Chapter 10
Incorporating Patient Generated Health Data into Chronic Disease Management: A Human Factors Approach

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Abstract Understanding the relationships between technology design and Human Factors can help overcome barriers to incorporating patient generated health data (PGHD) into the day-to-day management of chronic disease. User Centered Design (UCD), a Human Factors approach that frames technology design in terms of users, tasks and contexts, can help developers to understand barriers to incorporating PGHD into patient and provider workflows and into electronic health record systems (EHR-S). An example of the application of UCD is presented within the context of primary care delivery for a hypothetical patient with Hypertension/Type II Diabetes Mellitus (DM2), with a focus on barriers and design issues inherent in incorporating PGHD into the EHR and into practice workflow. The results of a field trial are presented as an application of the UCD methodology in the evolution of a mobile application for collecting and using PGHD for patient disease monitoring.

Keywords Patient engagement • IT/information technology • Human factors • User centered design (UCD) • Stakeholders • End-users

10.1 Introduction

Patient generated health data (PGHD) is defined as health-related information that is "created, recorded, gathered, or inferred by or from patients or their designees" [39]. Its importance in health care has been articulated by the federal government through its projected incorporation into Stage 3 Meaningful Use criteria for certified electronic health record systems (EHR-Ss). In addition to secure messaging, health risk assessments and pre-visit questionnaires, mobile technology (smartphones) connected to EHR-Ss and data analytics hold great promise for supporting patients in chronic disease management. However, implementation and deployment of

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usable, successful and sustainable applications in healthcare present challenges for realizing the promise.

One approach to designing technology that supports the incorporation of PGHD into care lies in Human Factors. The focus of Human Factors is to understand users' (that is, patients' and providers') capabilities and needs within the contexts (day-to-day management of chronic disease) and tasks they must perform (effective management of PGHD). This approach to design and development has been shown to result in technology systems that are successful in achieving user goals and reducing costs [25, 46].

10.2   Patient Generated Health Data

Clinicians and policy makers have long advocated for active engagement of patients with chronic diseases in self-care [3, 4, 21, 35]. Clinical and population health research has demonstrated better outcomes when patients are engaged in at least some aspects of their own care [4, 13, 27, 28, 44, 45]. Important components of successful engagement of patients are:

- **Data collection by patients and its incorporation into ongoing care**
  When combined with traditional clinical data (physical examination, test results, etc.) and provider observations, PGHD can provide the physician a fuller picture of the day-to-day circumstances that describe patients' life situations and disease trajectories [4, 5, 41].

- **Self-awareness and learning by the patient**
  Patients attending to their health data, on their own but in the context of a patient-physician relationship, can learn how to take better care of themselves [4, 5, 41]. Evidence from the multi-year Project HealthDesign [5] has shown that patients can and do utilize their own "observations of daily living [to] draw interpretations about their daily life" and make better health and care choices.

Design of information systems to realize PGHD management has been challenging. Self-monitoring (e.g., tracking of one's behavior through journaling) has been recognized as the single most effective technique for bringing about behavior change, yet its uptake is modest. Most successful changes in patients' health behaviors are not explained by their use of existing tools, and even when urged by their health care providers to use such tools, many patients remain unable to make sustainable health behavior changes [12].

Paradoxically, healthcare providers, the principal consumers of PGHD, pose another challenge to its incorporation into care. In a recent study of physicians from 13 European countries, participants, when asked about patients' engagement in their own care, reported concerns about the potential impact of PGHD on their (the physicians') workloads [14].

On the US policy level, Stage 3 Meaningful Use (MU) criteria for certified EHR technology will focus on specific objectives for using PGHD in shared decision-making and for clinical quality measures. However, mixed success of implementing Stage 2 MU criteria [15, 43] has raised concerns and continuing debate about the feasibility of Stage 3 objectives [1, 41]. Nevertheless, interest and momentum for incorporating PGHD into care continues and is being increasingly driven by regulatory policy and insurance reimbursement decisions that impact on all stakeholders.

Given these conflicts, a fruitful approach is to examine them from a Human Factors standpoint with User-Centered Design as a tool to study, understand and mitigate the barriers and to present approaches that align stakeholders to reach the laudable and challenging goal of incorporating PGHD into chronic disease management. Beginning with definitions, the approach is applied to the primary care flow of patients with an ongoing chronic condition (Hypertension/Diabetes Mellitus, Type II).

10.3   A Brief Overview of the Human Factors Approach

Human Factors refers to a group of disciplines that share the goal of designing systems that are suited for the abilities, skills and preferences of users (i.e., people) and the task to be accomplished.

> The historical roots of Human Factors can be traced back to the early phases of industrialization. As machines replaced work previously done by humans, engineers began to consider the new relationships between man and machine. One concept was that functions could be reduced to measurable sequences of inter-related and repeatable tasks, which can be optimized and taught to workers with limited skills (known as "Taylorism") [42]. Within healthcare, productivity can be improved through systematic organization of tasks and processes and "good" design.

Users are humans with physical, cognitive and psychosocial capabilities that support decision-making

> The term "Human Factors and Ergonomics" originated during World War II. A major impetus that moved the discipline forward was the observation of a large number of human errors in aviation [20]. Analyses found that approximately a third of all deaths were attributable to combat, while two thirds occurred during training and normal operations [7, 9, 20]. Researchers found significant problems in training, operations and in the design of cockpit controls (which affected pilots' performance on button-pressing sequences under duress, work teams' perceptions of critical messages under noisy conditions and flight crews' work coordination during missions. [7])

Task-analysis has become a major methodology to understanding workflow requirements [26].

> Defined as "the study of what an operator (or team of operators) is required to do, in terms of actions and/or cognitive processes to achieve a system goal" [26], task-analysis can provide a pragmatic understanding of workers as a starting point for a better design and fit of technology [22, 24]. Techniques used in task-analysis include: activity sampling, observation, critical incident identification, and interviews. [26]

User-centered design (*UCD*) focuses on the user, the tasks and the context of work that are key factors in contributing to the overall success of system design [16, 17]. UCD stresses the importance of iterative design for evolving successful systems. In UCD, users are involved early in the design process, before any implementation, and then throughout the refinement of the system through further testing with representative intended users.

As computing has become progressively "horizontal" (general in focus) and platforms have broadened from mainframes to personal computers to mobile technologies and smartphones, the view of IT user skill sets has changed from "special expertise" (requiring training to use IT) to average knowledge (requiring little to no training). This change in user expectations has required application design and user training to be simpler, more transparent and easier to master or intuit.

Ease of use has become an important driver of design.

As sophisticated IT applications, enabled by personal computers and Web-based technologies, have become available to a wide range of users, there has been reduction/elimination of paper instruction/documentation and increase in common design conventions/metaphors across interfaces [6]. Guidelines for interface designs and help systems have been developed for consistency [33], with the goal of enabling average users to interact with applications with minimal training, disruption and error. Such guidelines have been embodied into standard reusable design toolkits for new applications [31] that simplify data entry and decrease other errors in data collection. As *discretionary* users (those who are not compelled/forced to use) of a given application, patients consider ease of use as a pre-requisite to using it (with the alternative being to abandon the application). This is an important factor in designing PGHD tools.

User engagement is important to implementing PGHD into IT-driven clinical information work.

Patients must be convinced and assured that providing accurate health data has value to them and that it provides positive return on investment (ROI), both initially and over the long-term, for management of health and chronic disease. In wellness, frequent abandonment of self-initiated usage of health tracking applications suggests that currently available tools do not provide sufficient value or ROI to the (healthy) patient over the long-term. [30]

Coordination and collaboration among the multiple users involved in the use of PGHD is a major area of concern for developers.

"Groupware" (collaborative) applications may fail for a number of reasons that go beyond the scope of technology [18, 19]. These include:

- *Uneven distribution of costs and benefits of the work involved in adoption.* In one example, a radiology department adopted speech recognition technology that enabled radiologists (physicians) to produce reports without the need of a human transcriptionist. The application used discrete speech recognition technology that requires users to modify their way of speaking (perceived as "unnatural") in order to be recognized by the system. Physicians were required to edit the final report (with a keyboard, something they equated with "clerical work" and not in keeping with their job role) (Danis, unpublished manuscript 1992). The department administrators strongly favored the tool because of the cost saved on transcription. The distribution of costs and benefits is more complex in the case of PGHD where both patients and providers are expected to share in the costs (and work) and would be expected to derive benefits. But, the nature of the costs and the benefits remains to be further elucidated.

- *Differential perceptions in the advantages of sharing personal information*. In an example of opposing incentives within a consultancy organization, younger consultants guarded personally-obtained information they believed gave them a competitive advantage. In contrast, senior consultants, whose positions were secure, saw advantages to the free flow of information [32]. This differential perception may be seen clinically (regarding privacy in seeking care) with adolescent patients who confide in their physicians about sensitive health issues and their parents who may wish to be alerted about by insurers whenever their teens go to the doctor. [34]

Over time, concerns for Human Factors practitioners have shifted as the nature of the machines with which humans interact has changed. Ease of use is important, but it is just one concern that potentially determines acceptance of a technology by its intended users. Increasingly, the social context in which system use is embedded has gained prominence as a factor to be considered in design. With applications that now enable multiple users, with differing roles and work incentives (such as EHR systems), social and organizational structures become an increasingly integral aspect of context. For EHR systems and other health IT, added dimensions of context and complexity are introduced by policy and regulatory constructs and constraints.

10.4   An Example of UCD in PGHD for Chronic Disease

We present a case of the field use of a mobile reporting application for PGHD to illustrate the iterative application of User Centered Design (UCD) to meet the challenges of designing an application and workflow for chronic disease management.

10.4.1   The Study

In a previously described study, a commercially available mobile reporting application tool was implemented for collecting PGHD in a primary care practice for a 6-month field trial. Seventeen patients, each of whom had a primary diagnosis of chronic hypertension (HTN) or Diabetes Mellitus, Type 2 (DM2) were enrolled [10, 11]. Data collected from use of the deployed system plus field study interviews of stakeholders provided a more realistic analysis of their needs, concerns, capabilities and limitations than possible with an experimental laboratory study. This approach also enabled a view into the important organizational and reimbursement contexts in which the application must function.

In the study, hosted by an urban, primary care practice with a largely college educated, adult patient population, the data collected included:

- Automatically logged PGHD via a mobile application.
- Pre-study interviews from a sample of participants prior to the start of PGHD collection. Patients were asked to discuss the "three most important things your physician has told you to do in regard to your primary health condition". The

interview results provided information about the challenges patients face in putting into practice the medication and lifestyle directives communicated to them by their physicians.

- Post-study interviews feedback on experiences with using the tool to accomplish the task. These provided information on patients' experiences with incorporating the task of data-generation into their daily lives, as well as with actual use of the tool.

- Questionnaire responses from physicians on attitudes and medical practices regarding their patients' self-care of their chronic medical conditions.

    During the data collection period:

- Patients' tasks consisted of a "check-in" response to an automated daily request for his or her status on three health indicators. Questions were sent through a secure mobile application each morning with 24 h allotted for a response to be counted as meeting the daily requirement. The three questions were:

    1. Did you take all your prescribed medication for the day before: "Yes" or "No"?
    2. For HTN, patients were asked to measure and report their morning blood pressure. For DM2, patients were asked to measure and report their morning blood glucose level.
    3. How do you feel: Response on a 5-point scale (1–5), 5 indicating the "best"?

- Physicians' tasks was limited to an expectation that they would respond to alerts if a patient-reported blood pressure or blood glucose level exceeded threshold levels set by the medical practice. The levels selected to trigger alerts corresponded to clinically dangerous levels that normally require immediate medical intervention. The research team failed to convince the medical practice to add alerts corresponding to "high normal" (blood pressure or blood glucose) levels, which could have been used to trigger a consultation or an instruction for the patient. The medical practice defined a process whereby alerts would be sent to the on-call practice care coordinator for triaging the message according to established protocols, including one for passing the alert on to the physician if appropriate.

10.4.2 Initial Findings and Commentary

Results. Seventeen patients/participants generated health data for at least 4 months, some for up to 6 months. Only two participants produced daily responses for the duration of the study. The modal length of time between responses rate was every other day, with the maximum time between responses being as high as 1 week. About 80 % of patients who enrolled did not transition to the study phase (that included actively reporting data). No alerts were generated based on PGHD, so physicians were not contacted.

Patients. Patients are *discretionary* users of the application, that is, they cannot be compelled to use it. To participate in the study, patients had to have a primary diagnosis of either HTN or DM2. They were required to own a personal smartphone (iOS or Android) and to self-report as meeting a target level of proficiency with using the device for computing tasks. Observations re: lower than expected participation rates:

- Usability did not appear to be a barrier. All interview participants gave the application the top score on usability. This was not unexpected as the application used standard controls and navigation conventions for the iOS and Android systems.
- Some patients stated it was not necessary for them to respond every day to get value from using the application. Since their data did not vary significantly from day to day, they felt that reporting less often was sufficient. In addition, reporting once or twice a week was sufficient to keep them focused on their health indicators and enabled them to detect changes in their trends, if any occurred.
- A few patients reported being disappointed that "no one seemed to be paying attention" to their reports and thus they stopped replying to the daily check-in request. In fact, the physicians were largely unaware of the day-to-day progress of the study because, as we noted above, the medical practice adopted a policy that physicians were to be notified only when patient-reported levels reached thresholds that required immediate medical attention and reported levels never reached these thresholds.

Smartphones. The smartphone ownership criterion disqualified 75 % of the patients approached for participation [11]. Low penetration of smartphone ownership among this population of patients may be temporary as ownership is projected to increase rapidly over the next 5 years [40]. Smartphone ownership is inversely correlated with age, with current smartphone ownership for those aged 65+ significantly lower than younger groups [36, 37]. It is unclear if the current age related differences will be eliminated in the future due to younger users maintaining ownership of their phones as they age. Alternatively, they might abandon them due to high cost as they age, as has been reported by current seniors on fixed incomes [37].

Physicians. Physicians are *indirect* users of the application. The literature indicates a wide range of attitudes among physicians regarding patient engagement in self-care, from quite supportive to highly negative. One chief source of negative views on some types of patient engagement stems from their concerns about patients' dependence on getting medical information from untrusted sources [2, 38], requiring physician time and effort to "un-do" impressions their patients form as a result of incorrect or inapplicable information [2, 8]. Physicians in the study were found to welcome patient involvement. They believed patient involvement should include following physician directives but were less clear on the value of incorporating PGHD into care practices.

The medical practice. The practice management indicated a commitment to exploring integrating PGHD into practice, but their plans for consuming the data were constrained by the realities of their reimbursement model. Under the fee-for-

service model, the practice could not afford financially to dedicate a member of their clinical team to respond solely to the incoming data (as required). Thus, they agreed to receive notifications of rare cases/reports flagged as clinically suspicious. Awareness of such events would give the medical practice a previously unavailable capability and thus it incorporated the alert-handling function into its workflow, but it was unwilling to incorporate them into the EHR system. Instead, alerts were routed to the email of a practice care coordinator at the medical practice who was responsible for handling care needs that arose outside of medical appointments.

10.4.3 UCD in Redesign Considerations

In considering design changes, questions from the previously described study include:

- How is it possible to satisfy patients' desire for feedback (i.e., acknowledgement that someone is paying attention, thus motivating them to continue)?
- Are there other configurations for data flow and response that are possible within the user-task-context of the practice that will satisfy the constraints (not having a full time care coordinator for managing incoming data from the application)?

An adaptive part of a possible solution is to use a worker already in the practice: the medical assistant (MA) who is paired with a physician to deliver patient care. The MA or a licensed practical nurse (LPN), already familiar with history taking, taking vital signs and blood glucose measurements, could perform the role of the care coordinator, thus providing contact to the patient, supplemented by reports generated by data analytics [23, 29]. An example of how this might play out for a hypothetical patient, John Smith:

> Mr. John Smith has had DM2 for five years. His HbA1c is at 7.0 and has trended upwards over the past year from a level of 6.0. John has agreed, at his physician's urging, to use the mobile check-in application to report his morning blood sugar level, medication adherence and "feeling good" score "a few times a week" during the three months leading up to his next regular diabetes control appointment. His reports are aggregated at a central server that logs his responses and automatically computes analytics from the data in those responses. Analyses will have been programmed to categorize glucose measurements as:
>
> 1. Low
> 2. Normal
> 3. Elevated but not critical
> 4. Critical
>
>   Critical levels result in an immediate alert being communicated to the MA who follows up according to the rule-based protocols in place at the medical practice. Protocols have also been instituted to provide the MA with responses to the other new category levels, which are designed to:
>
> - Provide weekly feedback for Mr Smith on how he is doing
> - Identify opportunities for educating Mr Smith on elevated but not critical levels, and
> - Generate easily consumable, quarterly reports for his physician to view during the Mr Smith's next appointment.

Each of these new protocols may cover the following issues identified as barriers to use in the field study:

(a) Weekly feedback satisfies Mr Smith's need to know that someone at the practice is paying attention. If all the reported levels fell within the "normal" guidelines, he receives simple feedback noting the "normal" condition and encouragement to continue.

(b) If on occasion levels exceed normal, this would be communicated in a straightforward manner, as, for example: "Mr Smith, your blood glucose level went to 190 mg/dL once this past week. Try to keep it below 140 mg/dL each time". If a pattern of elevated levels is detected by the analytics, then an agreed upon protocol can be automatically dispatched to him. For example, perhaps elevated levels occur during the weekends but are normal for the rest of the week. The medical practice might send a message alerting the patient of the pattern, as well as directing him to take action to get more information. Perhaps something like the following: "This coming weekend, after you send in your numbers, we're going to send you a brief form for you to write in what you ate and drank the night before to see if we can figure out why you're having the higher than normal blood glucose levels. Is that OK?"

(c) If the pattern persists in spite of the dispatch of the protocol to increase awareness, then the medical practice might recommend a meeting with a diabetic educator who will be able to explore issues one-on-one with the patient.

The proposed role of automation is to detect conditions that indicate an event for which the practice wants to respond. This limits the work required by staff in consuming the new stream of data. The MA's role, when the patient comes into the office, is to review with the patient the actions taken over the past 3 months.

This scenario is a preliminary sketch of what a follow-up design might include in order to address the low participation rates by patient and physician as identified in the field trial. Targeted follow up investigations would be needed to validate each of the following components of the proposed solution, which would include:

- Will data analytics be capable of identifying patterns with the fidelity required by the medical practice to map them on to automatic response protocols?
- Will the patient accept an automated response as indication that "someone is listening"?
- How do the summary sheets have to be designed to enable the MAs to effectively and efficiently review the patient's progress during appointments?
- How can an effective summary be designed for the physician to review at the time of an appointment?

The UCD methodology provides detailed guidance for using prototypes with different degrees of fidelity (from paper sketches, through wire-frame screens, through working stand-alone systems) as a means of exploring and refining design ideas. This is particularly valuable with respect to the introduction of technologies to facilitate new processes into contexts already served by other IT systems, such as is the case with respect to technology for PGHD, and constrained by real-world conditions that

create initial barriers to their adoption. Limited deployments enable all stakeholders to begin making necessary adjustments under circumstances where value is clear and to identify for themselves additional potential values from the use of the technology.

10.5 Conclusion

Designing an application in the area of PGHD requires understanding the context of use for the application. Using a Human Factors approach, in particular User Centered Design, provides a fruitful approach for sorting and understanding the myriad factors that embed users of an application within a clinical context. Clearly, understanding these factors does not automatically lead to an optimal design solution and good design is a continually iterative process. Such an approach (and others) will be needed to realize the vision of incorporating PGHD into EHR systems and clinical care of chronic disease as will be required in Stage 3 Meaningful Use of Certified Electronic Health Record Technology.

References

 1. Ahern D, Woods SS, Lightowler MC, et al. Promise of and potential for patient-facing technologies to enable meaningful use. Am J Prev Med. 2011;40(5S2):161–72.
 2. Anderson RM, Funnell MM. Patient empowerment: myths and misconceptions. Patient Educ Couns. 2010;79(30):277–82.
 3. Berwick DM. What "patient-centered" should mean: confessions of an extremist. Health Aff. 2009;28(4):555–65.
 4. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. JAMA. 2002;288(19):2469–75. Brennan, PF. Incorporating patient-generated information to manage health HIT policy committee hearing, 8 Jun 2012. Available from http://www.healthit.gov/archive/archive_files/FACA%20Hearings/2012/2012-06-08%20 Policy%3A%20Meaningful%20Use%20WG%20Patient%20Generated%20Health%20 Data%20Hearing/patti-brennan-patient-generated-data-hearing-testimony-060812.pdf.
 5. Brennan PF. Project health Design: rethinking the power and potential of personal health records. 2014. Available from http://www.rwjf.org/content/dam/farm/reports/issue_briefs/ 2014/rwjf412107.
 6. Brockmann RJ. Writing better computer user documentation: from paper to online. New York: Wiley; 1986.
 7. Chapanis A. The chapanis chronicles: 50 years of human factors research, education, and desing. Santa Barbara: Aegean Publishing; 1999.
 8. Chase D. Patients gain information and skills to improve self-management through innovative tools. The Commonwealth Fund, Dec 2010/Jan 2011.

9. Coury BG, Ellingstad VS, Jolly JM. Transportation accident investigation: the development of human factors research and practice. Rev Hum Factors Ergon. 2013;6(1):1–33.

10. Danis CM, Ballen S, Minitti MJ, et al. Bringing patients into the loop: using technology to engage patients and improve health outcomes. J Health Inf Manag. 2014;28(1):20–7.

11. Danis CM, Minniti MJ, Ballen S, et al. Patient engagement at the point of care: technology as an enabler. In: Grando M, Rozenblum R, Bates D, editors. Information technologies for patient empowerment in healthcare. Berlin/Boston/Munich: Walter De Gruyter Inc. 2015.

12. DiMatteo MR, Haskard-Zolnierek KB, Martin LR. Improving patient adherence: a three-factor model to guide practice. Health Psychol Rev Health Psychol Rev. 2012;6:74–91.

13. DPP (The Diabetes Prevention Program Research Group at the Biostatistics Center, George Washington University). Description of lifestyle intervention. Diabetes Care. 2002;12:2165–71.

14. ECDG (European Commission Directorate General for Communication). Eurobarometer qualitative study on patient involvement. 2012. Available at: http://ec.europa.eu/public_opinion/archives/quali/ql_5937_patient_en.pdf. Accessed Nov 2013.

15. Emont S. Measuring the impact of patient portals: what the literature tells us. Oakland: California Health Care Foundation; 2011. http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/M/PDF%20MeasuringImpactPatientPortals.pdf. Accessed 19 Apr 2015.

16. Gould JD, Lewis C. Designing for usability: key principles and what designers think. Commun ACM. 1985;28(3):300–11.

17. Gould JD. How to design usable systems. In: Helander M, editor. Handbook of human-computer interaction. Amsterdam: Elsevier Science Publishers; 1988.

18. Grudin J. Why CSCW applications fail: problems in the design and evaluation of organizational artifacts. ACM conference on computer supported cooperative work (CSCW 88); Portland; 1988. p. 362–69. p. 85–93.

19. Grudin J. Groupware ane social dynamics eight challenges for developers. Commun ACM. 1994;37(1):93–104.

20. Harris D. Improving aircraft safety. Aviat Psychol. 2014;27(2):90–5. Available from: http://www.aerotelegraph.com/sites/default/files/n238/Artikel.pdf.

21. Hibbard JH, Mahoney ER, Stock R, et al. Self-management and health care utilization: do increases in patient activation result in imposed self-management behaviors. Health Res Educ Trust. 2006. doi:10.1111/j.1475-6773.2006.00669.x.

22. Irby C, Bergsteinsson L, Moran T, et al. A methodology for user interface design. Xerox Palo Alto Research Center Internal Report. 1977.

23. James G, Witten D, Hastie T, et al. An introduction to statistical learning. New York: Springer; 2013.

24. Jones L, Danis C, Boies SJ. Avoiding the mistake of cloning: a case for user-centered design methods to reengineer documents. System sciences. 1999. HICSS-32. In: Proceedings of the 32nd annual Hawaii international conference on, Volume: Track2.

25. Karat C. Cost-justifying human factors support on development projects. Hum Factors Soc Bull. 1992;35(11):1–8.

26. Kirwan B, Ainsworth LK, editors. A guide to task analysis: the task analysis working group. Boca Raton: Taylor & Francis Group, LLC.; 1992.

27. Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum. 1993;36(4):439–46.

28. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. Med Care. 1999;37(1):5–14.

29. McNeill D, editor. Analytics in healthcare and the life sciences. Upper Saddle River: Pearson; 2013.

30. Michie S, Abraham C, Whittington C, et al. Effective techniques in healthy eating and physical activity interventions: a meta-regression. Health Psychol. 2009;28(6):690–701.

31. Myers B, Hudson SE, Pausch R. Past, present, and future of user interface software tools. ACM Trans Comput-Hum Interact (TOCHI) – Spec Issue Hum-Comput Interact New Millennium. 2000;7(1):3–28.

32. Orlikowslki WJ. Learning from notes: organizational issues in groupware implementation. In: Proceedings of ACM conference on computer supported cooperative work (CSCW 92). Toronto; 1992. p. 362–69.

33. Paap KR, Roske-Hofstrand RJ. The design of menus. In: Helander M, editor. Handbook of human-computer interaction. Amsterdam: Elsevier Science Publishers; 1988.

34. Paperny DMN. Privacy issues. In: Lehmann C, Kim GR, Johnson KB, editors. Pediatric informatics: computer applications in child health. New York: Springer Verlag; 2009.

35. PCPCC (Patient Centered Primary Care Collaborative). Transforming patient engagement: health IT in the patient centered medical home. 2010. Available at: http://www.pcpcc.org/guide/transforming-patient-engagement. Accessed 30 May 2014.

36. Pew Research Center. Mobile technology fact sheet. 2014. http://www.pewinternet.org/fact-sheets/mobile-technology-fact-sheet/.

37. Pew Research Center. Older adults and technology use: usage and adoption. 2014b. http://www.pewinternet.org/2014/04/03/usage-and-adoption/.

38. Schulz PJ, Nakamoto K. "Bad" literacy, the internet, and the limits of patient empowerment. AAAI Spring Symposium. 2011.

39. Shapiro M, Johnston D, Wald J, Mon D. Patient-generated health data: white paper prepared for the Office of the National Coordinator for Health IT by RTI International. Apr 2012. http://www.rti.org/pubs/patientgeneratedhealthdata.pdf.

40. Statista. Number of smartphone users in the US from 2010 to 2018. 2014. http://www.statista.com/statistics/201182/forecast-of-smartphone-users-in-the-us/.

41. Sujansky & Associates LLC. A standards-based model for the sharing of patient-generated health information with electronic health records. 2013. Available from http://www.projecthealthdesign.org/media/file/Standard-Model-For-Collecting-And-Reporting-PGHI_Sujansky_Assoc_2013-07-18.pdf.

42. Taylor F. Principles of scientific management. New York: Harper & Row; 1911. Available from https://www.marxists.org/reference/subject/economics/taylor/principles/.

43. Terry K. Meaningful use 2: a work in progress for physicians. 2014. Available from http://medicaleconomics.modernmedicine.com/medical-economics/news/meaningful-use-2-work-progress-physicians?page=full.

44. vonKorf M, Gruman J, Schaefer JK, et al. Collaborative management of chronic illness. Ann Inter Med. 1997;127:1097–102.

45. Whelton PK, Appel LJ, Espeland MA, et al. A randomized controlled trial of nonpharmacologic interventions in the elderly (TONE). JAMA. 1998;279(11):839–46. Erratum in: JAMA, 24;279(24):1954.

46. Wixon D, Jones S. Usability for fun and profit: a case study of the design of DEC RALLY version 2. Internal report, Digital Equipment Corporation. 1991.