

# Chapter 28

## Dimensions of the Patient Journey: Charting and Sharing the Patient Journey With Long Term User-Driven Support Systems

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### ABSTRACT

*The ways a person's illnesses and afflictions are socially constructed and culturally conceived amongst relatives and friends as biographically contextualized in the narratives of a known life-journey are contrasted with modern conceptions of "Patient Journey" in the digitizing of medical care in hospitals and in computerized GP Consultations. In this chapter most relevant dimensions of a personal life-journey support system – across health, handicaps and illness - are outlined. The chapter demonstrates a new road to facilitate private logging of phenomena, a coherent and sedimenting self-narrative not only in text, picture and sound, but also through user-network-developed pictographic fonts. Inclusion of biotelemetric data and virtual body imaging as part of such support systems are considered. And questions are raised concerning the future of thus skilled chronic patients' interfacing most trusted helpers, fellow-sufferers and wider shared social platforms of Patient Journey Records.*

### INTRODUCTION

Public and private expenses for healthcare are surging. As medical advances are made, unhealthy lifestyles are spreading in the industrialized world and people are living longer. We get more and more chronic patients. Public prophylactic measures and health-educational efforts to increase health-awareness and self-care create numerous private

profitable health-enterprises. With the spread of Internet access, many offers of such services and drugs, programs and technological gadgets are advertised. The transition to digital records, and networking in professional health-related social networks, brings the medical rationalizing and formalization of descriptions to its force, with many advantages.

The only problem is that while tremendous efforts and results are obtained to digitize and train the medical establishment, exemplified in

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the Hospital and GP settings, the chronic patients are left at their own to learn how to handle a computer, establish e-mail contact, and to hook up to whatever the digitized medical society has to offer - options, threats and promises - concerning their management of their own health.

Therefore the digitizing of citizen health situations has to be re-examined in the light of what is for now the receiving line of citizens, presently having to cope with their own information across all dimensions of their life-space and eventual patient journey, without adequate tools. This involves life-style, economy, employment, family and home life conditions, relative medical compliance, and the “story” and “role” assumed in family, neighborhood and workplace.

To repair this gap, and truly qualify patients to join and contribute to utilizing collaborative social networks and technologies, we must strive to qualify citizens as administrators of their own health, each developing their personal knowledge management skills, to become “life-long e-learners” (Pettenati 2008). It is proposed that personal healthcare and health-related interfaces of the future shall be considered in the full contexts of the citizens’ general interfacing themselves through their everyday use of a personal notebook computer from 1st grade in school to final palliative care. We will gain by broadly conceiving of the citizens as genuine individual explorers on their own personal everyday life-trails, along their own life-trajectories. We must favor their empowerment as self documenting “Citizen Scientists” qualified to reflect and deal with own health-data, physiological data, economical data and environmental data. Therefore we must find ways to at least enable and equip the autonomous individual citizens/patients to develop and maintain their own most basic and private sedimenting digital self-narrative of what seems relevant to them: an electronic diary and time-indexed database, as an empowering empirical tool, not least in health-related, body- and domestic habit-related matters.

## **MEDICAL PATIENT JOURNEY CONCEPTS**

Patient Journey is a pragmatic metaphor, an expression which may need some disambiguation, - especially in the context of patient narratives and experiences of illness. It can be used as referring to how patients proceed through an identified care delivery system. Seen from the angle of process mapping this refers to the total number of steps taken, as well as the total number of people involved, the total time taken to perform each process-step and all documents used.

*“When extensive process mapping for a considerable patient volume is done it is now possible to bring the data together and look at the care process from a unit/department perspective..... and perform a flow analysis (widely used in Manufacturing), and develop a current state flow analysis map: •Analyse patient flow across more complex processes •Identify whether the systems are managed and in control •See what adds value and where waste occurs \*Understand roles and responsibilities related to managing patient flows.” (NHS Scotland (2006) Understanding the Patient Journey – Process Mapping)*

But with the digitizing of health information, and the adoption of electronic patient records, highly professional tools are developed not only for hospitals but also for GP’s to organize and administer their patient scheduling, patient records and patient flows in complex and versatile frameworks. This means that recording of consultations, test results, medication, prescriptions and referrals can be integrated as it is approached by e.g. Microsoft Health Common User Interface (<http://www.ms-cui.net/>). The idea is, to formalize an interface in such ways, that an integrated patient-centric care record can transition seamlessly between care sessions and care settings. The doctor is offered to have a multidimensional “landing place” with appointment list, email-in box, reports received,

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