Review

Examining the evidence of the impact of health information technology in primary care: An argument for participatory research with health professionals and patients

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\textbf{A B S T R A C T}

\textbf{Purpose:} Health information technology represents a promising avenue to improve health care delivery. How can we use lessons learnt from existing health information technologies in primary care to inform the optimal design of newer developments such as personal health records?

\textbf{Methods:} The results of systematic literature reviews about the impact of different information systems on health outcomes in primary care are critically discussed in a narrative synthesis, with a focus on their implications for the development of personal health records.

\textbf{Results:} Given the proliferation of systematic reviews and randomized controlled trials, high quality evidence for health information technology in primary care is accumulating with mixed results. The heterogeneity of systems being compared and the quality of research can no longer account for these findings. One potential explanation may be that systems originally designed for acute care settings are being implemented in primary care. Early studies evaluating personal health records suggest that targeting patient outcomes directly and adapting systems to patients’ needs may be part of the solution.

\textbf{Conclusion:} In order to develop personal health records for primary care, studies are needed that involve the users, namely patients and primary care health professionals, in the design and evaluation of these systems from their inception. Participatory research is a recommended methodological approach.

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\textbf{Contents}

1. Introduction – health information technology ................................................................. 655
2. Methods ........................................................................................................................... 655

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1. Introduction – health information technology

There is no dispute that health information technologies (HIT) represent one of the most promising avenues to modernize and improve health care delivery [1]. The push for computerization has been largely motivated by concerns regarding the diminishing safety and increased variation of patient care [2–4]. Using HIT to have timely access to complete patient health information and to provide evidence-based decision support at the point of care is supposed to reduce medical errors and to enhance clinical decision making [1]. While this is expected to yield clinically significant improvements in patient health outcomes by reducing adverse events and improving quality of care, the reported results have not been straightforward. For instance, order entry systems have been shown to reduce rates of medical errors in the hospital settings [5], while the effect on safety in primary care has yet to be demonstrated [6].

A variety of systems have been developed and implemented in attempts to improve health care delivery. These systems include simple electronic health or medical records (EHR, EMR) that replace paper records for information storage and retrieval [7], and in the recent literature they are coupled with more sophisticated computerized physician order entry (CPOE) helping with the management of prescriptions or diagnostic tests [8]. The latter are often used together with clinical decision support systems (CDSS), which provide computer-triggered or on-demand advice according to clinical guidelines [9]. Personal health records (PHR) represent the most recent platform and allow patients to consult and manage their own health information, and sometimes even to communicate electronically with their health care providers [10]. With such a diversity of systems and functions, evaluating the impact of HIT can be challenging.

Certainly in North America, most HIT systems that have been successfully introduced with a demonstrated positive impact on patient health outcomes, have occurred in acute care settings. Only a small proportion of HIT systems have been successfully introduced into primary care settings in North America in contrast to countries such as the UK, the Netherlands and many European Union countries [11]. Acute care is concerned with the management of clinically serious acute episodes of care, while primary care generally manages patients with chronic illness and also provides preventive care [12]. Effective primary care requires access, continuity and comprehensiveness of care that is community focused [13]. Theoretically, the potential of HIT systems should be even greater in primary care, due to the ability to provide improvements in all these aspects of care. More concretely these factors include the large number of patients with chronic, co-morbid conditions that require therapeutic treatment, ongoing monitoring and where evidence and clinical guidelines are regularly being updated added to the fact that a large proportion of medications are prescribed by primary care physicians [12]. However, the evidence supporting improvements in health outcomes at the primary care level is neither straightforward nor readily convincing [6,14].

With over a decade of research behind us about the implementation of HIT in both acute and primary care settings [15], lessons should be drawn from the continued uncertainty of their impact, as we turn to the new, promising HIT currently being developed and implemented with PHR [16]. In other words, how can we use lessons learnt from primary care HIT to inform the optimal design of PHRs? The purpose of this narrative synthesis is to review the evidence of the performance HIT on patient health outcomes in primary care, and provide a coherent case to support the involvement of patients in the design of PHRs that directly target patient-level outcomes. We will develop our arguments of the potential explanations for the poor performance and our proposed approach for PHR development and implementation based on the latest published evidence. This will be done using the most current systematic literature reviews and articles published since the reviews.

2. Methods

An assessment of the findings of overlapping systematic reviews was carried out, with an examination of all the primary and secondary studies that focused on adverse drug events and patient health outcomes in primary care with adult populations. An adverse event was defined as “an unintended injury or complication caused by delivery of clinical care rather than by the patient’s condition” [17] (p. 1555). In light of the rapid development of information systems, the papers that formed the basis for our narrative synthesis were limited to literature published between 2005 and 2011. Systematic literature reviews were of primary relevance. We then adapted our search strategies in Medline and EMBASE to find new literature since the publication of the main systematic reviews that might have influenced the state of knowledge.

The results consist of a narrative synthesis critically discussing the evidence and the implications for the development of PHRs. The themes addressed include the mixed results of diverse information systems on health outcomes...
in primary care, the explanations that could potentially account for these results in light of an accumulation of high quality evidence, and finally the parallels that can be drawn with the early evaluative literature of PHRs. The conclusion offers recommendations to improve the implementation and evaluation of information technology in the context of primary care specifically, and suggests a research approach that may improve PHR utilization and thereby increase the positive impact on patient health outcomes in primary care.

3. Results

3.1. The poor performance of HIT in primary care as compared to acute care

There are considerably fewer studies about health outcomes and patient safety than about provider adherence with clinical guidelines and satisfaction. The results of a thorough review of systematic reviews by Black et al. highlights the gap between commonly expected benefits of HIT and empirical demonstrations [18]. While Buntin et al. found predominantly positive results when reviewing evaluations of HIT, studies focusing specifically on patient health outcomes in primary care tell a different story [19]. If we look closely at the care setting, the studies in the acute care inpatient setting more consistently report significant improvements in reducing rates of adverse drug events and selected patient outcomes.

Many overlapping systematic reviews in primary care established the lack of clear evidence supporting improvements in quality of care or health outcomes. Eslami et al. [6] focused on CPOE in primary care and found 4 studies evaluating their impact on medication safety, with only one of these studies showing a reduction in ADEs. Conflicting results were also obtained in systematic reviews about the impact of CDSS [14,20,21]. Studying CDSS and patient outcomes in inpatient as opposed to outpatient settings, Sintchenko et al. [15] remarked that only 31% of the studies in the latter group had a positive change after implementation, as opposed to 100% of the inpatient studies. Overall, looking at the original studies reported in systematic reviews and studies published since then, it appears that between 2005 and 2011, 5 out of 10 studies testing various systems have failed to demonstrate improved patient outcomes in outpatient populations [22–31], while 6 out of 7 studies in the inpatient setting report improvements in diverse areas such as thromboembolism, adverse drug events, and mortality rates [32–38] (Table 1). In conclusion, the positive impact of HIT on patient safety and health outcomes in primary care has not clearly been demonstrated as it has in acute care settings.

3.2. Strength of explanations for poorer performance

The poorer performance of HIT in primary care despite their even greater potential deserves examination. While there may be several reasons that might account for these differences, we have focused on the main explanations that have been proposed and explore the strength of the rationale behind each of them in this section.

There are several problems affecting the evaluation of HIT that are not specific to primary care. Many authors admit that we still have a poor understanding of why certain information systems are successfully implemented and yield improvements in patient-level outcomes while others do not [18]. Electronic health records (EHRs) and similar terms are used to describe heterogeneous systems that often include inconsistent or unspecified applications, such as information storage and retrieval, medication and laboratory order entry, email functions, decision support and reminder alerts. Many of these systems are country-specific, homegrown or simply unspecified in the articles, so that comparison of the research about their implementation and impact is inherently problematic. As Weir et al. point out, [39] a variable such as CPOE is very complex and can vary in terms of functions, decision-support features, implementation strategies, and customization.

In light of the poor construct validity of CPOE, no two studies appear to have implemented the same attributes, even while testing the same functions [39]. Two surveys in the US further revealed that over 60 different systems are used by general practitioners, most of them being reported by three or fewer respondents [40,41]. Shekelle and Goldzweig [42] point out that few studies exist evaluating commercially developed systems.

Similarly, measures of the actual usage of the systems during the intervention is often lacking in evaluations despite the fact that it would be important to know whether the results are non-significant simply because providers did not use the CDSS. Sintchenko et al. [15] further highlight the difficulty of producing clinically relevant changes with interventions that are only indirectly targeting patient-level outcomes. Improving provider compliance with clinical guidelines may only have diluted effects on the health of patients. However, from the evidence reviewed, we cannot conclude that these limitations and the difficulty of evaluating complex interventions in health organizations [43] are any less problematic for research that occurs in acute care settings. The lack of convincing results can no longer be attributed to the later introduction of these systems in the context of primary care as a considerable body of high quality evidence is accumulating.

Given the proliferation of systematic reviews and high level of evidence via randomized control trials (RCTs), the later introduction of the technology and the quality of research are no longer plausible explanations of the poorer performance of HIT in primary care.

We suggest that the remaining explanation concerns the different nature of primary care delivery and the misfit that may occur with information systems that were originally designed for acute care settings. Primary care physicians and other health professionals have been documented as noting the poor fit between the cognitive processes they go through in their clinical work and the implemented HIT [44]. Bates et al. [45] concur that primary care providers often expect HIT to interfere with their workflow. In other words, the implementation of systems that were designed for acute care may present one of the most compelling reasons for their disappointing performance, as these systems may simply not be tailored appropriately for improving downstream health outcomes and safety in primary care. For instance, HIT as we know it may be effective in reducing the risks of medication errors engendered by the cross-coverage of many health professionals in the event of intensive periods of care [1],...
which may be less relevant in primary care. In fact, while studies in the inpatient settings are more likely to address medication errors, adverse-drugs events, secondary prevention, and mortality rates, in primary care the health outcomes studied concern chronic diseases, such as diabetes, hypertension, elevated cholesterol, and osteoporosis. As we will explore, targeting patient-level outcomes directly in primary care with systems that are specifically designed to suit the needs of patients and primary care providers holds the most promise.

In sum, the challenges of comparing different systems and of coming up with robust research designs are equally important in the acute as in the primary care settings. What differs is the added difficulty of adequately implementing systems that were designed for intense episodes of care. In primary care, the variety of conditions, the volume of patients, disease presentation and the length of follow-up all differ from acute care [12]. In this context, part of the solution may be to design systems that target health outcomes and quality of care issues that are specific to primary care. As Buntin et al. concluded, the human element and staff “buy in” are crucial to the success of HIT [19], and offering personalized HIT systems would certainly contribute to securing the interest of stakeholders. If we are to demystify what exactly is failing in the mechanism of improving patient safety and patient health outcomes, evaluative research has to clarify the different steps that would lead from the introduction of a given system to tangible improvements in a specific patient-level outcome. There is no denying that health indicators are influenced by a wide range of factors beyond primary care delivery, and this is why incorporating different sources of information that may come from a new HIT such as personal health records (PHRs) is so promising for primary care.

3.3. The early performance of PHRs in primary care

The personal health record (PHR) is a relatively new HIT that is generally defined as some type of electronic platform that allows patients to manage their health information. This may include access to EHRs and to various other functions, such as electronic communication with health care providers [46]. With the disappointing performance of other HIT in primary care and growing dissatisfaction with the health care system on the part of patients, PHRs are now expected to yield significant outcomes in terms of quality of care, patient health outcomes, and most importantly, they are proposed as one means of involving patients in the therapeutic relationship [10,47]. Active involvement of patients in the patient–provider relationship, also called shared decision-making [48], is being increasingly advocated in preference-sensitive care [49] and in patient-centered care [50]. PHRs are unique in that they target patient outcomes more directly than previous HIT by involving patients in checking the accuracy of their information and in self-management plans. Even before the use of electronic platforms, patient involvement in self-management has yielded impressive results in terms of control of chronic illnesses [51,52]. Patients with chronic conditions are likely to benefit even more from having access to their personal health records,
making it easier to track their health, their treatment plans and appointments.

In terms of fulfilling its promises, early evaluations of PHRs on patient outcomes and quality of care are encouraging albeit modest [52-54]. Looking at original studies, we found 5 RCTs reporting small but significant improvements in some clinical outcomes, especially glycemic control in diabetic patients [55-59]. The study by Grant et al. is the only one that did not yield significant results: for diabetic patients using the PHR, baseline glycemic control did not change significantly in either the intervention or control groups over the duration of the trial [60]. Statistical significance is not a panacea, however, and the changes reported are often small, with the intervention by Holbrook et al. decreasing glycated hemoglobin by a mere 0.2% [56]. Archer et al. conclude that the results on patient-level outcomes remain disappointing, and point to a lack of patient-oriented functionalities as one explanation. Systematic reviews also warn that interventions tend to be complex and multi-faceted, so that the direct impact of patient involvement is not always straightforward [53].

4. Conclusion – harnessing the full potential of PHRs in primary care

As previously outlined, there is a need to develop optimal research designs to study health impacts with better internal validity and better construct validity by providing thorough descriptions of the systems being studied [39]. While these will be important for the appropriate evaluation of PHRs, the arguments we have presented indicate that if PHRs are to improve the health of patients in general, then systems need to be developed for and targeted to patients specifically [52,61]. In order to be certain this is achieved, as supported by a growing body of literature on knowledge translation, we propose that the involvement of the users of PHR, namely the patients, are essential for the development of platforms that will help harness the full potential of PHRs in primary care.

The current movement toward patient involvement in decision-making and self-management represents an unprecedented avenue to target patient health outcomes more directly. It is fair to assume that if patients and primary care providers had been systematically involved in designing information systems tailored to their needs, there would be scientific literature documenting this research and development process. To our knowledge, only one study has reported using patients’ feedback in PHR development and found that they can make significant contributions to their development by highlighting different elements of the systems [62]. Given the scarcity of evidence, it appears that most HIT systems have not only been designed for acute care, but they have also been designed for the use of providers rather than patients [52]. It is reasonable to expect that replicating these earlier systems will produce PHRs that are poorly suited to involving patients in primary care delivery. Patient participation in the provision of accurate and relevant information is one of the missing links to improve health outcomes in primary care. But more than being only involved in checking the accuracy of information in their PHRs, patients should participate in designing systems that they will be willing and able to use.

Early research about poor uptake of PHRs and about security concerns demonstrates the need for such involvement. PHRs have the potential to improve patient–provider relations and to promote shared decision-making by taking the patient’s perspective into account [10]. Chronic care would greatly benefit from information about the patients’ lifestyle and beliefs about the condition, as this could contribute to the development of feasible treatment plans that can be realistically adhered to by patients. Involving a diverse group of patients may also help offset the divide that has been observed in adoption rates of PHR in ethnic minority groups [63]. This would foster the development of systems that make room for a variety of patients’ perspectives, and thus also contribute to promoting shared decision-making and self-management of long-term illness.

An efficient way of developing user-oriented PHRs would be to carry out a study that involves patients in the design and use of these systems from their inception, in order to make sure that they meet their expectations in terms of functions and security. Participatory research is the process of producing new knowledge by “systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change” [64]. Such a study could involve patients in every step of the research process, to develop systems in consultations with patients, and to come to an agreement about what patients want to achieve with an access to their health information. When stakeholders collaborate in research as equals, the approach has been found to maximize community and lay involvement [65]. Asking users what they want may represent an excellent strategy to improve the uptake, enrich innovations and increase the impact of diverse HIT in primary care. In light of the evidence reviewed, unless both patients and health care providers are involved in the design and use of new generations of PHRs specifically for primary care, the problems of persistent uncertainty over their impact on health outcomes will recur, and the tremendous potential of patient participation in chronic disease management at the primary care level may never materialize.

Authors’ contributions

EB conducted the literature search and drafted the article under the supervision of GB. All authors reviewed the paper multiple times during the writing process and contributed significant ideas to the overall argument.

Conflict of interest

The authors declare that they do not have any conflict of interest.

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Summary points
What is already known about the topic?

- Health information technology has great potential to improve patient health outcomes in primary care.
- High quality evidence is accumulating that health information technology is not having a clear impact on patient health outcomes in primary care in contrast to the consistent benefits seen in acute care.

What the study adds?

- The lack of fit between health information technology and the specific needs of patients and health care providers in primary care represent the most plausible explanation for the lack of impact on health outcomes.
- Both patients and providers should be involved in the design and use of new generations of PHRs if we are to harness their potential in primary care.

in the Age of Personal Health Record. Emmanuelle Belanger, MSc, McGill University; Gillian Bartlett, PhD; Charo Rodriguez, MD, PhD; Martin Dawes, MD).

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