

# Informatics Systems and Tools to Facilitate Patient-centered Care Coordination

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## Summary

**Introduction:** There is a growing international focus on patient-centered care. A model designed to facilitate this type of care in the primary care setting is the patient-centered medical home. This model of care strives to be patient-focused, comprehensive, team-based, coordinated, accessible, and focused on quality and safety of care.

**Objective:** The objective of this paper is to identify the current status and future trends of patient-centered care and the role of informatics systems and tools in facilitating this model of care. **Methods:** In this paper we review recent scientific literature of the past four years to identify trends and state of current evidence when it comes to patient-centered care overall, and more specifically medical homes.

**Results:** There are several studies that indicate growth and development in seven informatics areas within patient-centered care, namely clinical decision support, registries, team care, care transitions, personal health records, telehealth, and measurement. In some cases we are still lacking large randomized clinical trials and the evidence base is not always solid, but findings strongly indicate the potential of informatics to support patient-centered care.

**Conclusion:** Current evidence indicates that advancements have been made in implementing and evaluating patient-centered care models. Technical, legal, and practical challenges still remain. Further examination of the impact of patient-centered informatics tools and systems on clinical outcomes is needed.

## Keywords

Patient-centered care, personal health records, telehealth, clinical decision support systems, registries

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## Introduction

Technological advances and knowledge discovery in biomedicine have advanced the concept of patient empowerment, where patients have the tools and resources to play an active role in the delivery of health care services. In the 2001 report, “Crossing the Quality Chasm,” the Committee on Quality of Health Care in America of the Institute of Medicine (IOM) defined patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The report further states that practicing patient-centered care requires healthcare institutions to focus on qualities such as empathy, transparency, and responsiveness to needs, preferences, and values of the individual patients and their families [1]. Although often cited, the 2001 IOM report was not the first publication to advocate for patient-centered care. In 1993, Gerteis et al. provided dimensions of patient-centeredness that included respect for patients’ values, preferences, and expressed needs, coordination and integration of care, access to information, communication, and education, physical comfort, emotional support, and involvement of family and friends at the extent desired by the patient [2]. Specifically, in terms of care coordination and integration, one of the challenges in many health care systems pertains to the fragmentation of health care services whereby patients and their families experience episodic encounters with various health care entities that operate as silos.

A model of primary care that is often described as an approach to ensure patient-centered comprehensive and team based care maximizing quality and safety, is that of the patient-centered medical home (PCMH) [3].

The core principles of a PCMH are team-based care, patient-centered orientation, care coordination across all elements of a system and community, timely access to information and communication, and a systems-based approach to quality and safety. More specifically, in the United States, the National Committee for Quality Assurance (NCQA) identified nine standard categories that PCMHs must meet. These categories are: access and communication, patient tracking and registry functions, care management, patient self-management and support, electronic prescribing, test tracking, referral tracking, performance reporting and improvement, and advanced electronic communication [3]. Information technology is expected to facilitate processes and procedures that serve these core principles of a PCMH. The electronic health record, for example, can facilitate care coordination and increase access to information. Bates and Bitton identify seven major informatics areas that are critical components of a comprehensive system that would support patient-centered medical homes, namely clinical decision support, registries, team care, care transitions, personal health records, telehealth, and measurement [4]. Of these dimensions, two (team care and care transitions) are sub-goals of patient-centered care, three (clinical decision support, personal health records, telehealth) are means to achieve these goals, and two (registries and measurement) are means to address quality improvement.

While the concept of a patient-centered medical home, or patient-centered care more broadly, is not entirely new, we still face challenges in implementing patient-centered care systems. In 2014, Osborn et al. surveyed 15,617 adults aged 65 or older in Australia, Canada, France, Germany, the Netherlands,

New Zealand, Norway, Sweden, Switzerland, the United Kingdom and the United States. This study suggests that patient-centered care is still a difficult goal to achieve. Between 3%, in New Zealand, and 87%, in the United States, of the older adults surveyed reported having at least one chronic condition. Excluding respondents in France, between 20% (in New Zealand) and 41% (in Germany) of the surveyed older adults reported having experienced at least one coordination problem in the past two years. Problems in coordination included lack of availability of medical records or test results at a time of a scheduled appointment, and communication problems between specialists and primary care providers. Additionally older adults in all countries, ranging from 14% in the US to 48% in Sweden, reported that their medications had not been reviewed by any healthcare professional in the past year. This was surprising given that between 29% in France and 53% in the United States of the older adults surveyed reported regularly taking four or more prescriptions [3]. This study demonstrates the need to design clinical informatics tools that will lift care coordination barriers, and facilitate communication between health care team members, patients, and their families. Although more patient-centered technology is needed, the shift to patient-centered care is not simply a technological challenge. It also will require cultural, educational, and policy transformation.

The purpose of this paper is to examine recent advancements and evidence in the design, implementation, and evaluation of informatics tools to promote patient-centered care. We have primarily focused on technologies that directly support patient-centered medical homes and care coordination. We aim to analyze recent scientific literature (of the past four years) that addresses patient-centered care covering any of the seven informatics domains identified by Bates and Bitton [4].

## Methods

We conducted two separate literature searches for this review. The first search was performed to gain an understanding of the literature base using the specific terms

“patient centered medical home” and “care coordination.” For this review we searched PubMed, CINAHL, and PsycINFO using combinations of the search terms “technology,” “electronic health record,” “electronic medical record,” “health information exchange,” “informatics,” “patient centered medical home,” and “care coordination.” We focused on primary data research articles published between 2010 and 2014. The combination of “patient centered medical home” and “care coordination” provided a broad but limited overview. We therefore performed a second search to specifically focus on the role of informatics in this area.

Our second literature search specifically targeted the informatics domains established by Bates and Britton. We conducted this search using the terms “patient centered medical home” and “care coordination” paired with the search terms derived from the Bates and Bitton framework: clinical decision support, patient registry(ies), team care, care transition(s), personal health record(s), telehealth/telemedicine, and measurement. The second search was also conducted using PubMed, CINAHL, and PsycINFO. We focused on primary data studies that were published between 2012 and 2014. Although our priority was to include studies that provided sufficient sample sizes, there were some topics that only included literature on smaller trials. For this analysis, we reviewed both qualitative and quantitative studies.

There was significant overlap between findings from the two searches, resulting in 50 unique studies. In the following section we summarize findings of these studies grouped using Bates and Bitton’s seven informatics domains.

## Results

### 1. Patient-Centered Care

There are many models of patient-centered medical homes, and PCMH definitions vary widely. One common element in all PCMH models is striving towards patient-centered care. When healthcare systems misunderstand the term “patient-centered,” inappropriate adoption of non-patient centered amenities and systems may occur. Addi-

tionally, focus may be taken away from the most challenging barriers to patient-centered care, such as care coordination, in support of the other actions [5]. For this review, we have focused on two important pillars of patient-centered care: facilitating team care and improving care transitions.

### Team Care

Patient-centered medical homes are tasked with providing “whole-person orientation,” described by NCQA as a model whereby “the personal physician is responsible for providing all of the patient’s health care needs or for arranging care with other qualified professionals” [6]. To accomplish this PCMH, practices often include many different types of care provider’s including physicians, nurses, pharmacists, medical assistants, specialists, and social workers. Not surprisingly, PCMHs face many problems with coordinating care among these various medical providers. Challenges reported in literature include: obtaining buy-in on new team care based clinical processes, learning how to appropriately divide new tasks among the clinical workforce, and maintaining communication between the care providers, patients, and caregivers [7]. Although these problems have been discussed in literature, few publications focus on technology interventions to mitigate or solve these issues preferring to focus instead on face-to-face communication strategies, such as multidisciplinary rounding and regular team huddles, to better coordinate care within a team environment [8, 9].

As shown through these studies, face-to-face solutions may be useful in managing care activities; however, face-to-face solutions have drawbacks. Relying on face-to-face communication may leave patients and their caregivers out of critical care discussions, and not all PCMH care providers will always be able to attend the meetings. Therefore, it should not be surprising that many PCMHs use electronic health records (EHRs) as the primary communication tool. In the literature, EHRs were used to facilitate communication between the care team, support evidence-based clinical practices, and organize clinical information to help role-based healthcare workers complete their jobs more efficiently. A recent study of 25 PCMHs ex-

amined differences between patient-centered medical homes that had made significant advancements in diabetes quality of care metrics within an 18-month period, and those PCMHs that did not. The research team found three main differences between the groups: duties of the care manager, using the electronic health record to the fullest patient-tracking capabilities, and the integration of the care manager into the care team. Although two of the differences were personnel-related, care managers that performed better on diabetes quality measures described having full access to the electronic health record, and being integrated into the patient's care team. Care managers at low performing PCMHs described "more administrative care manager duties, little EMR [electronic medical record] use, and minimal integration of care management and information sharing" [10].

Despite the difficulties with the team-based care models required for PCMH practices, the literature demonstrates that practices can overcome these barriers with workflow changes and well designed information systems [11]. In order to mitigate the challenge associated with dividing new tasks among the clinical team, a PCMH uses the EHR to create tasks lists and delegate roles. In addition, in order to better facilitate communication among the entire care team, electronic communication such as instant messaging is used for immediate concerns in addition to the more routine clinical notes, team huddles, and telephone conversations [7]. Unfortunately, many of the solutions proposed to solve the challenges with team-based care still leave patients and families outside of the communication channels. In their 2010 paper, Bates and Bitton advocated for developing communication tools to connect patients to their care team, as well as coordinate care tasks among PCMH providers [4]. More research is needed to better understand how patients and families can be connected to, and integrated with, the care coordination processes of PCMHs.

## Care Transitions

Transitions among levels of care, either within an organization or between organizations, are well known as a significant challenge for healthcare organizations. Since providing

quality care and maintaining patient safety are the "hallmarks of the medical home," [6] much attention should be paid to how to support patients and families through these care transitions. Recent literature focuses on the transition from an acute care facility to home. To assess this transition for patient safety and quality of care, recent studies have been monitoring patient mortality, 30-day readmission rates, and other clinical quality measures [12, 13]. These studies have focused on a variety of technologies to improve these quality indicators. One area of study has focused on tools to support medication management. Electronic health records are updated to facilitate appropriate referrals and care plans [14], post-discharge telephone calls are placed to patients at home [15], and technology-enhanced pill boxes have been used to help facilitate correct medication administration in the home [16]. Our review found that the technology intervention does not always lead to improved quality measures above and beyond non-technology based care coordination efforts. A 2013 study by Marek et al., describes a three arm randomized control trial on medication management during care transition processes. Although the two care coordination study arms had significantly better outcomes than the control, the arm with the automatic medication dispenser and alarm system did not perform better than the care coordination and regular pill box arm [16].

The Australia's Chronic Disease Management Service for diabetes care demonstrated provider satisfaction [17], as well as a significant improvement in diabetes quality outcomes such as frequency of HbA1c checks, reduction in HDL cholesterol, and microalbumin checks related to the program's team care arrangement (TCA) and general practitioner management plan (GPMP). Both the TCA and GPMP are electronic care plans that are completed, tracked, and monitored by clinical teams. While the GPMP is only completed by a single provider group, the TCA is a multidisciplinary care coordination tool that was shown to have the greatest affect on the above diabetes quality outcomes [18].

Our review shows that care transitions continue to be a significant barrier to patient safety. Although there has been a significant refocus on care transitions in literature over

the past four years, long-term improvements in outcomes are difficult to find.

## 2. Technology Supporting Team Care and Care Transitions

Team care and care transitions can further be promoted by the use of specific technology tools. Although there are many tools in literature that could be used to support team care and care transitions, in this paper we will follow the Bates and Bitton's framework and discuss the three most prominent tools in recent literature: clinical decision support, personal health records, and telehealth systems [4].

### Clinical Decision Support

Bates and Bitton describe clinical decision support systems as "systems that aim to improve decision making around diagnosis (clinical prediction rules), prevention and disease management (routine care reminders to doctors or patients), and treatment (electronic medication prescribing)" [4]. Since 2010, with the increased adoption of electronic medical records and computerized physician order entry systems, clinical decision support (CDS) has been widely covered in informatics literature, including literature targeted specifically on patient-centered medical homes and care coordination. The majority of the articles reviewed focus on how clinical providers use CDS to make decisions around prescribing and administering medications in acute care settings. These studies measure standard patient safety outcomes, such as improvement in quality measures, reduction of medication errors, and adherence to guidelines. Although there is a large CDS research base, only two studies reported on randomized control trials that compared clinical decision support tools and regular care on adherence to patient-centered quality measures [19, 20]. Unfortunately our review continues to support Bates and Bitton's message that more quality, longitudinal studies on how CDS is used to support patient-centered care is still needed.

There was one area of the literature reviewed that was not mentioned in Bates and Bitton's original article. In the past four years, clinical informatics researchers have

been using smartphone applications and web-based tools to support patient-centered decision support processes known as shared decision-making (SDM). Consumer tools often used in these conversations are patient decision aids (PDAs). Although SDM discussions often occur in-person, there have been a few pilot studies testing whether technology can help support the process. An example of a technology tool to aid in shared decision making processes is the *Choice* tool that was built and tested on cancer populations in Norway. This tool was developed to help patients input their own symptoms and values, and to provide targeted patient education. The patient-entered data were used to facilitate shared decisions and better customize treatment plans based on the patient's stated preferences [23]. Our search did not find any reports of large randomized trials of shared decision-making processes or patient decision aids. Therefore it is unclear what affect these tools may have on patient-centered care and/or quality of care. Additionally, there has been some recent criticism on the "one sized fits all" approach to consumer facing decision support aids. In 2014, Alden et al. argued that multicultural clinical environments require tailored decision support tools [24, 25].

### Personal Health Records

The Markle Foundation defines personal health records (PHRs) as "an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure, and confidential environment" [26]. Recent studies show that adoption of personal health records remains slow, even in countries that provide integrated medical records connected to multiple providers and healthcare organizations [27]. As called for in the Bates and Bitton article, much of the literature that we reviewed focused on the barriers to adoption.

There are numerous reasons cited in the literature for poor adoption, and each patient population faces different challenges. For example, in the Netherlands where Internet usage is extremely high, the top barriers to adoption were found to include lack of awareness, usability issues, and lack of motivation by the patients [27]. In other studies,

such as one conducted in Virginia in the US, patient demographics (race, gender, age, and condition) played a significant role in adoption rates. Internet access, computer literacy, and other factors are also hypothesized to play a role in the lack of diffusion [28].

In many cases communication from the provider and clinical organization were important factors that played into PHR adoption measures [27, 28]. One study from California gave patients tablets during their hospital stay to increase patient engagement. These tablets gave the patient access to patient education, and their PHR. Overall patients were satisfied with the tablet and found it useful [30]. Providing patients access to their personal health record during periods of down time, such as during a hospital stay or clinic wait, may be one way to reduce the barrier of initial engagement with the PHR. Despite the lack of strong evidence that PHRs improve clinical care outcomes, increase patient engagement, and/or provide better care coordination, the concept of PHRs is still strongly favored by both clinicians and patients [31-34]. More studies are still needed to connect PHR use to patient-centered process measures and clinical outcomes.

### Telehealth/Telemedicine

One of the pillars of patient-centered medical homes is providing increased patient access [6]. Telehealth technologies can help bridge the gap between a patient's medical care team and self-care routines. There have been many large-scale telehealth demonstration projects since 2010. Bates and Bitton cited a computer simulation experiment that suggested healthcare organizations could expect medium to large improvements for implementing telehealth systems [4]. Unfortunately, the recent body of literature does not provide clear support for telehealth systems. Steventon et al. conducted a pragmatic multisite cluster randomized trial comparing home telehealth with usual care for patients with chronic conditions (diabetes, chronic obstructive pulmonary disease or heart failure) [35]. The study involved 179 general practices and 3,230 patients in the United Kingdom. In this study, home telehealth was associated with a significant drop in mortality and emergency admission rates. On the other hand, Takahashi

et al., conducted a randomized controlled trial with 205 older adults who were at high risk for rehospitalization in the US. While the older adults in the study embraced the concept of home telemonitoring, this study did not result in a significant drop in hospitalizations or emergency department visits. Additionally, mortality was also higher in the telemonitoring group. Despite the large number of telehealth demonstration projects, there has been little advancement with connecting these technologies to patient-centered medical home models. Much of the recent literature has focused on creating conceptual models for a specific population targeted for telehealth, and outlining quality metrics that should be tracked to ensure that the telehealth system is working for the desired population [37-39]. Our review shows that telehealth systems have yet to realize their promise as outlined by Bates and Bitton. More research is needed to better understand how telehealth systems affect patient-centered care.

## 3. Technology Supporting Clinical Quality Improvement

Quality improvement is a primary tenant of the patient-centered medical home model [6]. Technology can help support clinical quality improvement by collecting, processing, and analyzing clinical data. Following the Bates and Bitton framework, this review evaluated two types of technology tools: measurement of clinical data, and patient registries.

### Measurement

Recent literature continues to support creating and evaluating measurement frameworks to assess patient-centered care measures [42-45]. For example, the Oregon Department of Human Services completed one of the largest patient-centered medical home demonstration projects in the United States. Before starting the project, over the course of several months, the Oregon Department of Human Services held several stakeholder meetings to determine the 6 core attributes, 15 standards, and 27 individual measures that were tracked by each one of the PCMH's in the demonstration project [42].

In addition to creating new measurement frameworks, researchers have also been trying to consolidate and evaluate the existing frameworks [46, 47]. In one recent study, a group of researchers looked at the similarities and differences between the published quality measures required for Accountable Care Organizations (ACO), the Independence at Home (IAH) demonstration projects, and the Community-based Care Transitions Program (CCTP) in the United States. This study compared the measures required for participation, whether or not patient-centered care was captured in the required measures, and whether the measures aligned with the patient and population needs as assessed in existing literature. This research study found that ACO quality measures did not address patient-centered care, but chose to focus more on continuity of care measures. Additionally, it was found that none of the measures proposed in the IAH demonstration project supported the most important needs of the target patient population [46]. Although there are challenges with choosing the correct measurement frameworks, the importance of the measures is demonstrated in one recent study from New York State. This study found that clinics that were part of a patient-centered medical home project had greater clinical quality gains than those that participated in other program initiatives; however, this improvement may be associated with the large number of quality measures tracked by PCMH organizations as compared to the other quality initiative projects [48].

Despite the strong support for measuring PCMH and care coordination efforts, there have also been recent studies that highlight the problems that may be created when organizations focus on incorrect quality measures. A qualitative study at the US Veteran's Administration shows that some clinical providers believe that competing measurement frameworks, such as patient-centered care measures and operation metrics, can create conflicts for staff. For example, one clinical member in the study discussed the challenges with balancing the time allotted for a patient appointment, the needs of the patient at that time as assessed through the visit (the patients mental health

issues), and all the evidence-based quality measures that are required to be addressed during the visit (colonoscopy, cholesterol checks, etc.) [49]. Other studies have cautioned against using "one-size fits all" quality measures that may not be appropriate in certain clinical environments, such as rural or safety net providers [44, 50, 51].

### Patient Registries

Electronic patient registries have been used to support the NCQA PCMH standard to manage population health, and to support activities of care management and care coordination [6]. Bates and Bitton describe this technology as, "applications that define patients with specific conditions while also specifying their disease status. Some registries also include tools that facilitate disease management" [4]. From our review it appears that Bates and Bitton's call for more robust research on the use and functionality of patient registries has been accomplished during the past four years. Our literature review demonstrates that the patient populations being managed through registries are diverse. Recent examples of registries reported in literature include child immunization records [52], adult veterans with HIV infections [53], and rural adults with type 2 diabetes [54].

All of the studies that we reviewed paired patient registries with other clinical information systems such as electronic health records, telehealth systems, and care coordination activities. The use of electronic patient registries, in combination with other efforts, has been shown to improve quality measures. For example, newborn registries in Ohio supported nurses in identifying newborns that had missed their newborn appointment, and contacting the parents to reschedule within 2 days of the missed appointment. This led to a 30% drop in the average age at the first newborn appointment for those being managed through the registry, and an increase in the percentage of children that attended their two month well child visit and their four month well child visit on time. During the same time period, the children in the comparison group did not see improvements in either metric [55]. Unlike the patient registries described in the Bates

and Bitton article, patient registry literature indicates that non-physician team members, such as nurses and case managers, are now the primary users of these systems.

One area of advancement in electronic patient registries that was not described by Bates and Bitton is the addition of patient-reported outcomes (PROs) into registries. One example of a program that is using PROs in their patient registry is the University of California Los Angeles's Alzheimer's and Dementia Care Program. At the beginning of the program enrolled patients and their families complete an electronic questionnaire, and the results of this initial survey are used to structure the patient's care based on individual needs and resources [56].

## Discussion

Patient-centered care coordination is the focus of many national and international initiatives. In the US, for example, new payment approaches and bundled payment options as well as meaningful use requirements that promote care coordination, act as facilitators for providers to participate in health information exchange (HIE) to share medical information in order to increase efficiency and effectiveness of health care services. This is similar to the call for action by the European Commission to prioritize informatics tools "with strong user involvement, focusing on interoperability and the integration of emerging patient-centric technologies for cost-effective healthcare" [57]. As reflected in our review, the number of studies examining approaches and models to achieve patient-centered care continued to grow in recent years. Similarly, the body of evidence continues to grow, although in some areas we are still lacking large randomized clinical trials that provide the gold standard for documented evidence. This may be because of continuously emerging technologies, evolving legislative and policy initiatives, and the challenges of conducting controlled experiments in ever changing landscapes. The concept of pragmatic trials, namely trials that examine whether an intervention works under real-life conditions and whether it works in

a way that makes a difference for the patient and other stakeholders, is one that can address some of the challenges we face when conducting large exploratory trials using informatics tools in health care systems.

The themes of access to information and other health care related resources, patient self-management, test tracking, and advanced electronic communication, partly reflected in the NCQA standards for PCMHs, are explored in scientific literature and reflect a move towards patient empowerment, where patients are actively involved in the care process and are able to sustain ongoing and meaningful communication with all members of the care team and access timely and high quality information.

While the seven dimensions by Bates and Bitton provide a useful outline to facilitate the study of informatics to support patient-centered care, it is important to recognize that patient involvement is a key element in this care model. Patient involvement can be supported through technological means (such as portals or other tools to facilitate communication with providers and access to information), but does not rely solely on technology availability. Instead it is a desirable outcome that requires for all stakeholders and involved processes to be supportive of patients who want to be actively engaged in their own care. Technological advances and legal initiatives can increase the likelihood of successful implementation of patient-centered care; however, this paradigm shift does not only depend on technical, legal, and infrastructural attributes. It also calls for a culture change in health care organizations and among health consumers. One strategy that can facilitate this shift pertains to the education of the next generation of health care providers. There are already numerous efforts to revise medical, nursing and other clinical curricula, to prepare clinicians to effectively perform as team members recognizing the patient's role in shared decision making, and utilizing informatics tools that can enhance clinical decision making. In this process, it is important to recognize all stakeholders (including physicians, nurses, social workers, physiotherapists, psychologists, clinical pharmacologists and others) who are part of a team. Informatics

can play a central role in such interdisciplinary team based efforts to implement and increase the success of patient-centered care coordination.

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