The Mature Personal Health Record for the Empowered Consumer

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Abstract. The purpose of this paper is to present a future scenario projecting a fully developed, i.e., mature, personal health record (MPHR) that is instrumental in linking health care services delivery with preventive and wellness activities to provide informed and responsive consumer-driven health care. Various challenges to implementation are discussed to guide future policy development in this area.

Keywords. Personal health record, mature personal health record, health information, challenges.

Introduction

The Personal Health Record (PHR) has become a point of focus for a number of the trends characterizing medical informatics, health information technology and their intersection with public (community) health in the early decades of the 21st Century. “Meaningful use” of the EHR stipulations required by the American Recovery and Reinvestment Act for reimbursement for providers under US Medicare and Medicaid programs, patient-centered care, patient-provider partnerships, accountable care organizations (ACOs) all can be seen as converging on the ultimate goals of the empowered consumer of health care and preventive services. Parallel to these factors is the priority given to translational research in medicine and public health to inform and justify evidence-based clinical practice to insure patient safety and cost-effective delivery of health care and community health interventions to eliminate health disparities and sustain the public’s health and wellness at the local, regional and global levels.

The purpose of this conceptual paper is to provide a future vision and scenario of a “mature” PHR (referred to subsequently as the MPHR) and to identify the potential challenges to MPHR implementation. By doing so, we wish to focus attention on the MPHR as a useful focus for health system reform from the perspective of the empowered consumer. A future paper will focus on the legal, ethical, technological and privacy challenges for the MPHR.

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1. Defining the Personal Health Record

Although various but similar definitions of the Personal Health Record (PHR) have been proposed, the following language is succinct and consistent with the HIPAA regulatory logic. The US Office of Civil Rights defines the PHR as “an electronic record of an individual’s health information by which the individual controls access to the information and may have the ability to manage, track, and participate in his or her own health care.”[1] The PHR as defined and discussed above is viewed not only as a repository for Personal Health Information but more importantly as a channel and mechanism for enhanced communication between the individual consumer of health care and related services and the provider system.

2. Future Scenario for the MPHR

To suggest the potential capacities and benefits of the “mature” PHR (MPHR), we provide the following brief scenario of the empowered health consumer using her MPHR in 2020:

After checking her Outlook calendar in preparation for the work week ahead, Maria realizes that she has a potential conflict with a mandatory staff meeting on Monday at 11:00 and a previously scheduled routine follow-up visit with her PCP three months after knee surgery. She accesses her PHR though her Apple MyPhone/MyLife Pad. She places an instant message to the office of her PCP, requesting a cancellation and new appointment on one of the available dates and times highlighted in her on-line calendar. Within 10 minutes the confirmation of the new appointment the following week is received along with a copy of an inquiry to her physical therapist whether the range of motion data for Maria’s knee is current. If not, Maria is asked to schedule a PT appointment prior to the PCP visit. Also she is reminded to update her fitness and dietary plan with the current week’s entries and to complete the six-month personal wellness survey. Once she does so she will receive a table of her responses during the past three years of key variables, e.g., weight, BM, HCL levels, blood pressure, pulse/OX reading, mood (depression) scale, as compared to statistics for the health plan of which she belongs and national benchmarks in the aggregate and by age, gender and Regional cohort. If she had been interested Maria might have accessed her cumulative use and cost of services history again with benchmarks comparisons. Having requested a PT appointment later in the week, the PT office Maria provides an on-line Pain Chart for her to complete on the touch screen, 24 hours prior to the confirmed appointment. After her meeting Maria finished her workout at her employer’s fitness club. During lunch she enters her weight training and aerobic exercise data and her calorie count for the lunch she is enjoying, intending to trade off excess calories for the slice of fruit cheesecake with a light dinner of fish and rice. While completing her records, she receives an alert from the County Health Department about a food-borne illness associated with a salad bar at a chain of family restaurants in the Region with a request that anyone who dined at any of the locations identified within the past 48 hours should complete an on-line survey attached and if experiencing any severe gastric symptoms, contact the PCP or
receive expedited treatment at the closest ER. Finally a broadcast message in her Healthy Community folder alerted subscribers of a current need for her blood type at the Blood Bank and that first time donors would receive bonus points toward a discount of their health plan premium payment. Next Maria logged into the MPHR of her aging mother who had recently been diagnosed with early onset Alzheimer’s. Having obtained power of attorney for all her mother’s affairs, Maria had complete access to her PHR and the tethered EHR. She duly noted the alert that her mother had missed her medication last evening, an issue that Maria intended to address with the home health aide directly. Realizing that the time was drawing near when her mother would require institutional long term care, Maria used the messaging utility linked to her MPHR to contact the local Area on Aging to access their quality ratings and prices for long term care facilities with dementia care unit.

2.0 Challenges to the vision of the Mature PHR

The scenario described above presents a PHR fully embedded in the consumer’s preferred communication channels and serving as the nexus for linking medical care, personal health behaviors and public health services and information potentially relevant to the consumer and family members. The supporting technology is already in place and almost certainly will become more powerful and available at lower cost within this decade. So the technological infrastructure for the applications identified is neither remote nor radical. The challenges presented by this scenario from a public health policy perspective are related to use, acceptance and satisfaction with the MPHR on the consumer side and the will and capacity for data system integration, provider system commitment and inter-institutional bridge building on the provider side.

3. Conclusion

In summary, the evolution of the PHR beyond its current state of adoption, use and functionality into a more mature and widely used tool for the empowered health consumer is an exciting prospect but one that presents an array of challenges, both regulatory, managerial, socio-cultural and technological. We conclude that the potential pay-offs for enhancing the individual’s health and well-being and protecting and sustaining the public’s health overall is worth a considerable investment in policy analysis, technological R&D, partnership building and the expenditure of political capital by influential advocates and decision makers.

References