

Chapter 2

The Information Paradox: Researching Health Service Information Systems Development

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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

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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, Pagliari (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 documenting 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 NHDirect 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 information 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.*, 2010a; Kellermann & Jones, 2013; Kidd, 2008; Waterson, 2014).

Even without access to millions of dollars, the questions of design should have considered other issues 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

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