NHS contacts; and links to online health information (Pagliari et al., 2007). The system provides
patients with access to their NHS Summary Care Record—a snapshot of the general practice record docu-
menting allergies, adverse reactions, and drug treatment (Pagliari et al., 2007). “Although HealthSpace
will not provide access to detailed care records, clinicians can add data to the summary record with the
patient’s agreement. Other features under consideration include allowing patients to enter their needs
or preferences, such as for wheelchair access or translators; greater use of text and email alerting; and
enhanced tools for patients with chronic disease. The link with NHSDirect Online (www.nhsdirect.nhs.
uk) also offers possibilities for integrating electronic consulting and education in the future. Although
HealthSpace promises a national solution to electronic personal health records, it will be some time
before its full potential is realised.” (Pagliari et al., 2007).

It seems that despite the level of advancement in IT and database technology and after allocating
billions of dollars, creativity has been limited mainly to digitising the paper format. The heavy emphasis
on intervention and clinical data has removed all concerns for converting data into valuable informa-
tion to gain insight into the process of disease development (Shahtahmasebi, 2008). For example, the
creation of electronic health records is testimony to the narrow and unwise focus of governments and
health services decision makers; why spend billions of dollars to recreate what is already available?
Furthermore, given the emphasis of the strategy on access to clinical/administrative data (Boonstra et
al., 2014; Garrety et al., 2014; Soumerai & Avery, 2010; Waterson, 2014) for governments to go ahead
with e-records is like reinventing the wheel!

It is claimed that the technology will lead to enhanced health maintenance and self-care, participation
in decision making, better health and quality of life, improved quality of care including patients’ safety,
and lower costs (Pagliari et al., 2007). The main problem is that such statements are often made without
any supportive evidence. It is plausible that the high level of technology integration is based on presumed
benefits. It is not surprising that a technology solution based approach will be of limited application
(Boonstra et al., 2014; Buntin et al., 2011; Coiera, 2011; Garrety et al., 2014; Trisha Greenhalgh et al.,

Even without access to millions of dollars, the questions of design should have considered other is-
ues besides reproducing clinical data that is already available on a different platform. The design should
have included the role of other actors such as the public, researchers, other disciplines, information and