

Enabling Patient-Centered Care Through Health Information Technology

Executive Summary

Introduction

The Institute of Medicine defines patient-centered care (PCC) as “care that is respectful of and responsive to individual patient preferences, needs and values,” ensuring that patient values guide all clinical decisions.¹ The Institute of Medicine has recognized PCC as one of six major domains of health care quality. While the health care community widely recognizes the potential of health information technology (IT) in enabling PCC, we have yet to see an evidence-based comprehensive analysis of its impact on quality of care. In addition, there does not yet exist a systematic review of barriers and facilitators for health IT-enabled PCC. This report reviews the evidence on the impact of health IT applications developed and implemented to enhance the provision of PCC. The report identifies barriers and facilitators for the use of health IT applications to deliver PCC. It also identifies gaps in the literature and recommends future research endeavors. The report pays particular attention to the role of health IT in improving shared decisionmaking, patient-clinician communication, and access to medical information by patients.

Key Questions

The following Key Questions are addressed in this report.

Key Question 1. Are health IT applications that address one or more components of PCC effective in improving the following outcomes,

Evidence-based Practice Program

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

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and how do the outcomes vary by type of health IT application?

- a. Health care process outcomes (e.g., receiving appropriate treatment)
- b. Clinical outcomes for patients (including quality of life)
- c. Intermediate outcomes such as patients' improved health knowledge, health behaviors and physiologic measures, patient satisfaction, and reduced costs
- d. Responsiveness to the needs and preferences of individual patients
- e. Shared decisionmaking between patients, their families, and providers; patient-clinician communication; or providing patients or clinicians access to medical information

Key Question 2. What are barriers or facilitators that clinicians, developers, patients, and their families or caregivers encounter that may impact implementation and use of health IT applications to enable PCC?

Key Question 3. What knowledge or evidence deficits exist regarding needed information to support estimates of cost, benefit, impact, sustainability, and net value with regard to enabling PCC through health IT?

Key Question 4. What critical information regarding the impact of health IT applications implemented to enable PCC is needed to give consumers, their families, clinicians, and developers a clear understanding of the value proposition particular to them?

Methods

We used a conceptual framework to guide our systematic review and based it on a synthesis of existing models of PCC. We used a systematic approach to searching the literature to minimize the risk of bias in selecting articles for inclusion in the review. Searching the literature involved identifying reference sources, formulating a search strategy for each source, and executing and documenting each search. For the searching of electronic databases, we began our search process by identifying relevant medical subject heading terms.

Our comprehensive search included electronic and hand searching of peer-reviewed literature databases and gray literature databases. We ran searches of the MEDLINE®, Embase®, Cochrane Library, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, INSPEC, and Compendex databases through July 31, 2010.

The systematic review followed the protocol of the Evidence-based Practice Center Program and included the following steps: title review, abstract review, article review, data abstraction, quality assessment, data synthesis, and grading of the strength of evidence.

Results

The search process identified 17,749 citations that were potentially relevant to Key Questions 1 and/or 2, and 150 additional articles were identified through hand searching. Ultimately, we found 327 articles that met our eligibility criteria and that were applicable to Key Question 1 (184) and/or Key Question 2 (206), with 63 articles that were eligible for both questions.

Key Question 1a. Are health IT applications that address one or more components of PCC effective in improving health care process outcomes, and how do these improvements vary by type of health IT application?

We identified 97 articles evaluating the effect of health IT applications that facilitate PCC on health care process outcomes. The studies most commonly employed the following health IT applications: clinical decision aids (34 studies), IT-guided disease management (17 studies), and telemedicine or telemonitoring systems (20 studies). The components of PCC addressed most frequently were related to coordination and integration of care, and an enhanced clinician-patient relationship. The process outcomes most frequently focused on compliance with standards of care for testing and treatment, or use of health care resources. The study results suggested an overall positive effect of health IT interventions on process outcomes. Overall, study quality was high, but quality scores were highly variable. The primary reasons for lower quality scores were issues with studies not being double blinded or not describing loss to followup.

Many high-quality randomized controlled trials have examined the effectiveness of health IT applications on process outcomes, and the breadth of clinical conditions studied has been substantial. Study populations have varied from as few as 10 patients to more than 1,000. The studies have targeted physicians, nurses, and patients and have used many different types of health IT. Settings have included hospitals, outpatient practices, and patients' homes. These numerous differences make direct comparisons between studies difficult, and yet the majority of effects on process outcomes have been positive, and many of them have been statistically significant.

Each type of health IT application studied, from decision support to telemedicine to tools for patient self-management, has resulted in positive, and often significant, improvements in process outcomes. The evidence is insufficient to determine whether any particular type is more effective than the others, but telehealth applications and care management tools were the health IT types most frequently cited as having a positive impact on at least one health care process outcome.

Key Question 1b. Are health IT applications that address one or more components of PCC effective in improving clinical outcomes for patients, and how do these improvements vary by type of health IT application?

Ninety-two studies evaluated the impact of health IT applications on clinical outcomes. They most commonly employed the following health IT applications: clinical decision aids (23 studies), IT-guided disease management (19 studies), and telemonitoring systems (18 studies). The studies related to this Key Question most commonly targeted heart disease (16 studies), diabetes (21 studies), asthma (9 studies), obesity (7 studies), mental health (6 studies), chronic obstructive pulmonary disease (COPD) and chronic lung disorders (4 studies), and cancer (4 studies). The components of PCC addressed most frequently were related to coordination and integration of care, and an enhanced clinician–patient relationship. Overall, we found that various health IT applications implemented to enhance PCC generally improved clinical outcomes for patients with diabetes, heart disease, cancer, and other health conditions, and several of these interventions showed a statistically significant favorable impact. The evidence is insufficient to determine whether any particular type of health IT application is more effective than the others, but the studies we reviewed more frequently cited telehealth applications and care management tools as having a positive impact on at least one clinical outcome.

Key Question 1c. Are health IT applications that address one or more components of PCC effective in improving intermediate outcomes for patients, and how do these improvements vary by type of health IT application?

Eighty-seven studies evaluated the effect of health IT applications on intermediate outcomes. The health IT applications most commonly addressed in these studies were telemonitoring (18 studies), clinical decision aids (16 studies), and IT-guided self-management (16 studies). The studies most commonly targeted diabetes mellitus

(13 studies), heart disease (6 studies), or cancer (6 studies, including breast cancer, prostate cancer, melanoma, and other cancer). The most frequently included components of PCC were related to coordination and integration of care, and an enhanced clinician-patient relationship.

While the number of studies is large, the studies are heterogeneous in a number of aspects. Many of the studies did not report patient characteristics that are relevant to interpreting intermediate outcomes. These studies considered a wide range of outcomes, which is both a strength, contributing to their applicability to clinical experience, and a weakness, making it more difficult to summarize the findings. The most prominent heterogeneity among these studies, however, was the lack of consistent measures of intermediate outcomes.

The target condition for which the most evidence is available for effective interventions is diabetes mellitus. This could be explained by the fact that diabetes had the largest number of studies considering intermediate outcomes.

The studies most frequently cited telehealth applications as having an effect on intermediate outcomes, but less than half of the telehealth applications had a statistically significant positive effect on at least one intermediate outcome. In contrast, for three of the health IT types that had fewer studies of intermediate outcomes (care management tools, personal health records/patient portals, and electronic messaging), the majority of studies reported a statistically significant positive effect on at least one intermediate outcome. This observation makes it difficult to formulate any strong conclusion about how the impact on intermediate outcomes varies by type of health IT application.

Key Question 1d. Are health IT applications that address one or more components of PCC effective in improving responsiveness to the needs and preferences of individual patients, and how do these improvements vary by type of health IT application?

Fourteen studies addressed the impact of health IT applications on improving responsiveness to the needs and preferences of individual patients. The studies evaluated several types of health IT, including clinical decision aids, IT-guided disease management tools, and shared decisionmaking tools. Three studies addressed cancer, and the remainder addressed asthma, COPD, hormone replacement therapy, obesity, osteoporosis, pregnancy, smoking, and wounds. The studies most commonly addressed components of PCC related to coordination

and integration of care, and an enhanced clinician-patient relationship.

The majority of identified studies reported positive outcomes related to the use of health IT. In the case of cancer (for which the review identified seven studies) and diabetes (for which the review identified three studies), most studies reported positive outcomes, suggesting a positive impact of health IT on improving responsiveness to the needs and preferences of individual patients.

The studies reviewed for this Key Question most frequently cited telehealth as the health IT application that improved responsiveness to patient needs, but only three of the seven telehealth studies reported a statistically significant impact. In contrast, for three of the health IT types that had fewer studies on responsiveness to patient needs (care management tools, personal health records/patient portals, and electronic messaging), at least half of the studies reported a statistically significant positive effect on at least one measure of responsiveness. This observation makes it difficult to formulate any strong conclusion about how the impact on responsiveness to patient needs varies by type of health IT application.

Key Question 1e. Are health IT applications that address one or more components of PCC effective in improving shared decisionmaking between patients, their families, and providers; patient-clinician communication; and access to medical information; and how do these improvements vary by type of health IT application?

Twenty-five studies addressed the impact of health IT applications on improving shared decisionmaking or related measures of patient-clinician communication or access to information. The studies most frequently used clinical decision aids (six studies), shared decisionmaking tools (seven studies), and telemedicine or telemonitoring systems (seven studies). The components of PCC addressed most frequently were related to coordination and integration of care, and an enhanced clinician-patient relationship. Heart disease was the clinical condition targeted most frequently (five studies). Three studies addressed cancer, and three studies addressed menopause or hormone replacement therapy.

The outcomes measured were highly variable. They included health care choices after exposure to health IT interventions, satisfaction with decisions, decisional conflict, and communications with providers. Overall, the health IT applications reviewed improved patient communication with providers and patient knowledge levels, thereby indicating improved access to medical

information. Interventions that focused on integration of care and information exchange had consistently positive effects. Decision aids for patients and providers had variable effects on shared decisionmaking and decisional conflict. The studies did not report any negative effects.

The studies most frequently cited shared decisionmaking applications as having at least one positive effect on shared decisionmaking or communication, and in most cases those studies reported a statistically significant effect. Although only four studies used care management tools to assess the impact on shared decisionmaking and communication, all four of those studies reported at least one positive outcome, which was statistically significant in three of the studies. Telemedicine and other interventions that focused on integration of care and information exchange generally had positive effects on patient-provider communications and satisfaction among patients and providers. Tailored health IT interventions aimed at increasing patient engagement during the clinical encounter yielded positive results on patients' question-asking behaviors and patient and provider satisfaction.

Key Question 2. What are barriers and facilitators that clinicians, developers, patients, and their families or caregivers encounter that may impact implementation and use of health IT applications that address patient-centered care, and how do these barriers and facilitators vary by type of health IT application?

Two hundred six studies addressed the barriers or facilitators for the use of health IT applications to enable PCC. The reviewed studies included randomized controlled trials, quasi-experimental studies, pilot studies, case studies, surveys, cost-benefit analysis, and qualitative research. Studies focused on a wide variety of clinical conditions, including diabetes mellitus, cardiovascular disease, heart failure, COPD, cancer, asthma, mental health, sickle cell disease, and chronic pain. Health IT barriers and facilitators can apply to the patients, clinicians, and developers.

The studies identified several barriers or facilitators for utilization of health IT applications to deliver PCC. The barriers included poor interface usability and problems with access to the health IT application due to older age, low income, education, cognitive impairments, and other factors. The studies also mentioned low computer literacy in patients and clinicians, and insufficient basic formal training in use of the health IT application as barriers to effective use. Studies also identified physicians' concerns about potential new work, problems with workflow, and problems related to new system implementation, including the lack of adequate funding. Both patients and physicians

worried about confidentiality of patient information. Other studies cited depersonalization, incompatibility with current health care systems, concerns over privacy, the need for standardization of health IT applications, and problems with reimbursement as potential barriers. Several studies suggested that a high rate of satisfaction with an application's ease of use, perceived usefulness, and efficiency of use can drive utilization of health IT in patients and physicians. Other studies mentioned availability of support, comfort in use, and site location as facilitators of health IT implementation and use.

In the published literature on care coordination tools, increases in workload or changes in workflow were noted as the most common barriers to use, while the most common facilitator was ease of use. Among telehealth studies, access, training, and usability were reported as frequent barriers to use, while satisfaction was the most prominent facilitator. More than 30 percent of studies examining use of personal health records and patient portals reported access as a barrier to use, while satisfaction and ease of use were seen as facilitators in another 20 percent of studies. Studies of secure electronic communication cited training and confidentiality issues as substantial barriers to use, while ease of use and efficiency were the most common facilitators of use. Two studies of shared decisionmaking reported increases in workload or changes in workflow as a barrier to use, while satisfaction, ease of use, and efficiency were commonly seen as facilitators of shared decisionmaking interventions.

Key Question 3. What knowledge or evidence deficits exist regarding needed information to support estimates of cost, benefit, impact, sustainability, and net value with regard to enabling PCC through health IT?

Despite the substantial body of evidence on Key Questions 1 and 2, we found important deficits regarding the information needed to support estimates of the cost, benefit, impact, sustainability, and net value of using health IT to enable PCC. Most of the existing evidence focuses on process outcomes, clinical outcomes, and intermediate outcomes, with a paucity of research on the effects of health IT on responsiveness to the needs, preferences, and values of individual patients or on shared decisionmaking with patients, their families, and providers. Also, very few studies addressed the cost or sustainability of using health IT to promote PCC. Without stronger evidence on specific PCC-related outcomes, it will be difficult to determine the net value of enabling PCC through health IT. Furthermore, few studies examined the role of health IT in improving PCC among pediatric and elderly populations, and no studies were designed to assess how the effectiveness

of health IT in promoting PCC may differ by racial and ethnic background, education, or socioeconomic status. Finally, relatively little evidence exists on the effectiveness of health IT for enabling PCC for patients with clinical conditions other than diabetes mellitus, heart disease, hypertension, or cancer.

Key Question 4. What critical information regarding the impact of health IT applications implemented to enable PCC is needed to give consumers, their families, clinicians, and developers a clear understanding of the value proposition particular to them?

To understand the value of health IT in promoting PCC, all stakeholders need information not only about the effectiveness of health IT applications for specific purposes, but also about their applicability to particular settings. To meet the needs of different types of stakeholders, investigators should engage consumers, their families, clinicians, and developers in the design of studies and the selection of the most important outcomes to assess. Stakeholders will gain better understanding of the value of health IT for promoting PCC if the selected outcomes are defined in a more standardized way. The outcomes in such studies should include measures of the effects of health IT on costs and provider efficiency.

Limitations

One of the major limitations of this review is the wide heterogeneity of included articles. We believe that this heterogeneity reflects the current trend of explosive expansion of health IT applications in various areas of health care delivery. However, such heterogeneity prevented us from being able to perform a meta-analysis, since too few articles had fully comparable interventions with similar outcomes. In addition to the heterogeneity of the subjects, settings, conditions, and technologies studied, a few other limitations to these studies are notable. First, the primary outcomes studied were very diverse even in the framework of each Key Question. While real improvements in all outcomes are the ultimate goal, standardization of core outcomes pertinent to each Key Question may be helpful in future analyses. Second, more studies are needed on clinical conditions other than diabetes, hypertension, and heart disease in order to determine the extent to which positive results can be achieved for a wide variety of conditions. Particularly lacking are studies focusing on women, children, the elderly, cancer, substance abuse, infectious diseases, surgical conditions, and critical illnesses. Finally, only a few studies presented here have described the effects of health IT implemented to enable PCC on cost and provider

efficiency, and even fewer have done so in a high-quality fashion. Without more demonstrations of health IT used to deliver PCC being at least cost neutral and time neutral, improvements in health care processes may not be enough to justify their implementation.

Implications

This review provides a comprehensive picture of the current state of the art regarding health IT interventions implemented to enable PCC. We conclude that significant evidence exists confirming the positive impact of PCC-related health IT applications on health care outcomes. The evidence points to clinical areas in which health IT is most likely to foster PCC and yield clinical benefits, but the evidence is not strong enough to provide clear guidance to health care systems on how best to use health IT in promoting PCC systemwide. We clearly need more research, as indicated above, to determine the extent to which health IT interventions will enhance the delivery of PCC and improve clinical outcomes for patients with different types of clinical conditions. We also need more research to give health care providers better information on how to weigh the value of health IT applications for promoting PCC relative to the investment of resources needed. To fully realize the potential for health IT applications to facilitate PCC, future research and development should incorporate the principles of PCC in a more systematic and comprehensive way.

Reference

1. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century, vol. 6. Washington, DC: National Academy Press; 2001.

Full Report

This executive summary is part of the following document: Finkelstein J, Knight A, Marinopoulos S, Gibbons MC, Berger Z, Aboumatar H, Wilson RF, Lau BD, Sharma R, Bass EB. Enabling Patient-Centered Care Through Health Information Technology. Evidence Report/Technology Assessment No. 206. (Prepared by Johns Hopkins University Evidence-based Practice Center under Contract No. 290-2007-10061-I.) AHRQ Publication No. 12-E005-EF. Rockville, MD. Agency for Healthcare Research and Quality. June 2012. www.effectivehealthcare.ahrq.gov/reports/final.cfm.

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