Chapter XVIII
Open Information Management in User–Driven Healthcare

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ABSTRACT

This chapter discusses the role of open health information management in the the development of a novel, adaptable mixed-platform for supporting health care informational needs. This platform enables clients (patient users) requiring healthcare to enter an unstructured but detailed account of their day-to-day health information requirements that may be structured into a lifetime electronic health record. It illustrates the discussion with an operational model and a pilot project in order to begin to explore the potential of a collaborative network of patient and health professional users to support the provision of health care services, and helping to effectively engage patient users with their own healthcare. Such a solution has the potential to allow both patient and health professional users to produce useful materials, to contribute to improved social health outcomes in terms of health education and primary disease prevention, and to address both pre-treatment and post-treatment phases of illness that are often neglected in the context of overburdened support services.

INTRODUCTION

Managing chronic medical illnesses in the community is a universal challenge. The traditional patient and health professional clinical encounter has evolved into a series of fragmented exchanges of information, often between several professionals. The information exchange between professionals mostly excludes the patient and is usually limited to a synthesized 'factual' written account – often referred to as 'the clinical (integrated) medical record'. The synthesized 'factual' written account however fails to convey much of the subtlety gained through the information exchanges in the encounter (which would have built a more valuable knowledge base about a patient) (Sturmberg, 2007). The clinical encounter has the potential to actually evolve into an informational collaborative process, i.e. ongoing learning persistent in virtual space and time. A persistent clinical encounter has immense potential advantages for the patient as well as her health professionals.

Medicine is a collaborative effort in problem solving between individual patients and their health professionals. The collaborations also involve others who are directly or indirectly related to the patient and health professional (for example, the patient's relatives, the practice staff, other members of the physicians' institutions etc) who provide the necessary support to the two main actors.

We suggest viewing such an integrated approach to health care as 'User driven health care' that may be defined as, "Improved health care achieved with concerted collaborative learning between multiple users and stakeholders, primarily patients, health professionals and other actors in the care giving collaborative network across a web interface." (Biswas et al., 2008 a) It needs to be differentiated from the current ubiquitous 'Consumer driven health care' model, which is essentially a strategy for users/consumers to decide how they may pay for their own health care through multiple stakeholders like employers who provide the money and insurance companies who receive the premiums (Tan, 2005).

OPEN INFORMATION MANAGEMENT AND HEALTH 2.0

Patient user generated and suitably anonymous informational content initially confined to email boxes or web based individual health record vaults can be further invested in online web pages linked to what is loosely termed as Web 2.0 technologies. That may provide opportunities for linking common experiences in order to generate improved patient and caregiver learning

In web sites using this technology user-generated tags would allow the site to evolve, enabling individual users to conduct more precise searches, make additional associations, and explore a diverse undercurrent of themes to synthesize for learning purposes.

Health 2.0 in realtion to health care has been described to be all about Patient Empowered Healthcare whereby patients have the information they need to be able to make rational healthcare decisions (transparency of information) based on value (outcomes over price).

The Four Cornerstones (Connectivity, Price, Quality, and Incentives) of the Value Driven Healthcare movement begin to create a virtuous cycle of innovation and reform. Transparency serves as a key catalyst in this process by creating positive sum competition that can deliver better outcomes at a lower cost...

As more information becomes available as a result of increased transparency, there will be a wave of innovation at all points along the full cycle of care, which includes phases where health care professionals Educate, Prevent, Diagnose, Prepare, Intervene, Recover, Monitor, and Manage the various disease states (Health 2.0 Definition, 2007).

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