

## What opportunities exist to improve consumer engagement in health care?

Proliferation of online health information, trends in health insurance coverage, and new ways to communicate with health care providers are among the phenomena creating new opportunities and challenges for the individual health care consumer. In this environment, understanding how consumers wish to engage with the health care system and how best to support them becomes increasingly important. Findings from this review suggest that many consumers wish to participate in their own medical decision making; furthermore, information that consumers seek on the Internet as well as their use of online health information tools can have a positive impact on their decision making among clinical options and, in some cases, on their relationships with providers. However, given wide variation across existing research, no one intervention or set of interventions stands out in areas such as increasing patients' trust in doctors or promoting adoption of shared decision making among health care professionals. Further work is needed to understand how, why, and for whom promising interventions may be most effective, particularly for racial/ethnic minorities, individuals with low health literacy, and members of other historically disadvantaged groups.

### Context for this review

At the request of the Robert Wood Johnson Foundation (RWJF), the nation's largest public health philanthropy, AcademyHealth undertook a review and synthesis of recent literature to better understand the state of knowledge about consumer engagement in health care – specifically, (1) consumers' interactions with clinicians and clinical settings and (2) their use of information to inform health care decisions. The goal of the review was to help RWJF understand the scope and strength of existing evidence and identify opportunities to improve consumers' engagement with their own health care.

### Findings

This synthesis identified 36 recent systematic reviews addressing the two dimensions of consumer engagement described above. High-level findings include:

- Most patients wish to have some role in their medical decision making and the number of people with this preference has increased over time. However, some patients prefer to delegate decisions to a physician, raising questions about which decisions patients wish to share and how to identify patient preferences during the medical encounter.
- Certain patient characteristics appear to be associated with higher or lower levels of trust in the patient-provider relationship, such as older age and higher disease burden, respectively. There is insufficient evidence to conclude that any one intervention may increase or decrease trust in doctors in particular.
- Regarding the information consumers use to inform health care decisions, it appears that patient decision aids may help individuals feel more knowledgeable about their care and help them make decisions more congruent with their values. However, further work is needed to understand the specific features of decision aids that are most effective.
- The design of a website and the clarity of information layout are among the factors associated with consumers' trust in online health information. Some evidence suggests this information has the potential to improve patients' relationships with physicians, though physicians' take on this issue has been understudied.
- Also on the provider side, there is no clear evidence to support specific interventions for promoting the adoption of shared decision making (SDM) among health care professionals. However, some evidence suggests that any intervention seeking to improve SDM is better than no intervention at all, and interventions that target both patients and providers are better than those interventions targeting either group alone.

### Additional considerations

- Readers should interpret findings with caution given wide variation in the definitions and measures used by researchers to study topics relevant to consumer engagement in health care, such as health literacy and SDM.
- Relatively few systematic reviews specifically sought to understand consumer engagement among racial/ethnic minorities, individuals with low health literacy, or other historically disadvantaged groups.
- Much of the included literature examined patient-provider interaction during a single clinical encounter and its impact on a variety of outcomes. Far fewer studies examined the patient-provider relationship over multiple visits.

*Three AcademyHealth staff completed this synthesis of research and a separate review of relevant RWJF investments over three months. Given the review's quick turnaround, the research synthesis focuses on systematic reviews published within the past five years. While this approach captures the most rigorous evidence from controlled studies, it does not capture insights from grey literature or research completed since the most recent systematic review of a particular topic, and it may not reflect "real-world" experience outside of controlled research settings.*

## I. Introduction

In recent years, changes in the U.S. health care system have created new opportunities and challenges for the individual health care consumer. From the proliferation of online health information to the growing influence of patient advocacy groups, several phenomena have helped to equip consumers with more health-related information and empowered them to use it. However, not everyone has benefitted from these trends, and some consumers also face increased responsibility when it comes to complicated tasks such as understanding and managing their health insurance and managing care for complex medical conditions. In this environment, understanding how consumers wish to engage with the health care system and how best to support them in this regard is increasingly important.

The Robert Wood Johnson Foundation (RWJF), the nation's largest public health philanthropy, is among the organizations contributing to our collective knowledge on this topic. Working with a diverse set of partners, RWJF has supported a range of research, tools, and other resources that assist providers, policymakers, advocates, and patients themselves in making health care more responsive to the needs, preferences, and values of patients and their caregivers. A key question moving forward is how best to target future investments in ways that leverage existing knowledge and address persistent gaps.

At the request of RWJF, AcademyHealth undertook a review of recent research as well as relevant Foundation investments to better understand the current state of knowledge on this topic. The review focused on two dimensions of consumer engagement in health care that represent RWJF's current areas of greatest interest: (1) patient interactions with clinicians and the clinical setting, and (2) individual consumers' use of information to inform clinical decisions. This document presents findings from AcademyHealth's review, with the goal of helping RWJF and its partners understand the scope and strength of existing evidence and identify promising areas for potential future investment. We begin with an overview of the review's approach before turning to a discussion of its findings, calling out key takeaways throughout. We conclude with some observations regarding the strengths and limitations of the current evidence base.

## II. Approach

At the outset of the project, AcademyHealth consulted with RWJF to determine the desired focus of the project and the scope of included evidence. Reflecting the Foundation's interests, the review focused on two dimensions of consumer engagement in health care: (1) patient interactions with clinicians and the clinical setting, and (2) individual consumers' use of information to inform clinical decisions. In exploring these topics, AcademyHealth consulted two sources of information: (1) recent, relevant peer-reviewed systematic reviews (described further below), and (2) relevant RWJF investments, such as research, expert and stakeholder convenings, and specific interventions related to consumer engagement. Appendix B describes each of these investments. In addition, Boxes A- F, interspersed within the narrative of this report, summarize the most relevant of these RWJF projects and, where appropriate, note how they relate to topics covered by the systematic reviews.

Given the Foundation's interest in digging deeper into the role of individual consumers in health system transformation and the scope of this review, AcademyHealth did not examine evidence on several other important topics related to consumer engagement in health care, such as patient participation in health research, patient/caregiver engagement in the organization and delivery of broad categories of care (e.g. critical care), and patient/caregiver engagement in

health system decisions (e.g. regarding resource allocation), among others. In addition, AcademyHealth focused primarily on engagement by adult consumers regarding their own health care, necessarily excluding evidence on children's engagement in their medical care as well as parents' engagement with the health care system on their children's behalf.

In order to identify relevant systematic reviews in the medical and social science literature to address the Foundation's interests, AcademyHealth searched two major databases: PubMed and the Cochrane Library. We consulted other databases, such as JSTOR, PsycARTICLES, and SocINDEX, though those searches did not generate significant relevant results. The databases were searched for text and subject heading keywords relating to 'consumers,' 'physician patient relationship,' 'trust,' and 'decision making' in a variety of combinations. We combined consumer-related terms (consumer participation / consumer involvement / consumer preference / consumer attitude) with 'decision making,' 'trust,' and 'consumer health information.' We also combined 'physician patient relationship' with similar terms. We conducted similar searches with specific populations as well, using terms such as 'elderly', 'low income population', and 'vulnerable population.' We filtered the search yields by systematic reviews.

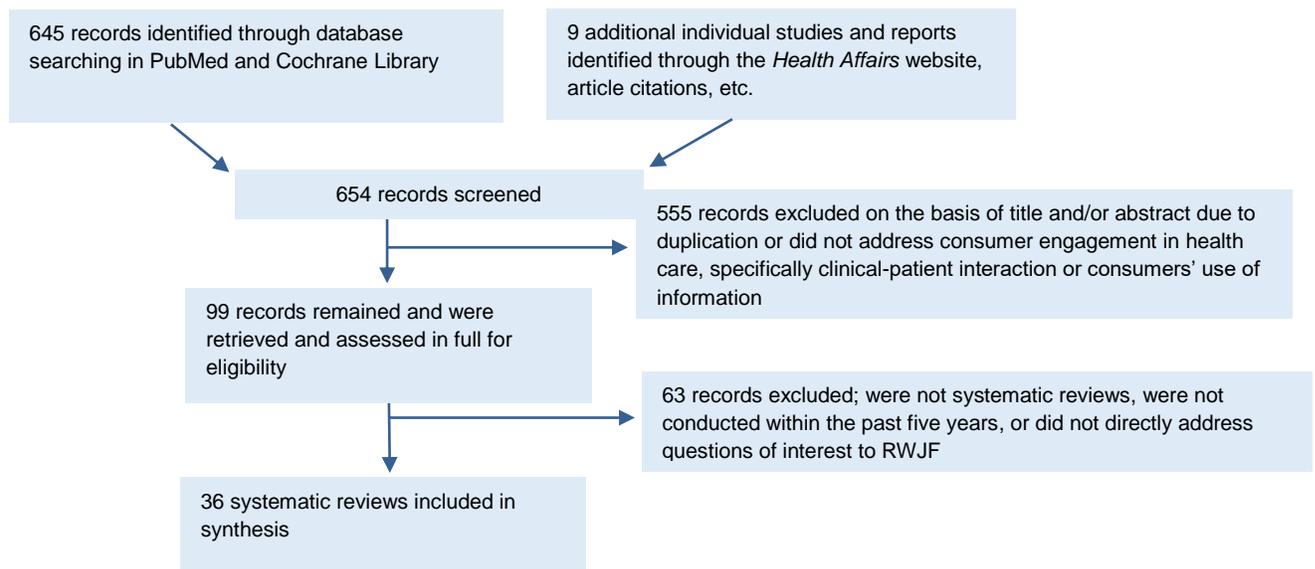
The various searches yielded a total of 645 articles. We identified nine additional individual articles and reports through searches on the *Health Affairs* website and by reviewing bibliographies of included literature. Project staff evaluated titles and abstracts of all search yields against specific inclusion and exclusion criteria, excluding duplicates and irrelevant reviews.

Articles were included that:

- Had been written in the English language;
- Reported on systematic reviews of relevant empirical research;
- Examined research on patient interactions with clinicians and the clinical setting, or individual consumers' use of information to inform clinical decisions.

Ninety-nine records remained and were categorized into two groups: clinical-patient interaction and consumers' use of information. We then sub-categorized the reviews in these major groups: for the clinical-patient interaction group, we sub-categorized reviews into impact of shared decision making/patient-centered care, effectiveness of patient decision aids, effect of patient-provider relationship on self-care, roles of patient-provider relationship in promoting value, role of trust in the patient-provider relationship, patient-provider relationship and disparities, and miscellaneous. For the consumers' use of information group, we sub-categorized reviews into consumers' attitudes/beliefs toward care, price comparison and other tools to support consumer decision making, sources consumers use to inform decision making, reference pricing, and miscellaneous. Given the recent increased emphasis on these topic areas and the number of recent relevant systematic reviews, we focused our synthesis on systematic reviews published within the last five years. Recent work likely incorporates or supplants earlier research and systematic reviews, and developments in this area within the last five years make earlier work less relevant. In addition, there were some reviews that met these criteria but were ultimately excluded because they did not directly address the questions of interest to the Foundation. A total of 36 full-text reviews were retained for review and synthesis; details of each review are provided in Appendix A. Figure 1 demonstrates the flow of data during the search strategy. Additional information about the strengths and limitations of this approach is provided in the Discussion section of this document.

**Figure 1: Systematic review selection process**



### III. Findings

We have organized findings according to the two broad focus areas of this synthesis: (1) patient interactions with clinicians and the clinical setting, and (2) individual consumers' use of information to inform clinical decisions.

#### Patient Interactions with Clinicians and the Clinical Setting

This synthesis identified 25 systematic reviews from the past five years examining various aspects of patient-clinician interaction within clinical settings. We group them here according to several different sub-topics.

##### *Patients' Preferred Roles in Health Care Decision Making*

In recent years, a wide array of research articles, reports, and other resources have sought to characterize patients' needs, preferences, and values when it comes to participating in decisions regarding their own medical care. However, AcademyHealth's search revealed relatively few recent systematic reviews on this topic.

- **Topline Findings:**

- Most patients wish to have some role in their medical decision making and the number of people with this preference has increased over time.
- However, some patients prefer to delegate decisions to a physician, raising questions about how patients perceive the decision-making process, which decisions they wish to share, which patients prefer to delegate decisions, and how to identify patients' preferences during the medical encounter.
- Patients and physicians generally welcome the involvement of family members, friends, and other patient companions in the medical encounter, though more

research is needed to understand patient and physician preferences regarding the role of companions in patients' decision making.

In one systematic review, Chewning et al. (2012) identified more than 100 studies since 1980 that measured patients' decision role preferences regarding treatment and screening across a variety of contexts and populations. The review authors divided included studies into two main categories, according to whether the majority of study respondents wanted to: (1) delegate the treatment or screening decision to the physician, or (2) participate in the decision, either by sharing the decision with the physician or deciding autonomously. Across the 119 analyses included in the review, 63 percent found that the majority of respondents wanted to participate in health decisions, while 21 percent found a majority preference for delegating decisions to a physician; findings from the remaining analyses were mixed. The authors also observed that the number of patients who prefer to participate has increased over the past three decades: in studies published before 1990, 43 percent found the majority of study respondents preferred shared or autonomous decision making; this number grew to 71 percent in studies published after 1999.

#### **Box A: Two Frameworks for Consumer Engaged Care**

RWJF has supported two recent efforts that both culminated in frameworks for consumer-engaged health care published in 2016 and 2017. Although they are very broad in their focus on the health care system as a whole, the two frameworks are relevant to both consumer-patient clinical interactions and individual consumers' use of information. As such, the terminology they employ, the relationships they posit, and the potential actions they suggest may be useful in identifying topics that RWJF or others may want to prioritize going forward.

**Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care.** Recognizing continued uncertainty about whether investments in patient and family engaged care (PFEC) will yield improved outcomes or what practical steps would make PFEC a reality, the National Academy of Medicine's Leadership Consortium for a Value and Science-Driven Health System convened a scientific advisory panel to identify relevant, rigorous evidence and to compile it into a comprehensive framework. The resulting framework and discussion paper identifies the elements of a strategy to realize and maintain a culture of PFEC, cites the supporting research, and provides examples of how these elements work in the health care system (Frampton 2017).

**Roadmap to Consumer Clarity in Health Care Decision Making.** With funding from RWJF, the Patient Advocate Foundation (PAF) undertook an effort to propose "actionable models" to promote person-centered health care at key decision points in the health care process. This included a focus on consumer engagement and the role of information in developing key skills, facilitating communication, and improving shared decision making. Through a literature review, in-depth interviews with 15 individuals diagnosed with a serious illness, four focus groups with persons of color living with or survivors of breast cancer, cervical cancer, or HIV/AIDS, and its own survey data and experiences working with patients, PAF proposed its "roadmap" linking together what it sees as historically discreet efforts to (1) engage consumers, (2) increase transparency about treatment options and their benefits, risks and costs, (3) improve patients', caregivers', and providers' skills in communication and shared decision making, (4) make better use of innovations that help patients and providers find and use information, and (5) systematically measure utilization and effectiveness of patient-centered activities, including the incorporation of patient-reported data. Published in May 2017, the roadmap makes a large number of specific suggestions for bringing these pieces together into an information-based, patient-centered health care system (Patient Advocacy Foundation 2017).

The authors also took a closer look at how these findings varied among patient population groups and according to the measures of patient preference used. They observed that, among 57 analyses involving patients with cancer or patients undergoing invasive procedures, the majority of patients preferred shared or autonomous decision making in three-quarters of the studies. This was true for only about half of the 62 studies involving patients with other chronic conditions as well as non-disease specific health concerns, many of which incorporated hypothetical scenarios. The review authors also found clear differences in patients' reported decision role preferences depending on the measure of patient preference used – for example, depending on whether the root stem of a sentence (measure) positively or negatively frames delegating or sharing decisions; whether the measure includes an explicit response option for shared decision making as well as decision delegation; and whether the measure presents a hypothetical scenario that the respondent may or may not have experienced.

Review authors suggested more work is needed to measure the construct of decision making itself, and more broadly, to understand “how patients perceive the decision process and which decisions patients most want to share.” They note, “Although the majority of patients wished to participate in decisions, all studies identified a subset of patients who wanted to delegate decisions. The question then is how to solicit a patient’s role preference and tailor visits appropriately.”

Our synthesis also identified one systematic review examining the role of companions – i.e. family members, friends or other caregivers – in the medical encounter and the preferences of patients, clinicians, and companions regarding the companions' involvement in communication and decision making. Laidsaar-Powell et al. (2013) reviewed approximately 50 studies focused on these triadic consultations, finding that companions regularly attend consultations and assume a variety of roles, which may vary according to patients' needs. For example, review authors note that among patients attending geriatric or primary care consultations, those who were older, less educated, or more unwell were more likely to be accompanied and less likely to be actively involved in the consultation. However, the companion attendance rate was also high among patients attending specialist consultations for life-threatening conditions (e.g. cancer), though demographic characteristics did not appear to affect accompaniment or involvement levels. The reviewers posit that companions provide more logistical support for geriatric/primary care patients, while providing more emotional support for cancer patients; informational support, such as note taking, question asking, and recalling of information, was deemed helpful regardless of illness severity/type.

Among included studies, both patients and physicians generally preferred companion involvement in the medical counter, though findings also highlight the unique challenges posed by triadic consultations. Patients found companions' informational support particularly useful, with review authors noting that companion involvement was also associated with improved patient understanding, improved quality of information exchanged, and “an increased patient perception of comfort and freedom of expression inside the consultation.” Physicians also appreciated companions' informational assistance, but sometimes preferred to let the patient answer questions for him or herself. Physicians perceived dominating or demanding companions to be particularly challenging, with other challenges including confusion about what role the companion should assume, family conflict, physicians or companions over-sharing information, and difficulty in discussing sensitive issues. For their part, some companions were unclear or uneasy about their role in influencing a patient's decision.

In reflecting on the communication and decision-making literature, the review authors note “it appears that most patients have the desire to retain control of who attends the consultation, what information is conveyed, and how decisions are made.” They suggest further work is needed to understand how the specific needs and characteristics of patients influence companion involvement levels; how companions are involved in the decision-making process and patient and physician preferences in this regard; and how best to manage difficult companions, among other areas of study. They add that while the quality of included studies was generally strong, not all the studies used the same measures of triadic consultations or measured the same outcomes. They suggest that the development of triadic theoretical frameworks, validated measures, and validated coding frames may also improve the quality of the research in this area.

### **Box B: Optimizing Value in Health Care: Consumer-Focused Trends from the Field**

In a 2015 solicitation managed by AcademyHealth, RWJF awarded 11 grants for research studies to better understand perceptions of value in the new and emerging health care landscape and to allow rapid learning from the field on consumers’ valuation of their health care. These grants cover a variety of health care settings, treatment scenarios, and financing mechanisms. They also employ a variety of types of analytic techniques and data collection, including techniques from behavioral economics and related fields, to elicit consumer preferences. Four of the studies examine how varying benefit designs and cost-sharing structures affect consumer health care decision making. Four of the grants examine how consumers value information about provider quality, site of care, and treatment options for several conditions. Results from two of these studies, which look at how consumers value clinical quality and/or providers’ interpersonal skills in choosing providers or hospitals, are summarized in a 2017 AcademyHealth blog post (Collado 2017a). The remaining three studies examined patient perspectives and experiences with telehealth, including the weight they place on access and convenience versus questions of quality, privacy, and care coordination, and equity.

Although some grantees were still in the process of publishing their findings as of October 2017, all of the researchers have shared relevant findings with RWJF. In many cases, these findings help inform the Foundation’s “Building Trust and Mutual Respect to Improve Health Care” solicitation summarized in Box D. A September 2017 post to the *Health Affairs* blog discusses what the Foundation learned from these grants that helped them conceptualize its more recent efforts around trust and mutual respect (Collado 2017b). Appendix B lists all 11 grants. Additional information about each project and links to findings where available can be found on AcademyHealth’s website (<http://www.academyhealth.org/node/6521>).

### ***Impact of Patient Participation in the Clinical Encounter on Patient Outcomes***

We identified several systematic reviews examining the association between patient participation in the clinical encounter and patient outcomes such as satisfaction, health behavior, and health status.

- **Topline Findings:**

- Taken together, these reviews suggest that while many studies have examined the relationship between patient participation in clinical encounters and patient satisfaction, whether and how patient participation influences health behavior and/or health outcomes is far less understood.
- Varying definitions of ‘patient participation,’ ‘shared decision making’ and other key concepts as well as inconsistent measures of patient participation and outcomes make it difficult to draw clear conclusions from existing evidence. Multiple review authors cite the development of shared definitions and measures as an important area of future work.

In a systematic review by Clayman and colleagues (2016), the authors identified more than 100 randomized controlled trials (RCTs) and non-RCTs examining the association between patient participation in decision making in the medical encounter and a range of outcomes that the authors categorized as psychosocial (e.g. satisfaction, anxiety, decisional regret, decisional conflict), behavioral (e.g. prescription filling and adherence), practice-related (e.g. physician satisfaction and encounter length), and biomedical (e.g. clinical asthma status). The authors note that “despite widespread belief that participation in health decisions is associated with better health-related outcomes for patients, we found relatively few studies that measured both participation and outcomes, and attempted to relate the two.” Among 10 RCTs reporting increased patient participation following an educational intervention (often physician training in shared decision making), only half reported a positive impact on patient outcomes, primarily on those that were psychosocial in nature, such as patient satisfaction.

Similarly, Shay et al. (2015) sought to characterize the patient outcome measures studied in relation to shared decision-making (SDM) when the decision-making process was explicitly assessed with a SDM measurement tool. The authors identified 39 studies that included 97 assessments of the relationship between an empirical measure of SDM and a subsequent empirical measure of a patient outcome, with outcomes categorized as affective-cognitive, behavioral, or health outcomes. Fewer than half of the assessments found a statistically significant, positive relationship between SDM and the patient outcome, and most assessed outcomes were affective-cognitive – primarily, patient satisfaction, decisional conflict, or other perceptions immediately after an interaction with a clinician. The reviewers observe that among included studies, health outcomes were studied least; when these outcomes were assessed, they were most often measured via patient self-report and often with unvalidated instruments. The reviewers conclude, “Results from this review thus indicate that the link between SDM and health patient outcomes, in particular, has yet to be fully established.” This finding is generally consistent with other systematic reviews on this topic identified by AcademyHealth, including Sanders et al. (2013) and Hauser et al. (2015), which could draw no conclusion about the effect of SDM on patient-relevant, disease-related outcomes.

Nearly all of the review authors referenced above recommend caution in interpreting review findings given wide variation across included studies. Studies varied not only in terms of the specific intervention, clinical setting, and patient population studied, but also in the measures used to assess patient participation and patient outcomes. Review authors consistently noted lack of a common definition for SDM, with one review citing work by Makoul et al. (2006) that identified 31 different conceptual definitions of this term. With these varying definitions comes diversity in the tools and approaches used for measuring patient participation in clinical care. In a systematic review by Phillips et al. (2016), the authors examined 33 studies reporting the reliability or validity of an instrument used to measure patient participation in a health care setting. Their review identified 24 patient participation measurement tools designed to be completed by patients, family caregivers, observers, or more than one stakeholder focused on aspects of patient-professional communication. However, the reviewers concluded that few of these tools provided valid and reliable measures of patient participation, identifying the dyadic Observing Patient Involvement in Decision Making (dyadic-OPTION) tool as the most promising. We identified a separate systematic review by Cout et al. (2015) that examines use of the OPTION tool more closely.

Across systematic reviews – here and in other parts of the AcademyHealth synthesis – review authors suggested that developing shared definitions and measures of patient participation will be important for strengthening the usefulness of future research and making sense of existing evidence. As Clayman et al. (2016) concluded in their review on SDM, “...it will be difficult to derive meaning from the research unless consistent measures of participation and outcomes are used whenever possible.”

### *Opportunities and Challenges for Providers in Engaging Patients in Clinical Encounters*

We identified four systematic reviews that characterize communication practices between health care providers and patients, examine provider-focused interventions for improving patient-centered care, and document providers’ perceived barriers in this regard.

- **Topline Findings:**

- Given the limitations of existing evidence, it is not possible to draw clear conclusions about the most effective types of interventions for increasing adoption of SDM among health care professionals.
- However, evidence suggests that any intervention seeking to improve SDM is better than no intervention at all, and interventions that target both patients and providers are better than those interventions targeting either group alone.
- Many different types of provider-focused interventions can promote patient-centered care more broadly. In some cases, short-term training lasting fewer than 10 hours can be just as effective as longer training.
- Physicians working in hospital intensive care units identify lack of communication skills and their own values and beliefs as among the barriers to patient- and family-centered care toward the end of life.

Land et al. (2017) reviewed 28 conversation analytic studies of health care encounters in an effort to map communication practices that encourage or constrain SDM. They identified 13 different practices across four elements of decision making: (1) broaching decision making (e.g. health care providers “flagging up” an approaching commitment point or eliciting patient perspectives about decisions, or patients requesting a specific treatment or test); (2) putting forward a course of action (in which providers put forward a single option or multiple options, or rule out an option); (3) committing or not to the action put forward (which may involve patients/companions making a commitment, withholding commitment, or actively resisting commitment); and (4) health care providers’ responses to patients’ resistance or withholding of commitment (which may include pursuing agreement without changing course, modifying the potential course of action, or leaving the decision open). Among their findings was providers’ tendency to reach a commitment point by putting forward a single course of action, which the reviewers note involves practices that are “imbued with varying levels of assumption that the patient should/will follow that course of action.” Reviewed studies indicated that providers were less likely to put forward multiple options from the outset, a practice that, while not a guarantee of patient-led choice, can help foster SDM by conveying a different, more collaborative relationship between the provider and the patient.

Our search identified two systematic reviews – both from the Cochrane Collaboration – that examined the effectiveness of provider-focused interventions aimed at improving adoption of SDM and other practices that support patient-centered care. Legare and colleagues (2014) reviewed 39 studies (nearly all RCTs) that evaluated interventions to improve health care

### Box C: Can We Talk?

One dimension of consumer engagement is the integration of cost considerations into the discussion of treatment options. In two related grantmaking solicitations managed by Avalere Health in 2016, RWJF awarded eight one-year grants that attempt to improve cost-of-care conversations between clinicians and patients. Preliminary research by Avalere identified six potential approaches to improving such conversations: (1) educating patients about how to talk about costs and helping clinicians internalize why they are important; (2) developing specific tools to support these conversations; (3) integrating these conversations into the clinical workflow so they are easier to have; (4) training clinicians about how to use the support tools in clinical settings; (5) developing measures of these conversations that focus on patient outcomes; and (6) insuring that successful interventions become part of regular clinical practice throughout the health care system (Avalere 2016b). Collectively employing a wide variety of approaches, the projects are scheduled to end in December 2017 and are listed in Appendix B (Ganos 2016; Avalere 2017b).

professionals' adoption of SDM. The review authors organized study interventions into three categories based on a taxonomy of interventions developed by the Effective Practice and Organization of Care Group, a Cochrane Review Group: (1) interventions targeting patients, (2) interventions targeting health care professionals, and (3) interventions targeting both. The authors then compared studies in each category to other studies in the same category, to studies in the other two categories, and to usual care, resulting in nine comparison groups. The review's primary outcomes of interest were observer-based outcome measures (OBOM) or patient-reported outcome measures (PROM) of health care professionals' adoption of SDM.

The review authors conclude that, given the low quality of reviewed studies, they cannot draw a robust conclusion about the most effective types of interventions for increasing the adoption of SDM among health care professionals. However, their findings suggest that SDM interventions that "actively target patients, health professionals, or both, are better than no intervention at all. Also it appears more promising to use interventions that target both the patient and the health care professional together than those that target either the patient or the health professional alone." In further describing the quality of the evidence, the authors note that studies varied widely in the types of interventions evaluated and the risks of bias observed; moreover, only five of the 39 included studies had the same primary outcome of interest as that of the systematic review. In addition, the authors suggest that the range of measures used by included studies confirms there is still no standardized instrument for assessing adoption of SDM by health care professionals.

An earlier Cochrane review by Dwamena et al. (2012) examined the effect of provider-focused interventions aimed at promoting patient-centered care (PCC) approaches in clinical consultations. Several included studies that focused specifically on SDM were included in the Legare et al. review described above. Among 43 RCTs reviewed by Dwamena and colleagues, most evaluated training interventions directed at primary care physicians or nurses practicing in community or hospital outpatient settings, though some studies targeted specialists. The authors found fairly strong evidence suggesting that most interventions to promote PCC in the clinical consultation lead to significant increases in the patient-centeredness of consultations, as indicated by a range of measures related to clarifying patients' concerns and beliefs; communicating about treatment options; levels of empathy; and patients' perception of providers' attentiveness to them and their concerns, as well as their diseases. In a new finding from an earlier Cochrane review on this topic, the authors found that short-term training lasting less than 10 hours was as successful as longer training. The authors note that the effects of provider training on patient satisfaction, health behavior, and health status were mixed. While

there is some evidence to suggest that complex interventions targeted at providers and patients that include condition-specific education materials have beneficial effects on health behavior and health status, the authors note this conclusion is tentative, with the number of studies too small to determine which elements of the intervention are most important.

Finally, we identified one systematic review that examined provider-related barriers to patient communication and decision making, specifically, from the perspective of physicians working in hospital intensive care units (ICUs). Across 36 included studies, Visser and colleagues (2014) identified 90 different physician-related (and physician-reported) barriers to adequate communication and patient- and family-centered care toward the end of life in the ICU. These barriers – which the authors framed in relation to 23 indicators of palliative care quality developed by the Robert Wood Johnson Foundation’s Critical Care End-of-Life Peer Workgroup – addressed not only physicians’ interaction with patients and their families, but also with other members of the care team. The authors grouped the barriers into three categories: ICU physicians’ knowledge and skills, attitudes, and practices.

With respect to the first category, the review authors found strong evidence for physicians’ lack of communication training and skills in end-of-life discussions, which played out in interactions with colleagues as well as patients and families. In particular, physicians lacked the training and skills to communicate to patients and their families the futility of further treatment. In regard to physician attitudes, the reviewers found strong evidence that physicians’ personal beliefs and values, their focus on clinical and technical parameters, and their narrow interpretation of when a patient is actually dying can contribute to lack of consensus among members of the care team and hinder the process of establishing clear, realistic care goals with patients and their families. The reviewers note, “The barriers we found with regard to physicians’ attitudes demonstrate that physicians often see their job as more to save patients’ lives than to let patients die in the best possible way.” Regarding physicians’ practice, the review found physicians often report lacking the confidence to take responsibility for the care of the dying patient. The review authors conclude that their results suggest ICU physicians need to be trained in communication competencies and in using a holistic approach to treating patients at the end of life. They also suggest a role for palliative care guidelines and support teams in ICUs that could help the ICU team “trigger a learning process in caring for patients toward the end of life.”

### ***Effects of Race on Patient/Provider Communication***

We identified two reviews exploring ways in which aspects of patient-clinician communication may mitigate or exacerbate health inequalities.

- **Topline Findings:**

- Recent studies find black patients report poorer patient-physician communication than white patients, though variation across these studies makes it difficult to say conclusively that patient-physician communication is worse for black patients than for white patients.
- Differences in patients’ and physicians’ racial identities often predicts poor communication across several communication domains.
- Moderate evidence suggests SDM interventions can improve knowledge, participation, decisional conflict, and self-efficacy among disadvantaged groups and potentially help close the gap between high literacy groups in some of these domains. However, these findings should be interpreted with caution given the varying design and quality of reviewed studies.

Shen and colleagues (2017) reviewed 40 U.S.-based studies that examined the effect of patient race and patient-physician racial concordance (i.e. patient and physician share similar racial identities) on observational and patient-reported measures of patient-physician communication. Most of these studies found that black patients report poorer patient-physician communication than white patients, particularly in the communication domains of quality and satisfaction, information giving, partnership building, participatory decision making, visit length, and non-verbal communication, among others. The authors also observed that racial discordance almost always predicted poorer communication, particularly in the domains of satisfaction, information-giving, partnership building, participatory decision making, visit length, and supportiveness and respect of conversations.

As with the reviews referenced above, the authors cited significant variation in the communication measures used across studies, noting that they could not say conclusively that patient-physician communication is worse for black patients than for white patients. In one interesting finding, the authors noted that black patients tended to report better quality of patient-physician communication than white patients in studies in which the measurement tools used assessed broad categories of overall satisfaction and shared goal setting. Conversely, black patients reported worse patient-physician communication in studies using specific measures of communication quality, such as interpersonal exchange, fairness, and respect.

The second review on this topic explored the impact of SDM interventions on outcomes for disadvantaged groups – such as ethnic minorities and individuals with low literacy, education and/or socioeconomic status – and on health inequalities. Durand et al. (2014) reviewed 19 studies examining a range of interventions (21 in all) to promote SDM, including communication skills workshops or education sessions for patients, coaching sessions targeted at patients or health professionals, computerized decision aids, and video-based interventions, among others. Among 10 studies included in a meta-analysis, the review authors found a moderate positive effect of SDM interventions on disadvantaged patients across the domains of knowledge, participation, decisional conflict, and self-efficacy, though they advise interpreting results with caution given the varying quality and design of included studies and the fact that some interventions were designed with the needs of disadvantaged groups in mind. Seven of the included studies compared the intervention's effects for low and high literacy groups; in five of these studies, disparities in knowledge, decisional conflict, uncertainty and treatment preferences narrowed following the intervention. The reviewers note that “simple and concise interventions, written in plain language and specifically tailored to disadvantaged groups’ information and decision support needs appeared most beneficial to underprivileged patients.” They add that none of these interventions had a significant effect on disadvantaged patients’ adherence levels, anxiety and health outcomes, and had no clear effect on screening/treatment preferences, intentions or uptake.

### ***Role of Trust in Patient/Provider Interactions***

Trust is a critical component in the relationship between a patient and a health care provider, yet little evidence exists on how to build trust and respect in medical encounters. We found four reviews that focused on measures of trust and strategies for promoting trust in the patient-provider relationship.

- **Topline Findings:**
  - It appears there is insufficient evidence to conclude that any specific intervention may increase or decrease patients’ trust in doctors in particular.

- Certain patient characteristics appear to be associated with levels of trust in the patient-primary care provider relationship (involving physicians and physician assistants in particular). For example, older age and lower education are among the factors that appear to be associated with higher trust, while belonging to the African American race and experiencing increased disease and treatment burden are two different factors that appear to be associated with lower trust.
- Further work is needed to explore the reciprocal nature of the trust relationship over time, from both the patient and provider perspectives.

#### **Box D: Building Trust and Mutual Respect to Improve Health Care**

In an effort to improve our understanding of how to build trust and mutual respect to meet vulnerable patients' health care needs, RWJF has allocated \$1.1 million to fund three to five empirical research studies of 18 to 24 months in length as part of a 2017 solicitation being managed by AcademyHealth. Research topics of potential interest include: how vulnerable patients understand and talk about trust, the factors that impact patient trust, strategies and infrastructure to build trust and mutual respect, and particular concerns for vulnerable patients, especially those with stigmatized health conditions and previous exposure to trauma. The Call for Proposals outlines the Foundation's interests in greater detail and provides an overview of past work funded by RWJF and others on building trust and mutual respect (Robert Wood Johnson Foundation 2017).

Regarding trust measures, one systematic review by Ozawa and Sripad (2013) evaluated the quality of 45 existing measures of trust (from 42 studies), focusing specifically on developed scales and indices that measure trust, distrust, or mistrust. They found existing evidence to be narrow in scope, with half of included studies examining the relationship between doctors/nurses and patients, and the majority of studies designed, tested, and validated in the U.S. The review authors developed a "health systems trust content area framework," in which they identified that honesty, communication, confidence, and competence were captured frequently in existing measures, with less focus on concepts such as fidelity, system trust, confidentiality, and fairness. They suggest ways to improve measures of trust, for example, by strengthening validity by using qualitative methods, pilot testing scales and indices, and extending reliability assessment beyond internal consistency.

The next three reviews focus on promoting trust in the patient-provider relationship. One integrative review by Murray and McCrone (2015) looked at 47 articles (13 conceptual articles, 28 empirical articles, and six methodological articles) published in multiple countries, the majority of which were from the U.S. and published from a medical perspective. The predominant methodology used in the qualitative studies was grounded theory; all of the quantitative studies were cross-sectional (one pre-test/post-test, one RCT). The review authors propose a new conceptual definition for promoting trust, which they define as a provider demonstration of interpersonal and technical competence, moral comportment, and vigilance to support positive patient outcomes. They identified several variables in the quantitative literature that were associated with trust in the patient-provider relationship: older age and lower education were associated with higher trust; belonging to the African American race was associated with lower trust; increased disease and treatment burden was associated with lower trust; and disparity in patient trust existed with regard to the provider race/ethnicity. The review authors suggest that future efforts to develop interventions to establish, maintain, or improve trust should focus on modifiable provider behaviors, which include each of the aforementioned core qualities.

A systematic mapping review by Brennan et al. (2013) looked at nearly 600 studies published between 2004 and 2010 on trust in the health care provider-patient relationship in order to see if and how the perspectives and focus of trust research may have changed since a previous systematic review by Rowe (2004) that examined trust research published up until 2004. Most of the included studies were carried out in the U.S. and involved questionnaires, interviews, and focus groups. The review found an increase in trust research into the patient-provider relationship since the previous systematic review by Rowe (76-110 studies published per year between 2004 and 2010), though the overall number of publications is still relatively low and fluctuating. The reviewers' most significant finding was that providers' trust in patients remains a neglected area on the trust research agenda. In addition, further work is needed to explore the reciprocal nature of the trust relationship over time, from both the patient and provider perspectives. The reviewers note that observational methods could provide important insights into how trust relations are established between patients and providers in consultations across different specialties.

As an update to an earlier systematic review, Rolfe et al. (2014) looked at 10 RCTs (including seven new trials), all of which were conducted in North America, to assess the effects of interventions intended to improve patients' trust in physicians. The studies gave conflicting results, and overall, the review found that there remains insufficient evidence to conclude that any intervention may increase or decrease trust in doctors. Among included studies, interventions showing a small but statistically significant increase in trust included: physician disclosure of financial incentives; providing choice of physician based on concordance between patient and physician beliefs about care; group visits for new inductees into a health maintenance organization; training oncologists in communication skills; and group visits for diabetic patients. However, trust was not affected in a subsequent larger trial of group visits for uninsured people with diabetes, nor with a decision aid for helping choose statins, another trial of disclosure of financial incentives, or specifically training doctors to increase trust or cultural competence. Future research could explore the impact of medical training or the use of a patient-centered or shared decision making approach on patients' trust.

### ***Effectiveness of Decision Aids***

We found five reviews that focused on the effectiveness of patient decision aids (PtDA) among people facing treatment or screening decisions.

- **Topline Findings:**
  - Overall, it appears that PtDAs may help patients to feel more knowledgeable and better informed, and help them to make decisions more congruent with their values.
  - Future research should focus on how to address the needs of lower health literacy users and on the effects of specific attributes of PtDAs, such as personal stories.

One review by Feldman-Stewart et al. (2013) looked at a Cochrane Collaboration review of 50 RCTs conducted through 2009 that examined the effects of PtDAs on patient knowledge and on their feeling of being informed. The review authors supplemented these studies with a review of 10 RCTs published in 2010. Thirty-nine RCTs compared a PtDA to usual care and all showed higher knowledge scores for patients in the PtDA groups. There was a small overall advantage for more detailed information in the PtDA on knowledge scores. Overall, the review authors found that PtDAs result in patients having higher knowledge scores and in reduced feelings of being uninformed over patients who receive usual care. They also concluded that PtDAs with

more detailed information generally result in slightly higher knowledge and lower “Feeling Uninformed” scores than those with simpler information, but the differences are small and can be reversed under some circumstances.

In a 2017 Cochrane review of 105 RCTs involving approximately 31,000 participants, Stacey et al. (2017) assessed the effects of a broad range of decision aids in people facing treatment or screening decisions. Compared to usual care across a wide variety of decision contexts, people exposed to decision aids felt more knowledgeable, better informed, and clearer about their values. The review authors also found moderate quality evidence that decision aids lead to more accurate expectations of benefits and harms of health care options, and that individuals probably participate more in the decision making. The review also notes there is some evidence that the users of these tools probably reach decisions consistent with their values, but this evidence is of low quality and could change with additional research. They found no evidence of decision aids having adverse impacts. The review authors conclude that additional research is needed about whether decision aids affect treatment adherence as well as their cost-effectiveness, and impacts among lower literacy populations.

Similarly, Munro et al. (2016) looked at how well patients make value congruent decisions with and without PtDAs for screening and treatment options. They conducted a sub-analysis of 11 RCTs included in a 2014 Cochrane review of decision aids. The review authors found that patients struggle to make value congruent decisions, but PtDAs may help. They suggest current approaches are inadequate to support patients making decisions that are consistent with their values. There is some evidence that PtDAs support patients with achieving value congruent decisions for screening choices.

A review by Bekker (2013) examined findings from 13 studies investigating the effect of a PtDA with or without a personal story on people’s health care decisions. Personal stories provide illustrative examples of others’ experiences and are seen as a useful way to communicate information about health and illness. The personal story types included in this review were: first-person scripted narrative communications tailored to the characteristics of the decision maker; third-person scripted narrative describing other patients’ experiences; documentaries illustrating the illness and types of care; and conversations illustrating the interaction between patients and doctors. All studies found participants’ judgments and/or decisions differed depending on whether or not their decision aid included a patient story. However, findings exploring associations with narrative communications, decision quality measures, and different levels of literacy and numeracy were mixed. Overall, there is insufficient evidence that adding personal stories to decision aids increases their effectiveness to support people’s informed decision making. More rigorous research is needed to elicit evidence about the type of personal story that encourages people to make more reasoned decisions based on their own values, and motivates people equally to engage with health care resources.

Finally, McCaffery et al. (2013) systematically reviewed empirical evidence relevant to health literacy and PtDAs. They looked at the PtDA trials included in the latest Cochrane update (86), and identified 11 more trials in an updated search through 2010, so that the total set of PtDA trials evaluated was 97. They found that lower health literacy affects key decision-making outcomes, but few existing PtDAs have addressed the needs of lower health literacy users. The specific effects of PtDAs designed to mitigate the influence of low health literacy are unknown. More attention to the needs of patients with lower health literacy is needed to ensure that PtDAs are appropriate for lower as well as higher health literacy patients.

## ***Effects of Patient/Provider Interaction on Patient Self-Care***

We identified two systematic reviews examining how aspects of patient-provider interaction in clinical settings affect patients' self-care for specific conditions.

- **Topline Findings:**
  - Several different aspects of the patient-provider relationship have the potential to influence patients' self-care, for better or worse. Encounters that include individualized care and leave the patient feeling understood are helpful in this regard, as are health care professionals who are perceived to be accessible, listening, respectful, and collaborative in their approach.

Fu et al. (2016) identified 10 qualitative studies conducted since 1980 in their review examining the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain. Across included studies, the authors identified seven themes within patient-professional partnerships that have the potential to influence patients' ability to self-manage their pain: communication, mutual understanding, roles of health professionals, information delivery, patients' involvement, individualized care, and healthcare service. In particular, the authors cite effective communication as fundamental to the development of mutual understanding between patients and health professionals. In addition, all of the studies emphasized participants' need to be understood. Six of the studies emphasized patients' desire for individualized care, not only in terms of the treatment for chronic back pain but also the way in which it was delivered by health professionals. The authors note that some patients in the review who accepted that their pain was a long-term condition with no cure expressed greater interest in being involved in the treatment process, suggesting acceptance of the nature of the condition may be the first step to self-management.

Similarly, Currie and colleagues (2015) examined facets of the patient-professional relationship that patients perceived as influencing self-care for heart failure. Across 24 included studies, the review authors identified several themes that they categorized as either barriers or facilitators to effective patient self-care. They found that effective self-care was consistently supported when patients perceived health care professionals to be accessible, listening, respectful, and collaborative in their approach. Patients especially valued health care professionals who were perceived to openly share information and provided a range of options, yet respected patient choices. Barriers to effective self-care included inconsistent advice, poor communication (e.g. impersonal, indifferent to the individual patient, overly clinical), and lack of empathy for patients who are juggling the demands of self-care with other social roles and personal values. Other barriers included poor information regarding commonly prescribed medication as well as lack of continuity of care (e.g. problems accessing care, changes in provider). The authors note that while the studies included in their review were published over a significant timeframe and carried out in a range of geographical contexts, the consistency of the barriers and facilitators to self-care was notable.

## **Individual Consumers' Use of Information to Inform Clinical Decisions**

In seeking to understand individual consumers' use of information to inform their health care decisions, AcademyHealth found 11 systematic reviews that fall into three categories: (1) consumers' general attitudes towards and use of online health information; (2) the effectiveness of specific tools to facilitate health care consumers' use of information; and (3) the use of information by or on behalf of specific patient populations.

- **Topline Findings:**

- There is some strong evidence that providing consumers with information can have a positive impact on their decision making and on their relationship with their provider while resulting in no adverse impacts.
- Additional work is needed to understand:
  - 1) how best to make interventions effective for people whose literacy skills or health status inhibits their ability to understand or use this information;
  - 2) whether and how information results in improved health outcomes or other downstream impacts;
  - 3) the role of providers in assuring that consumers receive and understand information; and
  - 4) how consumer characteristics and nuances in the context in which information is provided are important to its effectiveness.

### ***Consumers' Use of Information from Online Sources***

Two recent systematic reviews address issues concerning consumers' online health literacy. One review by Diviani et al. (2015) of 38 studies published between 2001 and 2013, all non-experimental, looked at evidence about the relationship between low health literacy (or proxies such as educational level or general literacy) and consumers' evaluation of health information they find on the Internet. They found strong evidence that having low health literacy is negatively related to consumers' ability to evaluate the quality of online health information, but found inconclusive evidence of a relationship between health literacy and consumers' perceptions of the quality of such information or consumers' use of criteria to evaluate that information. The authors recommend that future research rely on shared definitions of health literacy and outcome measures, identify the particular criteria consumers use in evaluating health information, and assess the role health literacy plays in shaping the interplay among these criteria.

In another systematic review, Car and colleagues looked at whether interventions to teach consumers to locate, evaluate, or use online health information were effective. Limiting themselves to experimental designs, the reviewers found low-quality evidence from two studies that such interventions may improve online skills in certain populations, though they concluded that the body of evidence was too weak to draw any conclusions that could help design future educational efforts. Although this 2011 review falls outside the timeframe of systematic reviews included in AcademyHealth's analysis, it was the most recent review looking at interventions to improve online health literacy.

### Box E: Right Time, Right Place

In order to better understand the delivery, accessibility, and relevance of health care information, RWJF funded Oliver Wyman, a management consulting firm, and Altarum Institute, a health care research and client consulting firm, to undertake the Right Time, Right Place project, which published findings in two reports in 2017 (Oliver Wyman 2017a; 2017b). To assess the information needs of vulnerable consumers, the researchers surveyed 4,000 consumers, conducted focus groups with about 50 consumers, and produced 10 consumer ethnographies. They found that lower-income consumers were less satisfied with existing health care resources, especially cost information, and spent less time than other consumers seeking health information. Impediments to vulnerable consumers effectively receiving information include language barriers and a frequent perception that providers disrespect them. The most common way all consumers begin a search for health information is through Google, although lower-income consumers often do not know the precise search terms they should use. Family, friends, and other patients are influential information sources, especially in choosing a physician. The researchers found that caregivers make the greatest use of online health resources and apps, but find it difficult to locate information on respite care and financial assistance.

To better understand the extent to which the market is meeting vulnerable consumers' health information needs, the researchers conducted 100 interventions with providers, health plans, health information companies, employers, government agencies, financial investors, and other social and charitable organizations. They found that interviewees recognized that health information needs to be more accessible, understandable, and useful for consumers, but less than half were taking any action in this regard. Among those entities that were trying to meet consumers' information needs, most were using traditional mechanisms to publicize information, offering information in multiple languages, and displaying information in mobile-friendly formats. They found the biggest market impediment to better information provision was the lack of clear return on their investment, but regulatory hurdles, a lack of needed data sharing among actors in the marketplace, and difficulties in engaging consumers also presented challenges.

A third systematic review, published in 2017, examined patients' health information-seeking behavior on the Internet and its influence on the patient-physician relationship. Tan and colleagues looked for evidence concerning: (1) factors that facilitate or inhibit discussion of patients' online findings during consultations with physicians; (2) demographic factors that affect such discussions; and (3) patients' perceptions of the impact of these discussions on various aspects of their relationships with their physicians. Looking at 18 articles based on survey and interview methodologies published between 2003 and 2015, the reviewers conclude that the information patients seek on the Internet has the potential to improve their relationships with physicians. In particular, patients view Internet information as one tool for understanding the advice and recommendations physicians provide. The evidence suggests that Internet information seeking could change the traditional physician-patient consultation to one in which patients no longer perceive their doctors as the sole custodians of information relevant to their health care.

At the same time, Tan et al. noted the need for research using experimental designs to support causal inferences about how patients' information seeking affects their relationships with their doctors. They also note the lack of evidence about physicians' perspectives on patient information-seeking behavior or studies of how the communication strategies they employ during consultations affect their relationships with patients.

A fourth systematic review, also published in 2017, looked at a variety of issues related to consumers' trust in online health information and their perceptions of its credibility. From the 73 quantitative and qualitative studies included in the review, Sbaffi et al. found consensus that

trust and credibility were correlated with the design of a website, the clarity of the information layout, the inclusion of interactive features, and the authority of the owner. Having advertising on the site has a negative effect. Older consumers place less trust or credibility in online health information than do younger consumers. Adolescents, young adults, and the very old have difficulties evaluating online information, which low literacy skills can exacerbate. The review also found a difference by age in how consumers assess the quality of web-based health information. While the youngest adults based their assessments on aesthetics, familiarity with the site, and ease of information access, critical assessment skills increased with age. The authors noted a difference by consumers' perceived health status with trust in online information, associated with an ability to assess information and take care of one's own health. Some studies show women are more trusting of online health information than men, while others show no difference. Adults with more education and higher income trust and use online health information more than adults in lower socioeconomic groups.

### *Tools to Make Information More Available to Health Care Consumers/Patients*

Systematic reviews have examined a variety of tools intended to provide information to patients and caregivers or to improve its presentation as a way to help patients and caregivers make health care decisions. We found two systematic reviews that examined the impacts of specific tools to provide consumers with information and found little relevant high-quality evidence:

- Henderson et al. (2015) looked at the impact of providing performance data about specific surgeons to patients considering elective surgery, but found no studies that met their inclusion criteria.<sup>1</sup> The reviewers noted that the lack of evidence may reflect practical difficulties in conducting the research, such as surgeons' reluctance to participate. They suggest that future qualitative studies could help clarify how this tool is being used as well as the attitudes of consumers and patients toward them.
- Giardina et al. (2014) reviewed 27 studies (20 RCTs and seven uncontrolled observational studies) published through January 2013 looking at the effect of providing patients with access to paper or electronic medical records, concluding that there are few overarching trends. They found some limited evidence that this practice improved patient satisfaction, but impacts on other measures of effectiveness, efficiency, and patient-centeredness were less clear. The reviewers found no evidence of negative patient outcomes (e.g. patient anxiety), but noted that the effects of patient record access on safety, timeliness of care, and equity are understudied. They conclude that while the few positive findings favor patient access, more rigorous research is needed.

Finally, we found one systematic review that tried to identify the most effective way to present health care performance data to assist consumer decision making. Kurtzman and Greene (2016) looked at evidence from 31 studies with experimental designs published through April 2014 and concluded that consumers better understand and make informed choices when the display of information is less complex. They found evidence that simplification can be achieved by reducing the number of choices, displaying results in a positive direction, using non-technical language, employing evaluative elements like star ratings and icons, and grouping results by common attributes or contexts.

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<sup>1</sup> They searched for all RCTs, quasi-RCTs, cluster-RCTs, and certain robust designed controlled before-and-after studies through March 2014.

## *Use of Information by or on Behalf of Specific Patient Populations*

We found four systematic reviews that focus on how particular groups of patients or their advocates do or could use information relevant to their health care decisions. One focuses on older individuals, while the other three reviews focus on patients with particular conditions.

### **Box F: Understanding the Use and Impact of Price Data in Health Care**

In a 2013 solicitation managed by AcademyHealth, RWJF funded six research grants related to consumers' use of price data to inform health care decision making. The Foundation's goal was to contribute to the knowledge base on the use and impact of health care price data and to accelerate progress towards transparency and the effective use of this information. Four of the studies focused on consumers' use of price data, one investigated provider behavior, and one study examined the relationship between marketplace consolidation and prices.

Although each of the studies had its own detailed findings, several general themes emerged from this body of research during a May 2016 meeting in which grantees shared their results with each other and with the Foundation. Among them, consumer demand for and availability of price information is growing, but many consumers do not use price comparison tools when available, and the use of transparency tools did not significantly reduce out-of-pocket or total spending. In addition, although previous research has indicated that clinicians reduce their ordering rates when they are given information on prices, studies in this solicitation found no overall change in ordering rates when pricing information was displayed on physicians' ordering screens at point of care. Participants at the 2016 meeting concluded that additional research is needed to understand the types of price information and other dimensions of health care value consumers want and how to get this information to consumers in ways that assure its use. They further saw gaps in our understanding of (1) how providers engage with patients about price and value, (2) the point at which value-based payment leads to more cost-conscious treatment decisions, and (3) how to meet the needs of low-income and other vulnerable consumers who lack both market power and resources to use currently available price information (Robert Wood Johnson Foundation 2016).

In 2015, Bolle and colleagues published a systematic review of research testing the effectiveness of online "health information tools" (OHITs) that provide information, enhance information exchange between patients and providers, or promote self-management among consumers ages 65 years or older. Focusing on 13 RCTs, they found strong evidence that OHITs improve patients' self-efficacy in managing their own overall health, blood pressure, hemoglobin, and cholesterol levels. They found limited evidence to support any impacts on measures of knowledge, glycemic control, self-care adherence, exercise endurance, and quality of life.

In a systematic review examining the effectiveness of tools designed to support decision making about plans for vaginal versus caesarean birth among pregnant women who previously had a caesarean, Horey et al. (2013) found only three RCTs involving 2,270 participants that met their criteria for inclusion as of July 2013. They found no differences between women using decision support tools and those who did not in terms of: the type of birth planned, the type of birth actually experienced, the proportion of women unsure about what type of birth they wanted, the proportion of women who ultimately received their planned type of birth, or in reported harms (although only one of the three RCTs looked at harms). The authors note the need for additional research on decision supports designed to be used by women together with the health professionals caring for them.

### **Box G: Open Notes: An Initiative to Provide Patients with Access to Their Medical Records**

Although the Giardina et al. (2014) systematic review found only limited evidence showing benefit to providing patients with access to their medical records, RWJF funded a quasi-experimental exploratory study in 2010 evaluating the impact on doctors and patients of providing patients with access to doctors' office notes through secure Internet portals. The OpenNotes project involved 105 primary care providers and 13,564 patients associated with Beth Israel Deaconess Medical Center in Massachusetts, Geisinger Health System in Pennsylvania, and Harborview Medical Center in Washington. They found that patients consulted their notes frequently and majorities reported increased adherence to medication regimens and feeling more in control of their care. The study found patients had minimal concerns, and almost all patients wanted the practice to continue. Very small minorities of physicians reported longer visits, more time addressing patient questions, or greater time devoted to writing notes (Delbanco 2012). Because of these positive findings, OpenNotes now provides access to medical records to over 17 million patients in the U.S. and in other countries. Based out of Beth Israel Deaconess in Boston, the project continues to expand ([www.opennotes.org](http://www.opennotes.org)).

Kopke and colleagues (2014) reviewed 10 RCTs published as of June 2013 that studied the effectiveness of interventions that provided people with multiple sclerosis (MS) with information intended to promote informed treatment choice and improve patient outcomes. These interventions included the provision of written information or decision aids, educational programs, and personalized information, all focused on disease-modifying therapy, relapse and fatigue management, self-care, family planning, and general health promotion. The review found that providing information to people with MS increases knowledge relevant to the disease (moderate quality evidence). The review authors found mixed results about the impact on decision making and quality of life (low quality evidence), but the research found no negative consequences to informing MS patients.

Lastly, a "scoping review" by Cranley et al. (2017) focused on patients diagnosed with colorectal cancer (CRC). The review included 13 studies of various designs published between 1999 and 2015 that evaluated the state of literature on factors influential in treatment decision making among individuals with CRC. As a scoping review, it did not evaluate the quality of the research or conduct a formal synthesis of study findings. The authors' overall conclusion is that providers who initiate a dialog with patients to better understand their treatment goals can create rapport, improve patients' understanding of care options, and help

patients play the role they desire in their decision making. Among the factors that patients prioritize when deciding among treatment options are quality of life and trust in their physician. Several studies also found that while CRC patients wanted to be informed and involved in treatment decisions, they did not necessarily want to make the decision solely by themselves. The research indicated that many CRC patients prefer a more passive role.

## **IV. Discussion**

Focused on recent systematic reviews, AcademyHealth's evidence synthesis helps provide an understanding of the strength and scope of existing evidence on two key areas of consumer engagement in health care: (1) interactions between patients and providers in clinical settings, and (2) consumers' use of information to inform health care decisions. The synthesis identified 36 recent systematic reviews addressing these two topics.

Findings from these systematic reviews suggest that most patients wish to have some role in their medical decision making and that the number of people with this preference has increased over time. However, evidence also shows that some patients prefer to delegate decisions to a physician, raising questions about which decisions patients wish to share, which patients prefer

to delegate decisions, and how to identify patients' preferences during the medical encounter. On the topic of trust, certain patient characteristics appear to be associated with higher or lower levels of trust in the patient-provider relationship, such as older age and higher disease burden, respectively. However, there is insufficient evidence to conclude that any one intervention may increase or decrease trust in doctors in particular. Regarding the information consumers use to inform health care decisions, it appears that patient decision aids may help individuals feel more knowledgeable about their care and help them make decisions that are more congruent with their values. However, further work is needed to understand the specific features of decision aids that are most effective. The design of a website and the clarity of the information layout are among the factors associated with consumers' trust in online health information. Some evidence suggests this information has the potential to improve patients' relationships with physicians, though physicians' take on this issue has been understudied. Also on the provider side, there is no clear evidence to support specific interventions for promoting the adoption of shared decision making (SDM) among health care professionals. However, some evidence suggests that any intervention seeking to improve SDM is better than no intervention at all, and that interventions targeting both patients and providers are better than those interventions targeting either group alone.

While the literature discussed here is diverse in many respects, AcademyHealth observed a number of themes across this body of research that may be worth noting:

- Authors of included systematic reviews consistently noted the lack of common definitions and measures on key topics relevant to consumer engagement in health care, including SDM, health literacy, and patient participation, among others. In some cases, the measures used to assess whether a specific form of consumer engagement occurred and its impact on patients were so variable across included studies that review authors could not draw strong conclusions regarding existing evidence.
- In the reviews examining aspects of patient-provider interaction in clinical settings, physicians were the specific provider type studied most often (both primary care physicians and specialists). Far fewer studies, if any, examined patients' interactions with nurses, physician assistants, pharmacists, or other types of health care professionals.
- Much of the included literature examined patient-provider interaction during a single clinical encounter and its impact on a variety of patient outcomes. Far fewer studies, if any, examined the patient-provider relationship over multiple encounters and its role in fostering (or inhibiting) consumer engagement over the long term.
- While some of the systematic reviews specifically sought to understand consumer engagement among racial/ethnic minorities, individuals with low health literacy, individuals with low socio-economic status, and other historically disadvantaged groups, these reviews were relatively few in number, suggesting more work is needed to understand the needs and experiences of these populations.
- While the primary focus for this project was consumer engagement in the U.S., AcademyHealth found a significant amount of relevant literature produced abroad, both in terms of systematic reviews and the individual studies included in those reviews. While we recognize there are important differences in health policy and health care delivery across different countries, we opted not to exclude relevant literature simply because of the country in which it was produced.

As noted previously, these observations are limited to the select body of research included in AcademyHealth's review: systematic reviews published within the past five years in English that addressed aspects of consumer engagement of specific interest to RWJF. This approach was preferable given the quick-turnaround nature of the review as well as the Foundation's interest in rigorous, peer-reviewed research. Given the high level of rigor of the systematic reviews, which primarily included RCTs and studies with well-controlled experimental designs, this approach means that readers can have high confidence in the findings that are available. However, it also means that other types of information that could help provide a fuller understanding of the current consumer engagement landscape were generally excluded. These include individual research studies published after the most recent systematic review of a topic, various forms of grey literature, such as issue briefs, surveys, and media reports, and studies of interventions that employ observational designs. Strong observational studies have the potential to offer insights into the effectiveness of interventions under "real world" conditions, which may be different than the well-controlled settings of RCTs.

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December 2017

**AcademyHealth Synthesis: What Opportunities Exist to Improve  
Consumer Engagement in Health Care?**

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## Appendix A: Systematic Reviews Included in AcademyHealth’s Synthesis

Table A1: Patients’ Preferred Roles in Health Care Decision Making

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Laidsaar-Powell RC et al. Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. Patient Educ Couns. 2013 Apr;91(1):3-13.</p>	<p>The nature of triadic (physician-adult patient-adult companion) communication and decision-making within all medical encounters</p>	<p><b>Date range:</b> 1950-July 2011</p> <p><b>Inclusion criteria:</b> Studies were included if they included qualitative or quantitative analysis of primary or secondary data sets; included triadic communication/decision-making involving one of the following: adult patient, adult companion (e.g. spouse, family member, friend), physician; occurred in any type of medical setting; involved any type of physician-patient-companion communication and/or decision-making.</p> <p><b>Exclusion criteria:</b> The authors excluded publications that were not research studies and those that were not published in English. They also excluded studies involving non-physician providers and companions with a unique responsibility (e.g. paid</p>	<p><b>Studies included:</b> 52 studies (more than half conducted in the U.S.). The majority of studies provided descriptive evidence about the characteristics of triadic consultations and accompanied patients/companions, or focused on participant preferences for companion involvement.</p> <p><b>High-level findings:</b> Reviewed studies indicate that companions regularly attend consultations and assume a variety of roles within the consultation.</p> <p>Patients attending geriatric or primary care consultations were more likely to be accompanied and less likely to be actively involved in the consultation if they were older, less educated, or more unwell. For patients attending consultations for life-threatening conditions (i.e. cancer), the companion attendance rate was high, though demographic characteristics did not appear to influence accompaniment or involvement. The reviewers note that the role a companion assumes appears to be based on patient needs and includes logistical, informational, and emotional support.</p>	<p>The authors discuss a number of limitations of their review, including the focus solely on consultations involving physicians. They also note that this is not a well-indexed field, with lots of different terminology used; it’s possible that some relevant studies were not included.</p> <p>The authors identify a number of areas where further research is needed and highlight preliminary strategies for health professionals to improve communication/decision-making in triadic consultations.</p>	

		caregiver). Studies examining communication between only two members of the triad were also excluded.	<p>Both patients and physicians generally preferred companion support and appreciated the support companions provide. Additionally, the review found companion involvement can lead to positive consequences, such as improved patient understanding and the quality and quantity of information exchange.</p> <p>However, reviewed studies highlight various challenges in triadic consultations, including family conflict, the role of the companion, physicians or companions over-sharing information, and difficulty in discussing sensitive issues.</p>		
Chewning et al. Patient preferences for shared decisions: A systematic review. Patient Educ Couns. 2012 Jan;86(1):9-18	Patients' decision role preferences in a variety of contexts and populations	<p><b>Date range:</b> January 1980-December 2007</p> <p><b>Inclusion criteria:</b> Empirical, peer-reviewed journal articles that measured patient decision role preferences, described measures, presented findings as percentages or mean scores, and were published in English from any country.</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 115 studies (representing 119 analyses). Across the studies, the most frequently used measures of patient preferences were the Control Preferences Card Sort, the Autonomy Preference Index (API), API Modified, the Problem Solving Decision-Making Scale, and the Health Option Survey.</p> <p>The reviewers categorized included studies according to whether the majority of study respondents wanted to participate in decisions or to delegate decisions to the physician. They also categorized studies into four study population groups: patients with cancer, patients with other chronic illness, patients undergoing invasive procedures, and general population.</p> <p><b>High-level findings:</b> Across the 119 analyses, 63% found that the majority of respondents wanted to participate in health decisions. By comparison, 21% of the analyses found that the majority of respondents preferred to delegate</p>	<p>The reviewers conclude that interpreting the current literature on patients' role preferences for decision making is challenging due to methodological variances and a limited characterization of key constructs in decision making. However, taken together, the included studies suggest the number of patients who prefer participation has increased over the past three decades so that the majority of patients prefer to participate in decisions during the encounter.</p> <p>The reviewers note that all studies identified a subset of patients who wanted to</p>	

			<p>decisions to a physician. The remaining analyses reported mixed findings.</p> <p>In three quarters of the cancer studies and invasive procedure studies, the majority of patients preferred shared or autonomous decision making. This was true for only about half of the studies with non-disease specific study populations or other chronic conditions, many of which incorporated hypothetical scenarios.</p> <p>Patient preference for participating in decisions increased over time, particularly among the cancer studies.</p> <p>Clear differences occurred in patients' reported decision role preferences depending on the measure used. The reviewers provide examples of how reported decision role preferences are sensitive to the format and wording of question stems and response opinions.</p>	<p>delegate decisions, raising the question of how to solicit a patient's role preference and tailor visits appropriately.</p> <p>The reviewers suggest a need to better understand how patients perceive the decision process and which decisions patients most want to share. They cite a need for more longitudinal descriptive studies of how a patient's preferred role changes over time within different conditions and as health status changes.</p>	
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Table A2: Impact of Patient Participation in the Clinical Encounter on Patient Outcomes

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Clayman ML et al. The Impact of Patient Participation in Health Decisions Within Medical Encounters: A Systematic Review. Med Decis Making. 2016. May; 36 (4): 427-52.</p>	<p>The extent to which patient participation in decision-making within medical encounters is associated with measured patient outcomes</p>	<p><b>Date range:</b> Through late February 2015</p> <p><b>Inclusion criteria:</b> Publications had to be in the context of the physician-patient relationship; involve a measure of patient participation related to a decision addressed during the medical encounter; be empirical; have outcomes related to participation as part of the study; be published in English.</p> <p><b>Exclusion criteria:</b> Non-English studies; search was limited to PubMed and MEDLINE (and the references section of included publications).</p>	<p><b>Studies included:</b> 116 studies (11 RCTs; 83 cross-sectional designs, 13 longitudinal designs, nine choice versus no-choice designs). Among the RCTs, most were conducted in Germany or Canada.</p> <p><b>High-level findings:</b> Among 11 RCTs testing an educational intervention (often physician training in shared decision making), 10 studies found that the intervention increased patient involvement. Among the 10 RCTs reporting increased patient involvement, five studies reported at least one positive outcome.</p> <p>Included studies (both RCTs and non-RCTs) measured a range of outcomes that the reviewers categorize as either psychosocial, behavioral, practice-related, or biomedical. The reviewers note that psychosocial constructs (e.g. satisfaction, anxiety, decision regret) constituted the vast majority of outcomes studied.</p> <p>Although proportions differed, the authors found similar patterns across the 105 non-randomized studies. Among the non-randomized studies, 74% (78 studies) indicated an association between patient participation and at least one positive outcome, generally a measure of satisfaction.</p>	<p>Among the RCTs, a quality assessment by the reviewers found most had acceptable research designs and statistical analyses and responsibly-drawn conclusions. However, two were deemed of poor quality due to large and unaddressed potential for investigator bias and/or moderate attrition.</p> <p>The authors conclude that their review found “uneven application of methods and mixed results in terms of empirical support for the value of patient participation in medical decisions.” They note that “it will be difficult to derive meaning from the research unless consistent measures of participation and outcomes are used whenever possible.”</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Hauser K et al. Outcome-Relevant Effects of Shared Decision Making. Dtsch Arztebl Int. 2015 Oct 2;112(40):665-71.</p>	<p>The effect of patient participation in the form of shared decision making (SDM) on patient-relevant, disease-related outcomes</p>	<p><b>Date range:</b> Through June 2014</p> <p><b>Inclusion criteria:</b> Publications were included if they included a controlled study design; explicitly used the terms “shared decision making” or “participatory decision making” in the description of the intervention; fulfilled at least one additional SDM criterion according to Charles et al. (1997); assessed patient-relevant, disease-related outcomes.</p> <p><b>Exclusion criteria:</b> Use of a decision aid as the only difference between control group and intervention group; intended implementation of SDM in the control group, too; lacking statistical data supporting the reported results.</p>	<p><b>Studies included:</b> 22 controlled intervention studies. Studied interventions ranged from brief conversations with patients that immediately preceded doctor-patient contact to several hours of staff training delivered over several weeks.</p> <p><b>High-level findings:</b> In 12 of the 22 studies, the outcomes in patients who had received an SDM intervention did not show any greater improvement than the outcomes in patients of the respective control groups. Ten studies showed an advantage for SDM for patient-relevant, disease-related outcomes compared with the control groups. Observed effect sizes were high to very high in some cases.</p> <p>Among the 10 studies showing favorable results for SDM, 70% of the interventions were directly aimed at the patient. These 10 studies (as well as those showing no difference between the intervention and control group) included, among others, patients with cardiovascular disorders, respiratory disorders, mental disorders, or tumor disease.</p>	<p>The reviewers conclude that research on the effect of SDM on patient-relevant, disease-related outcomes is insufficient in terms of quality and volume. They note they can draw no conclusion based on their review.</p> <p>Among the challenges: there is no consistent definition of SDM in the literature; the studies included in this review varied widely in terms of the disorders, outcomes and interventions studied; the quality of the implementation of SDM interventions was low to moderate in many studies (though the reviewers acknowledge there simply may not have been enough implementation detail included in studies to assess accurately).</p>	<p>Reviewers are based in Germany and published in a German journal.</p>
<p>Phillips NM et al. A systematic review of reliable and valid</p>	<p>The reliability and validity of strategies for</p>	<p><b>Date range:</b> January 2004 – March 2014</p>	<p><b>Studies included:</b> 33 studies reporting two dozen patient participation measurement tools; majority of studies were descriptive</p>	<p>The reviewers note that their review was limited to</p>	<p>The reviewers are based at Deakin</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>tools for the measurement of patient participation in healthcare. <i>BMJ Qual Saf.</i> 2016 Feb;25(2):110-7.</p>	<p>measuring patient participation in health care</p>	<p><b>Inclusion criteria:</b> Studies reporting the reliability or validity of an instrument used in a health care setting to measure adult patient participation, published in English.</p> <p><b>Exclusion criteria:</b> Studies published in languages other than English, literature and systematic reviews, non-research studies, and studies focused on patient participation in health research.</p>	<p>psychometric studies using prospective, cross-sectional designs. The reviewers categorized studied tools according to whether they were designed for completion by patients (15), designed for completion by family caregivers (2), designed for completion by an observer (5), or designed for completion by more than one observer (3).</p> <p>In assessing included studies, the reviewers defined patient participation as including the core requirements of shared decision-making (SDM), acknowledging the patient as having critical knowledge regarding his/her own health and care needs, and promoting self-care/autonomy.</p> <p><b>High-level findings:</b> The reviewers observed significant variation in the concepts/variables used to measure patient participation. They note that almost all tools focused on aspects of patient participation; while the majority included a specific item referring to SDM, this was implicit rather than explicit in some studies.</p> <p>Overall, the reviewers conclude that “few of the reviewed tools designed for completion by patients provided an overall valid and reliable option for measuring patient participation,” while none of the observer-completed tools were successful in this regard. They note that the most promising tool reviewed was a revised version of the Observing Patient Involvement in</p>	<p>tools developed over a 10-year period.</p>	<p>University in Australia.</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>Decision Making (OPTION) tool that measures SDM from the patient, observer, and clinician perspectives. While this “dyadic-OPTION” tool was only in pilot stage at the time of the review, the reviewers found it was reliable and valid in measuring all stakeholder perspectives of care.</p> <p>The reviewers note that “while the tools completed by more than one stakeholder provided the most promise as a measurement of patient participation, the length of time required to either train raters, deliver the instrument and/or analyse results may preclude their use in many clinical settings.”</p>		
<p>Couet N et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. Health Expect. 2015 Aug;18(4):542-61.</p>	<p>The extent to which health care providers involve patients in decision making across a range of clinical contexts, based on studies using the OPTION tool</p>	<p><b>Date range:</b> 2001 (when the OPTION tool was created) – June 2012</p> <p><b>Inclusion criteria:</b> Publications were included if they included OPTION scores as reported outcomes and health care providers and patients as study participants.</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 33 studies taking place in nine countries (primarily in Europe; seven studies were from the U.S.). Nine of the 33 studies were RCTs.</p> <p>Observing Patient Involvement in Decision Making (OPTION): One of the first instruments designed to measure the extent to which health care providers involve patients in decision making from an observer’s perspective. Focuses solely on behaviors initiated by the health care provider. Based on recordings of the medical consultation, the observer rates the provider’s level of expertise for 12 key “patient-involving” behaviors using a scale from 0 to 4; sum is standardized to produce a value ranging from 0 to 100.</p>		

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p><b>High-level findings:</b> Across the 33 studies, measures of patient involvement were low overall but improved through interventions. The reviewers found results “hinting that clinicians trained in SDM, once they have integrated patient-involving behaviors into their practice, may continue to work this way (improved OPTION scores were sustained over time).”</p> <p>Behaviors that required tailoring care to patient preferences were attempted least consistently across studies (i.e. least observed behaviors were assessing the patient’s preferred approach to receiving information to inform decision making and eliciting the patient’s preferred level of involvement in decision making).</p> <p>While the reviewers observed variations in patient-involving behaviors by clinicians across subgroups of professions, it is unclear whether these variations reflected differences in overall aptitude for patient involvement rather than differences caused by varying consultation lengths. Longer consultations usually coincided with higher OPTION total scores.</p>		
Shay LA and Lafata JE. Where is the evidence? A systematic review of shared decision making and patient	The patient outcomes that have been studied in relation to shared decision making (SDM)	<p><b>Date range:</b> Through December 2012</p> <p><b>Inclusion criteria:</b> Studies were included if they empirically (1) measured SDM</p>	<p><b>Studies included:</b> 39 studies (most of which were observational in design) that included 97 outcome assessments (categorized as affective-cognitive, behavioral, or health-related outcomes). The majority of included studies used patient-reported measures of SDM; fewer</p>	The authors note that none of the studies identified in their review measured SDM across a long-standing provider/patient	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>outcomes. Med Decis Making. 2015. Jan; 35 (1): 114-31.</p>	<p>and the association between measurement perspectives (patient-reported, clinician-reported, or observer-rated) and types of patient outcomes</p>	<p>in the context of a patient-clinician interaction, and (2) evaluated the relationship between SDM and at least one patient outcome.</p> <p><b>Exclusion criteria:</b> Studies were excluded if they reported only qualitative data, were reviews or commentaries, did not explicitly measure the decision making process using a SDM measure and at least one patient outcome, or did not quantitatively model the relationship between measured SDM and at least one patient outcome.</p>	<p>used observer-rated or clinician-reported measures.</p> <p><b>High-level findings:</b> Fewer than half of the assessments of patient outcomes (43%) found a statistically significant and positive relationship between SDM and the patient outcome. Significant associations were most likely to occur when SDM was measured from the perspective of the patient, regardless of the outcome category. Regardless of how SDM was measured, affective-cognitive patient outcomes (such as patient satisfaction) were most likely to be associated with SDM.</p> <p>The reviewers suggest that with the measures of SDM currently available, the link between SDM and patient behavioral and health outcomes has yet to be fully established. The reviewers note that health outcomes are least studied, and when they are measured, it's mostly been via patient self-report and often with unvalidated instruments.</p>	<p>relationship, so they are unable to discuss how SDM may affect patient outcomes over time; they suggest that additional research is needed here.</p>	
<p>Sanders AR et al. Effects of improved patient participation in primary care on health-related outcomes: a systematic review. Fam Pract.</p>	<p>The effect of interventions aimed at improving patient participation in face-to-face primary care consultations on</p>	<p><b>Date range:</b> Through October 2012</p> <p><b>Inclusion criteria:</b> Randomized controlled trials examining patient-centered interventions aimed at affecting patients' ability to influence treatment decisions</p>	<p><b>Studies included:</b> Seven cluster randomized trials conducted in the following countries: England (2), Germany (2), U.S. (1), Canada (1), France (1).</p> <p>The providers involved were either general practitioners or primary care physicians; in four studies, primary care practice teams received the intervention training as a unit. Patients were</p>	<p>The reviewers note that studies varied widely in their aims, types of complaints/diseases, strength of the interventions, and outcomes of interest.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
2013 Aug;30(4):365-78.	patient-oriented and/or disease-oriented outcomes	during primary care encounters.  <b>Exclusion criteria:</b>	<p>seen for acute respiratory infections, osteoarthritis, depression, diabetes, hypertension, and cholesterol measurement.</p> <p><b>High-level findings:</b> The reviewers conclude that the seven studies included in the review show ambiguous (and sometimes conflicting) results. They found no significant effect of patient participation on patient-related outcomes, which they note is similar to or weaker than the results of other reviews.</p> <p>The reviewers posit that there simply are not many controlled intervention studies examining the effect of patient participation on health outcomes, perhaps in part because there is no precise definition of participation, which makes it difficult to operationalize. They offer some suggestions for how future trials could be designed.</p>	In addition, the reviewers state that a considerable risk of bias hampered all of the studies, and the internal and external validity of the overall results of this review is low.	

Table A3: Opportunities and Challenges for Providers in Engaging Patients in Clinical Encounters

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Land V et al. Communication practices that encourage and constrain shared decision making in health-care encounters: Systematic review of conversation analytic research. Health Expect. 2017 May 18.</p>	<p>Mapping decision making communication practices relevant to health care outcomes and examining their function in relation to shared decision making</p>	<p><b>Date range:</b> Through November 2016</p> <p><b>Inclusion criteria:</b> Studies were included if they were published in English in books or peer-reviewed journals; used conversation analysis as the primary analytic approach; included audio/audio-visual recording of naturalistic health care interactions between providers and patients/companions; included data and analysis examining broaching, considering, planning, and/or deciding health/illness-related actions.</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 28 studies (seven from the U.S., remaining studies from the United Kingdom, Canada, and Australia); all were conversation analytic studies of health care encounters spanning a wide variety of conditions.</p> <p><b>High-level findings:</b> Based on the 28 included studies, the review authors mapped 13 communication practices across four decision making elements: (1) broaching (actions prior to commitment points being reached); (2) putting forward a course of action (commitment becomes relevant); (3) how patients convey commitment (or not); and (4) providers' responses to patients' resistance or withholding of commitment.</p> <p>In reflecting on the 13 practices described in the review, the authors note there has been little focus on the provision of multiple treatment/care options by health care providers compared to single recommendations. They note that option listing conveys a different relationship between provider and patient and can (though not always) provide clear opportunity for patient participation.</p>		
<p>Visser M et al. Physician-related barriers to</p>	<p>Physician-related barriers to adequate</p>	<p><b>Date range:</b> 2003-August 2013</p>	<p><b>Studies included:</b> 36 studies (14 conducted in the U.S., others in China, the West Indies, and various western and eastern European</p>		<p>Review utilizes quality indicators for</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. Crit Care. 2014 Nov 18;18(6):604.</p>	<p>communication (within the care team and with patients and families) and adequate patient- and family-centered decision making toward the end of life (as reported by ICU physicians)</p>	<p><b>Inclusion criteria:</b> Studies were included if they: were published in English or Dutch; addressed a clear research question or objective and used primary qualitative or quantitative data; focused on ICU physicians treating adult patients; focused on physician communication within the team and with patients and families or on patient and family-centered decision making toward end of life of patients in an ICU; focused on physician-related barriers to communication and patient and family-centered decision making as described by physicians themselves.</p> <p><b>Exclusion criteria:</b></p>	<p>countries). Half the studies were qualitative studies; half were surveys.</p> <p><b>High-level findings:</b> Across the 36 included studies, the reviewers identified 90 different physician-related barriers to adequate communication and patient and family-centered decision making towards the end of the patient's life in intensive care. The reviewers grouped these barriers according to ICU physicians' knowledge and skills, attitudes, and practices:</p> <p>Regarding physicians' knowledge, the reviewers found strong evidence for physicians' lack of training in skills related to communication with patients, patients' families, and physicians' colleagues, including communication of the futility of further treatment, as a barrier.</p> <p>The reviewers found strong evidence for several barriers related to physicians' attitudes, including physicians' personal beliefs and values and their focus on only clinical and technical parameters; physicians' training only to save the patient's life; and physicians' narrow interpretation of when a patient is actually dying.</p> <p>Regarding physicians' practice, the reviewers found strong evidence for physicians' lack of</p>		<p>end-of-life care in the ICU developed by the RWJF Critical Care End-of-Life Peer Workgroup</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			confidence in taking responsibility for the care of the dying patient.		
Legare F et al. Interventions for improving the adoption of shared decision making by healthcare professionals. Cochrane Database Syst Rev. 2014. Sept; 15 (9).	The effectiveness of interventions to improve health care professionals' adoption of shared decision making	<p><b>Date range:</b> An earlier version of this review included relevant studies published before March 2009; this update by the authors included studies published from mid-March 2009 to August 2012, as well as a number of studies published after August 2012.</p> <p><b>Inclusion criteria:</b> Publications were included if they were randomized or non-randomized controlled trials, controlled before-and-after studies, or interrupted time series studies evaluating interventions to improve healthcare professionals' adoption of SDM where the primary outcomes were evaluated using observer-based outcome measures (OBOM) or patient-reported outcome measures (PROM).</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 39 studies (38 RCTs, one non-randomized controlled trial). Fourteen studies were conducted in the U.S.; the remaining were conducted in Europe, Canada and Australia. The setting was primary care in 22 of the studies and the three most frequent clinical conditions across all studies were cancer, cardiovascular disease, and multiple conditions.</p> <p>The reviewers organized study interventions into categories based on the Effective Practice and Organisation of Care Taxonomy of Interventions: (1) interventions targeting patients, (2) interventions targeting healthcare professionals, and (3) interventions targeting both. The reviewers then compared the three categories of targeted interventions to the same category of targeted intervention, to each of the other categories of targeted intervention, and to usual care, resulting in nine comparison categories in total.</p> <p><b>High-level findings:</b> The reviewers note that given the heterogeneity of the interventions used, the primary outcomes assessed, and the risks of bias that were observed, they cannot draw a robust conclusion regarding the most effective types of interventions for increasing</p>	The reviewers note that their findings confirm there is still no standardized instrument for assessing the adoption of SDM by healthcare professionals. They add that an interprofessional approach to SDM is an emerging field, with more studies needed to inform policymakers about the content, definition and effectiveness of an interprofessional approach.	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>the adoption of SDM by healthcare professionals.</p> <p>However, while one precise intervention cannot be recommended over another, the review suggests that SDM interventions that actively target patients, health professionals, or both, are better than no intervention at all. Results also suggest that interventions targeting health professionals may achieve more than interventions targeting patients when each of these is compared to usual care. Finally, the reviewers note that interventions targeting both patients and health professionals may be more likely to be effective than targeting the patient or health professional alone.</p>		
<p>Dwamena F et al. Interventions for providers to promote a patient-centered approach in clinical consultations. Cochrane Database Syst Rev. 2012 Dec 12;12:CD003267</p> <p><i>This systematic review is an update to an earlier</i></p>	<p>The effects of interventions for healthcare providers that aim to promote patient-centered care approaches in clinical consultations</p>	<p><b>Date range:</b> January 2000-June 2010</p> <p><b>Inclusion criteria:</b> Studies were included if they were RCTs; involved any type of healthcare provider (including those in training); and involved any type of intervention directed at healthcare providers and intended to promote patient-centered care within clinical consultations.</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 43 studies (includes 14 studies from the original review, plus 29 studies published between January 2000 and May 2010). Sixteen studies were conducted in the U.S., 10 were conducted in the U.K., and the remaining studies were conducted in Canada and several countries in Europe and Eastern Asia.</p> <p>Among the included studies, the interventions studied focused on a variety of clinical conditions, although the most common patients were adults with general medical problems. In most of the studies, training interventions were directed at primary care physicians or nurses</p>	<p>The reviewers note that the heterogeneity of outcomes studied and the use of single item consultation and health behavior measures limit the strength of the conclusions.</p> <p>The reviewers note wide variability in the measures used to assess the patient centeredness of consultations, patient</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p><i>Cochrane review on this topic:</i></p> <p>Lewin SA et al. <i>Interventions for providers to promote a patient-centred approach in clinical consultations.</i> <i>Cochrane Database Syst Rev.</i> 2001;(4):CD003267.</p>		<p>Studies were included if they considered cultural, disability, sexuality or other sensitivity training only for healthcare providers; evaluated training in psychotherapy or counselling for healthcare providers; trained providers to deliver a specific, secondary intervention in a patient-centered manner in clinical consultations.</p>	<p>practicing in community or hospital outpatient settings, though some studies targeted specialists.</p> <p>The reviewers classified interventions by whether they focused only on providers or on providers and patients, with and without condition-specific educational materials. They grouped outcomes data from the studies to evaluate both direct effects on patient encounters (consultation process variables) and effects on patient outcomes (satisfaction, health behavior change, health status).</p> <p><b>High-level findings:</b> The reviewers conclude that their review confirms findings from the Lewin et al. (2001) review that interventions to promote patient-centered care (PCC) are effective in transferring PCC skills to healthcare providers. They find fairly strong evidence to suggest that most interventions to promote PCC in the clinical consultation lead to significant increases in the patient-centeredness of consultation processes, as indicated by a range of measures relating to clarifying patients' concerns and beliefs; communicating about treatment options; levels of empathy and patients' perception of providers' attentiveness to them and their concerns as well as their diseases.</p> <p>In a new finding from the original review, the reviewers find that short-term training (lasting</p>	<p>satisfaction, and global health status.</p> <p>They also suggest that future work could include head-to-head comparisons of different configurations of complex interventions to identify the key or "active" elements; development of strategies for involving consumers in the design, planning and delivery of complex interventions to promote PCC; and examination of provider/patient training among health care teams.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>less than 10 hours) is as successful as longer training.</p> <p>The reviewers note that the effects on patient satisfaction, health behavior, and health status are mixed. There is some indication that complex interventions directed at providers and patients that include condition-specific educational materials have beneficial effects on health behavior and health status, though this conclusion is tentative and the number of studies is too small to determine which elements of the interventions are essential in helping patients change their healthcare behaviors.</p>		

Table A4: Effects of Race on Patient/Provider Communication

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Shen MJ. The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature. J Racial Ethn Health Disparities. 2017 Mar 8.</p>	<p>The effect of patient race (black versus white patients) and the interactive effect of physician and patient race (i.e. racial concordance of patients and physicians) on observational and patient-reported patient-physician communication</p>	<p><b>Date range:</b> 1995-2016</p> <p><b>Inclusion criteria:</b> Publications were included if they were peer-reviewed, quantitative studies conducted in the U.S. that had a patient population sample; compared black to white patients or racial concordance to discordance; assessed patient-physician communication within a medical setting; and measured communication through audio/video recordings or observation and/or patient surveys.</p> <p><b>Exclusion criteria:</b> Included not an adult patient/health setting; not original data; not authors' concept of patient-physician communication; no comparative analysis between black versus white patients or racial concordance; not a U.S. study in English; communication measure was only assessed post-intervention; communication</p>	<p><b>Studies included:</b> 40 studies (all conducted in the U.S.)</p> <p>The reviewers developed eight patient-physician communication domains based on the communication outcomes referenced most commonly in the included literature: (1) communication quality; (2) communication satisfaction; (3) information-giving; (4) partnership building; (5) patient participation and participatory decision-making; (6) positive and negative affect/talk; (7) length of visit/time and talk-time ratio; and (8) other.</p> <p>The majority of findings focused on the quality of patient-physician communication, satisfaction with patient-physician communication, or length of visit/time for patient-physician interactions.</p> <p><b>High-level findings:</b> The reviewers note that while the association between patient race (black or white) and patient-physician communication varies across studies, the majority of studies support the finding that black patients report poorer patient-physician communication than white patients.</p> <p>Namely, 38 out of 66 results from analyses show that black patients report lower patient-physician communication quality and satisfaction; less information-giving, partnership</p>	<p>The reviewers note that despite the preliminary insights provided by this review, it does not support an overarching hypothesis that patient-physician communication is worse for black patients than white patients. They cite a need for more consistent measures of patient-physician communication to improve the interpretability of review results.</p> <p>Specifically, the reviewers note that the specificity of the communication measures used matters. For example, black patients reported better quality of patient-physician communication than white patients in studies in which measurement tools assessed broad categories of overall satisfaction and shared goal-setting. Conversely,</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>was not a clear dependent variable.</p>	<p>building, participatory decision-making, and positive talk; more negative talk; shorter visits; physicians who were more verbally dominant; and worse outcomes on non-verbal communication, respect, and support.</p> <p>Seven findings show that black patients have better communication with physicians than white patients, while the remaining 21 findings indicate no significant effect of race on communication.</p> <p>The reviewers found that racial discordance (i.e. patients and physicians have different racial identities) almost always predicted poor communication in the domains of satisfaction, information-giving, partnership building, participatory decision-making, visit length, and supportiveness and respect of conversations. The only communication domain in which racial concordance seemly had no effect was in quality of communications, which the reviewers speculate may be due in part to the broadness of this category.</p>	<p>black patients reported worse patient-physician communication than white patients when more specific measures of quality communication were assessed, such as interpersonal exchange, fairness and respect.</p> <p>The reviewers note that results highlight that both physicians and patients may benefit from training to improve communication, which they add begins in medical school and continues with feedback and coaching throughout individuals' graduate training and beyond.</p>	
<p>Durand M. Do interventions designed to support shared decision-making reduce health inequalities? A</p>	<p>The impact of shared decision-making interventions on disadvantaged groups and on health inequalities</p>	<p><b>Date range:</b> Through June 2012</p> <p><b>Inclusion criteria:</b> Review authors included all studies that met the following criteria: (1) assessed the effect of shared decision-making</p>	<p><b>Studies included:</b> 19 studies (most undertaken in the U.S.; remaining studies from Australia and Nicaragua), including both RCTs and observational studies. Ten of the 19 studies were included in a meta-analysis by the review authors.</p>	<p>The reviewers note that the quality of included studies was variable and fairly low (which they note is consistent with quality assessment scores reported in an earlier</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>systematic review and meta-analysis. 2014. PLoS One. April 15;9(4):e94670.</p>		<p>interventions on disadvantaged groups and/or health inequalities, and (2) included at least 50% of people from disadvantaged groups (except if a separate analysis was conducted for this group). All conditions and clinical settings were included.</p> <p><b>Exclusion criteria:</b></p>	<p><b>High-level findings:</b> The 19 included studies evaluated 21 interventions including communication skills workshops or education sessions, coaching sessions targeted at patients or health professionals, computerized decision aids, video-based interventions to improve informed decision-making and shared decision-making, a counseling session, booklet or DVD decision aids, and paper-based handouts promoting informed decision-making.</p> <p>Study participants fell into one of five disadvantaged groups: minority ethnic group, low literacy/low education minority ethnic group, low literacy group, low socioeconomic status, medically underserved.</p> <p>The review suggests that shared decision-making interventions significantly improved outcomes in disadvantaged groups: increased knowledge, informed choice, participation in decision-making, decision self-efficacy, preference for collaborative decision making, and reduced decisional conflict.</p> <p>However, the reviewers' meta-analysis suggests one study was overinflating the overall effect estimates of both the knowledge domain and the included quasi-experimental designed studies. The reviewers note that the effect estimate calculated without this study is</p>	<p>Cochrane review of decision aids for people facing health treatment or screening decisions).</p> <p>In addition, among included studies, sample size was generally small and follow up was not systematic and limited. The reviewers note it is therefore difficult to infer whether the impact of these interventions would last beyond funded research and could reduce health inequalities in the long term.</p> <p>Also, 10 of the 21 interventions included in the review were designed with the needs of disadvantaged groups in mind, which may have increased the likelihood that the interventions would benefit these groups.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>much more accurate, indicating only a moderate improvement in knowledge.</p> <p>In five of seven studies that compared the intervention's effect between disadvantaged and higher literacy/higher socio-economic status groups, disparities in knowledge, decisional conflict, uncertainty, and treatment preferences were narrowed. The reviewers note that this suggests that SDM interventions were more beneficial to disadvantaged groups than to privileged participants.</p> <p>Two studies indicate that knowledge gain was affected by patients' literacy level, suggesting that the intervention's content may not have been sufficiently tailored to the needs of disadvantaged groups.</p>		

Table A5: Role of Trust in Patient/Provider Interactions

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Brennan N et al. Trust in the health-care provider-patient relationship: a systematic mapping review of the evidence base. Int J Qual Health Care. 2013 Dec;25(6):682-8.</p>	<p>The review aimed to classify the current evidence base on trust in the patient-provider relationship in order to identify strengths and weaknesses to point towards areas for future research. The question that guided the review was: What are the characteristics of empirical research in the healthcare setting examining the role of trust in the patient-provider relationship or reporting trust as an emergent finding?</p>	<p><b>Date range:</b> January 2004-November 2010</p> <p><b>Inclusion criteria:</b> Studies were included that had been written in the English language; reported on empirical research; had been undertaken in or alluded to health care settings; had patients and/or health care providers as participants; and had examined the role of trust in relationships, had investigated interventions that might influence levels of trust, had examined the consequences of trust or had reported on trust as an emergent finding.</p> <p><b>Exclusion criteria:</b> Excluded studies did not address the topic of interest; were not written in English; were not empirical research; were not in a healthcare setting; or did not include patients or health care providers as participants.</p>	<p><b>Studies included:</b> 596 studies were included. Most studies were carried out in the U.S. (44%), followed by other European countries (20%), and the U.K. (12%). The majority of methods employed were questionnaire surveys (34%), followed by interviews (30%), and focus groups (9%). Most reported on patients' trust in providers and collected data in family care or oncology/palliative care settings. Only one study explicitly set out to examine providers' trust in patients and &lt;5% of included studies reported on providers' trust in patients.</p> <p><b>High-level findings:</b> There has been an increase in trust research into the provider-patient relationship since the previous systematic review conducted through 2004. Providers' trust in patients remains a neglected area on the trust research agenda. Healthcare providers trust patients to seek medical advice in a timely fashion unmotivated by other concerns; yet, providers are increasingly also socially licensed adjudicators on contested or contestable claims by patients to illness, need for treatment, time off work, disability benefits, and so on. Further exploration of this area using observational methods is recommended.</p>	<p>This is a systematic mapping review, which is a defined method to build a classification scheme and structure a field of interest. It involves a search of the literature to determine what has been studied, and is particularly appropriate to identify gaps in research literature. Mapping reviews generally lack the specificity and quality assessment aspects of traditional SRs, potentially masking considerable variation between classified studies. Despite the wide-ranging literature searched there may have been some literature missed.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Murray B and McCrone S. An integrative review of promoting trust in the patient-primary care provider relationship. J Adv Nurs. 2015 Jan;71(1):3-23.</p>	<p>The aim of this article is to report the results of an integrative review of empirical studies on promoting trust in the patient-primary care provider relationship. The question used to guide the review was: What are the factors that promote trust in the patient and primary care provider relationship?</p>	<p><b>Date range:</b> 1998-2013</p> <p><b>Inclusion criteria:</b> Conceptual definitions of trust; original empirical research with a qualitative or quantitative design methodology; explored trust or correlates of trust in the context of the patient-nurse, -advanced NP, -PCP, -PA, or -physician relationship; descriptions of scales used to measure trust</p> <p><b>Exclusion criteria:</b> Focus on primary, community, or acute care trusts, organizational or administrative trust, physician trust in patient, trust in the nurse-physician relationship, or trust in the parent-physician relationship; focus on trust in the infant-, child-, or adolescent-provider relationship; opinion papers, editorials, and dissertations</p>	<p><b>Studies included:</b> 47 articles remained for analysis (13 conceptual articles, 28 empirical articles, and six methodological articles). The empirical literature was represented by multiple countries of publication: U.S. (19), Australia (2), Norway (1), Sweden (1), U.K. (1), Canada (2) and Taiwan (2). Nine were published from a nursing perspective, and the remaining 19 were published from a medical perspective.</p> <p><b>High-level findings:</b> A new conceptual definition of promoting trust is proposed that includes three core qualities: interpersonal and technical competence, moral comportment and vigilance. The core qualities could serve as target areas for interventions aimed at modifying provider behaviors so that trust can be established, maintained, or improved. Gaps exist related to rural, young adult, older adult and well patient populations, as well as trust with multiple primary care provider types.</p>	<p>This is an integrative literature review rather than a systematic review. When combining diverse methodologies, qualitative and quantitative, lack of rigor, inaccuracy, and bias can result. The inclusive criteria may have limited the sample and missed relevant studies. Publication bias potentially exists.</p>	
<p>Ozawa S and Sripad P. How do you measure trust</p>	<p>This paper attempts to fill the gap in evaluations</p>	<p><b>Date range:</b> Prior to April 2012</p>	<p><b>Studies included:</b> 42 studies (45 measures) were included in the analysis. With the exception of one scale, all measures were</p>	<p>The results are limited by the search strategies including databases</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>in the health system? A systematic review of the literature. <i>Social Science &amp; Medicine</i>. 2013 May;91:10-14.</p>	<p>of quality of trust measures by asking the following research questions: How many trust measures are there? What relationships and populations do they study? What content areas do they capture? How rigorous are the measures?</p>	<p><b>Inclusion criteria:</b> English; articles that developed a new scale or index, or revalidated an existing scale in a new population; measures within the health system</p> <p><b>Exclusion criteria:</b> Excluded studies included conceptual pieces that discussed but did not quantify concepts, and articles that measured trust without a scale or index or developed a scale or index to measure a related concept, of which trust was one of the components.</p>	<p>developed after 1990, with a majority (87%) published since 2000.</p> <p><b>High-level findings:</b> The review identified 45 measures of trust within the health system with an average of 12 questions each, which quantified levels of trust among various relationships across the health system. Existing evidence was narrow in scope, where half examined the relationship between doctors/nurses and patients, and the majority were designed, tested, and validated in the U.S. The authors developed a health systems trust content area framework, where they identified that honesty, communication, confidence, and competence were captured frequently in these measures, with less focus on concepts such as fidelity, system trust, confidentiality and fairness. The review identifies a need to develop measurements of trust beyond doctor-patient relationships and outside of U.S. contexts, and strengthen the rigor of existing trust measures.</p>	<p>searched and inclusion/exclusion criteria. The focus on English-language publications due to resource limitations and potential publication bias may have affected findings.</p>	
<p>Rolfe A et al. Interventions for improving patients' trust in doctors and groups of doctors. <i>Cochrane Database Syst</i></p>	<p>The aim of the review is to update the authors' earlier review assessing the effects of interventions intended to</p>	<p><b>Date range:</b> 2003-2013</p> <p><b>Inclusion criteria:</b> Randomized controlled trials (RCTs), quasi-randomized controlled trials, controlled before and after studies, and interrupted time series of</p>	<p><b>Studies included:</b> 10 randomized controlled trials (including seven new trials) involving 11,063 patients were included in the updated review. The studies were all published in English and undertaken in North America, and all but two took place in primary care. Interventions were of three main types: three employed additional physician training, four</p>	<p>The review was constrained by the lack of consistency between trust measurements, timeframes and populations.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
Rev. 2014 Mar 4;(3):CD004134.	improve patients' trust in doctors or a group of doctors.	<p>interventions (informative, educational, behavioral, organizational) directed at doctors or patients (or carers) where trust was assessed as a primary or secondary outcome.</p> <p><b>Exclusion criteria:</b> Studies that did not measure a change in trust (pre- and post-intervention) with a validated instrument; studies that were so compromised by flaws in their design or execution as to be unlikely to provide reliable data; studies that did not meet the criteria in study types.</p>	<p>were education for patients, and three provided additional information about doctors in terms of financial incentives or consulting style.</p> <p><b>High-level findings:</b> Trials showing a small but statistically-significant increase in trust included: a trial of physician disclosure of financial incentives; a trial of providing choice of physician based on concordance between patient and physician beliefs about care; a trial of group visits for new inductees into a Health Maintenance Organization; a trial of training oncologists in communications skills; and a trial of group visits for diabetic patients. However, trust was not affected in a subsequent larger trial of group visits for uninsured people with diabetes, nor with a decision aid for helping choose statins, another trial of disclosure of financial incentives or specifically training doctors to increase trust or cultural competence. Overall, there remains insufficient evidence to conclude that any intervention may increase or decrease trust in doctors.</p>		

Table A6: Effectiveness of Decision Aids

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Bekker HL. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. BMC Med Inform Decis Mak. 2013;13 Suppl 2:S9.</p>	<p>This article examines evidence to support the addition of personal stories to patient decision aid (PtDA) interventions.</p>	<p><b>Date range:</b> 2005-2012</p> <p><b>Inclusion criteria:</b> Studies that evaluated the effects of a personal story component of a patient decision aid intervention on people’s healthcare decision making; involved individuals making real or hypothetical decisions; presented personal stories in the first or third person; used experimental and/or RCT designs, before-and-after study designs, and/or cohort study designs; involved an adult population; and published in English.</p> <p><b>Exclusion criteria:</b> Discussion and/or review papers, as well as studies (a) assessing message-framing only; (b) using video or verbal (narrated) formats for information delivery only; (c) involving proxy decision making</p>	<p><b>Studies included:</b> The reviewers identified 11 articles reporting findings from 13 studies investigating the effect of a PtDA with or without a personal story on people’s health care decisions. The studies had three broad aims: informed decision making studies, informed choice studies, and informed engagement studies. Most studies assessed hypothetical choices or preferences.</p> <p><b>High-level findings:</b> All studies found participants’ judgments and/or decisions differed depending on whether or not their decision aid included a patient story. Knowledge was equally facilitated when the decision aids with and without stories had similar information content. Story-enhanced aids may help people recall information over time and/or their motivation to engage with health information. Personal stories affected both “system 1” (e.g., less counterfactual reasoning, more emotional reactions and perceptions) and “system 2” (e.g., more perceived deliberative decision making, more stable evaluations over time) decision-making strategies. Findings exploring associations with narrative communications, decision quality measures, and different levels of literacy and numeracy were mixed. The pattern of findings was similar for both experimental and real-world studies. There is insufficient evidence</p>	<p>This article reported on a survey of primary empirical research employing a systematic review method.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		(i.e., decision making by an individual for another); and (d) using non-experimental or single-case study designs.	that adding personal stories to decision aids increases their effectiveness to support people's informed decision making. More rigorous research is required to elicit evidence about the type of personal story that a) encourages people to make more reasoned decisions, b) discourages people from making choices based on another's values, and c) motivates people equally to engage with healthcare resources.		
Feldman-Stewart D et al. Providing information about options in patient decision aids. BMC Med Inform Decis Mak. 2013;13 Suppl 2:S4.	The purpose of this paper is to present the theoretical justification for evaluating PtDAs according to the quality dimension of 'providing information about options', to review the current empirical evidence for such evaluation, and to identify and discuss some emerging theoretical, evidentiary, and research issues about the provision of information in PtDAs.	<p><b>Date range:</b> This paper synthesizes the results of two systematic reviews: 1) a Cochrane Collaboration review up to the end of 2009, and 2) a supplemental review up to the end of 2010.</p> <p><b>Inclusion criteria:</b> Randomized controlled trials that compared (1) PtDAs to usual care, and (2) PtDAs with simple information to PtDAs with more detailed information.</p> <p><b>Exclusion criteria:</b> Non-randomized studies; studies that did not look at the outcomes of interest.</p>	<p><b>Studies included:</b> (1) Cochrane Collaboration review of the published reports about the effects of PtDAs tested in RCTs up to the end of 2009. This review identified 50 RCTs. (2) Supplementary review that included 10 RCTs from 2010. Of the 60 RCTs, 39 compared a PtDA to usual care, and 21 compared a simpler to a more-detailed PtDA.</p> <p><b>High-level findings:</b> Thirty-nine RCTs compared a PtDA to usual care and all showed higher knowledge scores for patients in the PtDA groups. Among them, 16 used the Feeling Uninformed subscale. There was a small overall advantage for more detailed information on knowledge scores. Only one study found higher mean knowledge scores for simpler information, and one study found that simpler information resulted in patients feeling more informed. It appears that PtDAs result in patients having higher knowledge scores and in</p>	This review relied on the Cochrane Collaboration review for assessments of the quality of the studies included in the review. In addition, they restricted all studies to RCTs to rely on the highest level of evidence but do recognize that there are numerous non-randomized studies that can provide some insights into relevant issues. Further, all the studies they relied on were conducted in English in Western countries. Further research is needed to clarify language and cultural issues within those	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>reduced feelings of being uninformed over patients who receive usual care. It also appears that PtDAs with more detailed information generally result in slightly higher knowledge and lower “Feeling Uninformed” scores than those with simpler information, but the differences are small and can be reversed under some circumstances.</p>	<p>countries, and what can be generalized beyond them. Finally, issues relevant to information presentation that have been identified in this paper come from very broad educational and psychological literatures, where further guidance can be found.</p>	
<p>McCaffery KJ et al. Addressing health literacy in patient decision aids. BMC Med Inform Decis Mak. 2013;13 Suppl 2:S10.</p>	<p>This paper systematically reviews empirical evidence relevant to health literacy and PtDAs with two principal aims: (1) To assess (a) the effects of health literacy / numeracy on selected decision-making outcomes, and (b) the effects of interventions designed to mitigate the influence of lower health literacy on decision-making outcomes; and (2) To assess the extent to which existing PtDAs</p>	<p><b>Date range:</b> For the first aim, this paper searched two existing systematic reviews conducted for AHRQ in 2004 and 2011, including the titles and abstracts of articles that had been excluded from the 2011 AHRQ review. For the second aim, the review authors examined the PtDAs included in the published Cochrane Collaboration review of RCTs (including trials published to the end of 2009). They additionally updated the review with studies published to the</p>	<p><b>Studies included:</b> When high-quality systematic reviews existed, the reviewers summarized their evidence. When reviews were unavailable, the reviewers conducted their own systematic reviews. For the first aim, 18 articles were included. For the second aim, the review authors included 97 RCTs (86 from the latest Cochrane update and 11 from the updated search through 2010).</p> <p><b>High-level findings:</b> Lower health literacy affects key decision-making outcomes, but few existing PtDAs have addressed the needs of lower health literacy users. The specific effects of PtDAs designed to mitigate the influence of low health literacy are unknown. More attention to the needs of patients with lower health literacy is indicated, to ensure that PtDAs are appropriate for lower as well as higher health literacy patients.</p>	<p>It is possible that some relevant studies were missed. Other limitations include the inherent potential for publication bias, the diversity of measures used for similar outcomes, and the small number of physicians (despite adequate numbers of patients) that were included in studies of health literacy and communication. There may be confounding and lack of control of relevant variables in some of the papers included in the</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
	<p>(a) account for health literacy, and (b) are tested in lower health literacy populations.</p>	<p>end of 2010 using the same search strategy.</p> <p><b>Inclusion criteria:</b>  Articles that included individual-level subjective assessments of health literacy, outcomes related to clarifying values, outcomes related to participating in decision making during the clinical encounter. All ages, races, ethnicities, and cultural groups in developed countries; health literacy and numeracy levels of individuals are measured and reported for individuals; included decision-making outcomes of interest; interventions that authors report are specifically designed to mitigate the effects of low health literacy; cross-sectional, cohort, and experimental studies; stratified by Health Literacy Level;</p>		<p>reviews. Also, the review only included RCTs. There is now mixed evidence regarding the benefit of alternate media on improving outcomes for lower literacy patients, and so review criteria may need to be revised for future reviews.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>peer-reviewed articles in English.</p> <p><b>Exclusion criteria:</b> Poor quality studies; systematic evidence reviews; no measure of health literacy; no outcomes of interest; developing country; studies published in abstract form only; intervention not designed to mitigate effects of low health literacy</p>			
<p>Munro S et al. Choosing treatment and screening options congruent with values: Do decision aids help? Sub-analysis of a systematic review. Patient Educ Couns. 2016. Apr;99(4): 491-500.</p>	<p>The aim of this paper is to understand how well patients make value congruent decisions with and without patient decision aids (PtDAs) for screening and treatment options, and identify issues with its measurement and evaluation.</p>	<p><b>Date range:</b> This systematic review was conducted as a sub-analysis of RCTs included in a 2014 Cochrane Collaboration review on decision aids. Citations were searched through June 2012 (MEDLINE, CENTRAL, EMBASE, PsycINFO) and to September 2008 for CINAHL.</p> <p><b>Inclusion criteria:</b> Measured value congruence with chosen option; reported a</p>	<p><b>Studies included:</b> 11 RCTs that provided quantitative results were included.</p> <p><b>High-level findings:</b> Patients struggle to make value congruent decisions, but PtDAs may help. While the absolute improvement is relatively small it may be underestimated due to sample size issues, definitions, and heterogeneity of measures. Current approaches are inadequate to support patients making decisions that are consistent with their values. There is some evidence that PtDAs support patients with achieving values congruent decisions for screening choices.</p>	<p>Quantitative findings should be interpreted with caution due to the small sample size and significant heterogeneity in trials' measurement of value congruence, values, and choices. Further, the Cochrane review follows strict inclusion and exclusion criteria. Thus other trials may have measured value congruence but were excluded from the sample at some stage of the review.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>relationship or measure of congruence between patients' values and choices, based on (a) a value clarification method that reported "the extent to which the positive and negative characteristics of different health care options are personally important to the patient", and (b) the patients' intended or actual choices.</p> <p><b>Exclusion criteria:</b> Studies that used a measure of "feeling clear" about one's values alone or did not provide quantitative data for pooling.</p>			
<p>Stacey D et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst</p>	<p>The purpose of this review is to assess the effects of decision aids in people facing treatment or screening decisions.</p>	<p><b>Date range:</b> The reviewers updated their previous review from 2014 with a search from 2012 to April 2015.</p> <p><b>Inclusion criteria:</b> All published studies that used a randomized controlled trial design</p>	<p><b>Studies included:</b> 105 RCTs involving 31,043 participants. This update added 18 studies and removed 28 previously included studies.</p> <p><b>High-level findings:</b> Compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision-making and more</p>	<p>The potential biases in the review process are due to limitations associated with having inadequate power to detect potentially important differences in effectiveness between subgroups, to differentiate between the most effective elements within</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
Rev. 2017. Apr 12;4: CD001431.		<p>evaluating patient decision aids; studies involving adults aged 18 years or older who were making decisions about screening or treatment options for themselves, a child, or an incapacitated significant other; studies that evaluated a patient decision aid as part of the intervention</p> <p><b>Exclusion criteria:</b>            Studies comparing detailed versus simple decision aids; studies that compared two different types of patient decision aids; studies in which participants were making hypothetical choices; studies of interventions that focused on decisions about lifestyle changes, clinical trial entry, or general advance directives; education programs not geared to a specific decision; interventions designed to promote adherence or elicit informed consent</p>	<p>accurate risk perceptions. There is growing evidence that decision aids may improve values-congruent choices. There are no adverse effects on health outcomes or satisfaction. New for this updated is evidence indicating improved knowledge and accurate risk perceptions when decision aids are used either within or in preparation for the consultation. Further research is needed on the effects on adherence with the chosen option, cost-effectiveness, and use with lower literacy populations.</p>	<p>the patient decision aid, and to investigate any differences associated with the type of comparison interventions used in studies. Furthermore, they limited the extracted study data to only two comparison groups (e.g. most intensive intervention including a patient decision aid and usual care); therefore, they did not investigate the possibility of intermediate effects with less intensive decision aid interventions.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>regarding a recommended option; and studies when the relevant decision aids were not available to the review authors and not adequately described in the article(s).</p>			

Table A7: Effects of Patient/Provider Interaction on Patient Self-Care

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Fu Y et al. Patient-professional partnerships and chronic back pain self-management: a qualitative systematic review and synthesis. Health Soc Care Community. 2016. May; 24 (3): 247-59.</p>	<p>The influence of patient-professional partnerships on patients' ability to self-manage chronic back pain and the key factors within these partnerships that may influence self-management</p>	<p><b>Date range:</b> 1980-2014</p> <p><b>Inclusion criteria:</b> Publications were included if they were primary research studies in which: patients were supported by having a partnership with health professionals to experience chronic back pain self-management; patients were actively involved with health professionals in developing treatment or care plans for self-managing chronic back pain; the influence of patient-professional partnerships on chronic back pain self-management was reported.</p> <p><b>Exclusion criteria:</b> Publications were excluded if they: were studies reporting views of the general public; were studies of patients undergoing cancer treatments or related therapies; were editorials, commentaries, or letters of opinion to peer-reviewed journals; were</p>	<p><b>Studies included:</b> 10 studies (all qualitative); unclear how many were conducted in the U.S.</p> <p><b>High-level findings:</b> The reviewers conclude that the studies reviewed support the notion that a partnership between patients and health professionals may support patients to manage their chronic back pain.</p> <p>Based on their review, they identify seven themes within patient-professional partnerships that have the potential to influence patients' ability to self-manage their pain: communication, mutual understanding, roles of health professionals, information delivery, patients' involvement, individualized care, and healthcare service. In particular, the reviewers cite effective communication as fundamental to the development of mutual understanding between patients and health professionals. In addition, all of the studies emphasized participants' need to be understood.</p> <p>Six of the studies emphasized patients' desire for individualized care, not only in terms of the treatment for chronic back pain but also the way in which it was delivered by health professionals.</p> <p>The reviewers note that some patients in included studies who accepted that their pain</p>	<p>All of the included studies were qualitative and involved small samples, and most of the studies were of medium or low quality. Thus, the reviewers suggest findings are not necessarily transferrable. However, they note that similar findings were reported by both low- and high-quality studies.</p>	<p>Review authors are based in the U.K.</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		published in a language other than English.	was a long-term condition with no cure expressed greater interest in being involved in the treatment process, suggesting acceptance of the nature of the condition may be the first step to self-management.		
Currie K et al. The importance of interactions between patients and healthcare professionals for heart failure self-care: A systematic review of qualitative research into patient perspectives. Eur J Cardiovasc Nurs. 2015. Dec; 14 (6): 525-35.	Facets of patient-healthcare professional relationships perceived by patients to influence self-care for heart failure (HF)	<p><b>Date range:</b> 1995-March 2012</p> <p><b>Inclusion criteria:</b> Studies were included if they reported primary qualitative data from full papers/theses and contained specific data from adults related to self-care needs in HF. Only papers reported in English were included.</p> <p><b>Exclusion criteria:</b></p>	<p><b>Studies included:</b> 24 studies (16 studies were conducted in North America; the remaining studies were conducted in Scandinavia (5), the United Kingdom (2), and Malaysia (1).</p> <p><b>High-level findings:</b> The reviewers identified several themes across included studies that they categorized as either barriers or facilitators to effective patient self-care.</p> <p>Effective self-care was consistently supported when patients perceived healthcare professionals to be accessible, listening, respectful, and collaborative in their approach. Patients especially valued healthcare professionals who were perceived to openly share information and provided a range of options, yet respected patient choices.</p> <p>Barriers to effective self-care included inconsistent advice, poor communication (e.g. impersonal, indifferent to the individual patient, overly clinical), and lack of empathy for patients who are juggling the demands of self-care with other social roles and personal values. Other barriers included poor information regarding commonly prescribed medication as well as</p>	The reviewers note that study quality was variable, with common weaknesses being superficial analyses of themes, over-reliance on convenience sampling, and inadequate inclusion of participant voices/illustrative quotations.	Review authors are based in Scotland and Canada.

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>lack of continuity of care (e.g. problems accessing care, changes in provider).</p> <p>The reviewers note that patients viewed healthcare professionals as responsible for the quality of information provided, though they could adversely affect the quality of interactions by deliberately avoiding asking questions or not sharing relevant information with health care professionals.</p> <p>The reviewers note that while the studies included in their review were published over a significant timeframe and carried out in a range of geographical contexts, the consistency of the barriers and facilitators to self-care was notable.</p>		

Table A8: Consumers' Use of Information from Online Sources

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Diviani N et al. Low Health Literacy and Evaluation of Online Health Information: A Systematic Review of the Literature. J Med Internet Res. 2015. 17(5): e112-e128.</p>	<p>Evidence on the association between low health literacy and (1) people's ability to evaluate online health information, (2) perceived quality of online health information, (3) trust in online health information, and (4) use of evaluation criteria for online health information</p>	<p><b>Date range:</b> No time limits set given that topic of online health information seeking is recent.</p> <p><b>Inclusion criteria:</b> Written in English; reported qualitative or quantitative original results; studied consumer online health information; mentioned evaluation of the information by consumers/patients; and conducted in a low literacy population or sample of low literacy proxies (e.g. general literacy) or subgroup analyses were conducted among low literacy or proxy samples.</p> <p><b>Exclusion criteria:</b> Non-empirical articles; empirical studies conducted among health care providers; content analyses of websites; quality assessments of</p>	<p><b>Studies included:</b> 38 studies conducted between 2001 and 2013: 24 in North America, five in Europe, four in Asia, four in Australia, and one in Africa. All non-experimental: 35 cross-sectional surveys, one focus group study, and two qualitative observational studies. Four studies investigated the specific role of health literacy in evaluation of online health information. Others examined the association between educational level or other skills-based proxies for health literacy and outcomes.</p> <p><b>High-level findings:</b> Low health literacy and related skills are negatively related to the ability to evaluate online health information and trust in online health information. Evidence on the association with perceived quality of online health information and use of evaluation criteria is inconclusive.</p> <p>Future research should: (1) focus specifically on health literacy; (2) identify criteria people use to evaluate online health information; (3) develop shared definitions and measures for commonly used outcomes in the field of evaluating online health information; and (4) assess the relationships between different evaluative dimensions and the role played by health literacy in shaping their interplay.</p>	<p>Not addressed in the review beyond describing study designs and methods.</p>	<p>Reviewers are based at the University of Amsterdam</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		websites; articles conducted among populations not fitting inclusion criteria.			
Car J et al. Interventions for Enhancing Consumers' Online Health Literacy. Cochrane Database of Systematic Reviews. 2011, Issue 6. Art. No. DC007092.	Assesses whether interventions to teach people to find, evaluate, or use online health information (online health literacy) improves those skills and peoples' health	<p><b>Date range:</b> January 1990 – March 1, 2008</p> <p><b>Inclusion criteria:</b> RCTs, cluster RCTs and associated economic evaluations, quasi-RCTs, controlled before and after (CBA) studies, and interrupted time series studies of any type of intervention that trained consumers to find, evaluate, or use health information from the internet. All languages included, but search conducted in English.</p> <p><b>Exclusion criteria:</b> Trial discontinued due to recruitment problems; intervention involved training in the use of WebTV; not finding, evaluating, or using online health information.</p>	<p><b>Studies included:</b> One RCT and one controlled before-and-after (CBA) study with a combined total of 470 participants. Both studies estimated the effect of adult education classes on the online health literacy of consumers. The CBA study was limited to adults ages 50 and older.</p> <p><b>High-level findings:</b> There is low-quality evidence that interventions to improve online health literacy may improve such skills in certain populations.</p> <p>The RCT showed significant positive effects related to health literacy in the intervention group for: “self-efficacy for health information seeking;” “health information evaluation skills;” and “number of times patient discussed online information with a health provider.” The CBA study showed significant positive changes only in a secondary behavioral outcome regarding readiness to adopt the Internet as a tool for preventive health information. No adverse outcomes reported.</p> <p>Due to the small number of studies and their variable methodological quality, the evidence is too weak to draw any conclusions about the</p>	The RCT was rated as having moderate risk of bias. The CBA study was rated as having high risk of bias.	The review's 2011 publication date (and 2008 search for studies) is technically outside window for systematic reviews included in this synthesis.

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			<p>implications for the design and delivery of interventions for online health literacy. There is a need for well-designed RCTs that involve different participants (by disease status, age, socioeconomic group and gender) to analyze the extent to which online health literacy reduces barriers to using the Internet for health information. Trials should be conducted in different settings and examine interventions to enhance online literacy (search, appraisal, and use of online health information), measuring outcomes for at least one year after intervention.</p>		
<p>Tan SS, Goonawardene N. Internet Health Seeking and the Patient-Physician Relationship: A Systematic Review. J Med Internet Res. 2017 19(1) e9-e23</p>	<p>Patients' Internet health information seeking behavior and its influence on the patient-physician relationship.</p> <p>The review covers: Strategies for using/revealing online information during physician consultations: (1) facilitators/barriers to discussion of online findings during consultations; (2) demographic factors affecting discussion of</p>	<p><b>Date range:</b> January 2000 – October 1, 2015</p> <p><b>Inclusion criteria:</b> Empirical studies focused on Internet health information-seeking behavior of health care consumers and aspects of the patient-physician relationship, published in English.</p> <p><b>Exclusion criteria:</b> Non-empirical articles (review articles, website content assessments, commentaries); study focus only on online</p>	<p><b>Studies included:</b> 18 articles (seven used surveys, six used interviews, nine used semi-structured interviews, and two used mixed methods). All published between 2003 and 2015. Six focused primarily on the implications for the patient-physician relationship, two studied the discussion of online information with physicians, and the rest studied both themes.</p> <p><b>High-level findings:</b> Patient Internet health information seeking has the potential to improve the patient-physician relationship. Patients see the Internet as an additional resource to help them better understand doctors' recommendations and advice. It has the potential to change the traditional structure of this relationship in which patients perceive</p>	<p>Quality of qualitative studies assessed using Critical Appraisal Skills Programme tool (10 questions focused on methods and study contribution). Quality of quantitative studies assessed using 14 questions adapted from three well-established tools. One of 19 studies assessed did not meet quality standards and was removed.</p> <p>Limitations noted by the reviewers: (1) the broad search criterion employed</p>	<p>The review group is based at National University of Singapore.</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
	<p>online information; (3) patients' perception of positive or negative impact on patient-physician relationship; (4) patients' sense of control, confidence, and empowerment during consultation; (5) patients' perceived consultation effectiveness; and (6) patient satisfaction.</p>	<p>health seeking; Internet is only one source of information studied; study was not of active online information seeking; full article not available; focus was on post-consultation information seeking; article examined health care professionals' information seeking.</p>	<p>physicians as sole custodians of medical information.</p> <p>Future research needs: research using experimental designs to determine causal effects of Internet information seeking on patient-physician relationships; studies to understand physicians' perspectives on patients' Internet health information-seeking behavior; studies of how physicians' communication strategies during consultation affect the patient-physician relationship.</p>	<p>to retrieve studies resulted in inconsistent terminology for the patient-physician relationship and its dimensions; (2) a decision to forgo MeSH terms in the initial search could have missed relevant articles, though a second search using basic MeSH queries was performed; (3) non-English articles were excluded.</p>	
<p>Sbaffi L, Rowley J. Trust and Credibility in Web-Based Health Information: A Review and Agenda for Future Research. <i>J Med Internet Res.</i> 2017. 19(6): 218-234.</p>	<p>Review of trust and credibility in use of web-based health information (WHI) with goal of: (1) presenting profile of research on consumers' trust and credibility in WHI seeking; (2) identify factors that impact judgements of trustworthiness and credibility; (3) explore role of demographic factors affecting trust formation. Review also sought to identify</p>	<p><b>Date range:</b> January 2000 – July 2016</p> <p><b>Inclusion criteria:</b> Relevance to one of the three main goals of the review.</p> <p><b>Exclusion criteria:</b> Focus not on trust or credibility, full article not available, full citation not available, not in English, not in a peer-reviewed journal.</p>	<p><b>Studies included:</b> 73 articles (55 quantitative, nine qualitative, seven mixed methods, and two conceptual). Thirty-seven articles studied adults ages 18-65; 20 studied undergraduate students; eight studied older people (ages 50-55+); two studied high school students; three studied younger people and adults; and one conducted website content analysis.</p> <p><b>High-level findings:</b> The review finds consensus that website design, clear layout, interactive features, and the authority of the owner have a positive effect on trust or credibility. Advertising has a negative effect. For content features, authority of the author and ease of use have a positive effect on trust or credibility formation. Demographic factors influencing trust formation are age (negative</p>	<p>Not addressed in the review beyond describing study designs and methods.</p>	<p>Reviewers are based at the University of Sheffield in the U.K. Demographic results in article are very detailed.</p>

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
	<p>knowledge gaps and a research agenda.</p>		<p>impact), gender (some studies show women more trusting than men; others show no difference), and perceived health status (trust in WHI associated with the ability to assess and look after one's own health).</p> <p>Adolescents, young adults, and the very old have difficulties evaluating online information, which are exacerbated by low literacy skills. Very young adults based assessments of WHI on aesthetics, familiarity with site, and ease of information access, with assessment skills increasing with age. Adults with higher incomes and educations trust and use online information more than lower socioeconomic groups.</p> <p>Future research is needed to clarify interactions among variables associated with health information seeking, provide consistency in measurement of trust and credibility, understand specific WHI sources, and provide more nuanced understanding of the impact of demographics on trust and credibility judgments.</p>		

Table A9: Tools to Make Information More Available to Health Care Consumers/Patients

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Henderson A, Henderson S. Provision of a Surgeon's Performance Data for People Considering Elective Surgery. Cochrane Database of Systematic Reviews. 2015, Issue 2. Art No. CD006327</p>	<p>To assess the impact of providing a surgeon's performance data to people considering elective surgery on patient-based and service utilization outcomes</p>	<p><b>Date range:</b> All databases searched from their beginning through March 2014. Review is an update of one that searched through November 2009.</p> <p><b>Inclusion criteria:</b> RCTs, cluster-RCTs, and quasi-RCTs. Also, controlled before and after (CBA) studies if they have at least two intervention and two control sites and if time periods and key characteristics of intervention and control groups are comparable. Studies of the impacts of providing surgeons' performance data to patients of any age (or their legal guardian) preparing for a planned elective surgical procedure to be performed by an accredited surgeon. Studies in any language</p>	<p><b>Studies included:</b> No studies met all of the inclusion criteria.</p> <p><b>High-level findings:</b> While public reporting of a surgeon's performance is not a new concept, the efficacy of this data for individual patients has not been empirically tested. A review of qualitative studies or new primary qualitative research may be useful to determine what interventions are currently in use and to explore the attitudes of consumers and professionals toward such interventions.</p> <p>The lack of evidence may reflect practical difficulties in researching the topic, such as a reluctance by surgeons to take part in such studies or legal and ethical problems in providing only some patients with information about a surgeon's performance.</p>	<p>No quality assessment since no studies met the inclusion criteria.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>included, but none found that required translation.</p> <p><b>Exclusion:</b> Study did not meet inclusion criteria upon review of abstract or full text.</p>			
<p>Giardina et al. Patient access to medical records and healthcare outcomes: a systematic review. J Am Med Inform Assoc. 2014. 21(4):737-41.</p>	<p>Effect of providing patients access to electronic or paper-based medical records on Institute of Medicine's (IOM's) six dimensions of quality: safety, effectiveness, patient-centeredness, timeliness, efficacy, and equity</p>	<p><b>Date range:</b> January 1970 – January 2013</p> <p><b>Inclusion criteria:</b> Studies of the impact of medical record access on measures of quality that reported comparative data between an intervention and comparison condition, including uncontrolled observational studies and RCTs.</p> <p><b>Exclusion criteria:</b> Studies that: (1) lacked a comparison group; (2) examined parental access to pediatric patient records; (3) focused exclusively on access to psychiatric records; (4) were not of humans; (5) were not of adults ages 18 and older; (6) were not</p>	<p><b>Studies included:</b> 20 RCTs and seven uncontrolled observational studies. “Almost half” focused on patient populations with chronic diseases including diabetes, cancer, heart failure, and hypertension.</p> <p><b>High-level findings:</b> The review revealed few overarching trends. Studies of interventions that provide patients access to their medical records have addressed 3/6 IOM quality dimensions: effectiveness, patient-centeredness, and efficiency. There is some limited evidence of improved levels of satisfaction, but the evidence is less clear on other dimensions. Effects of patient record access on measures of safety, timeliness, and equity are understudied. The review found no evidence to substantiate any negative patient outcomes resulting from medical record access, including patient anxiety. Although a few positive findings generally favor patient access, more rigorous research is needed.</p>	<p>The 20 RCTs were evaluated using the Quality of Study Rating Form (QSRF). The average score was 71 with range of 67-86.</p> <p>The reviewers note that because the review covered an emerging area of research with relatively few studies, they erred in the direction of including smaller and less methodologically rigorous studies. Heterogeneity of study populations, interventions, and measurement approaches made synthesis difficult. Selective reporting and publication bias are possible.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		published in a peer-reviewed journal, book, or monograph.			
Kurtzman ET, Greene J. Effective Presentation of Health Care Performance information for Consumer Decision Making: A Systematic Review. Patient Educational and Counseling 2016. 99: 36-43	Evidence about the effective presentation of health care performance information for consumer decision making	<p><b>Date range:</b> September 2003-April 2014</p> <p><b>Inclusion criteria:</b> English language; experimental methods; attempted to identify design features that optimize consumers' use of health care performance information.</p> <p><b>Exclusion criteria:</b> Did not meet inclusion criteria.</p>	<p><b>Studies included:</b> 31 studies, including two RCTs, one randomized crossover study, and two mixed methods studies. The remaining studies utilized either a between-subjects randomized design, a repeated measures design, or a combination of the two. Twenty studies tested consumers' responses to presentations of health care cost and/or quality information; others examined responses to other types of comparative health information (e.g. disease treatment or nutritional information). Seventeen studies were published since 2011. Ten studies were conducted in Europe, with the remainder conducted in the U.S.</p> <p><b>High-level findings:</b> Consumers better understand and make more informed choices when the information display is less complex. Simplification can be achieved by reducing the quantity of choices, displaying results in a positive direction, using non-technical language and evaluative elements (e.g. star ratings, word icons), and situating results by common attributes or contexts. Results suggest enhancing health care performance reports through use of recognizable, evaluative graphics and customizable formats, limiting the</p>	Not addressed in the review beyond describing study designs and methods.	The reviewers conducted thematic synthesis by information design features: quantity of information; simplifying and clarifying techniques; order and sequence; type of display (numeric, graphical, evaluative); and use of color.

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
			amount of information presented, and testing presentation formats prior to use.		

Table A10: Use of Information by or on Behalf of Specific Patient Populations

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>Bolle S et al. Online Tool Effectiveness for Older Patients: A Systematic Review of the Literature. Journal of Health Communication. 2015. 20:1067-83.</p>	<p>The impact of online health information tools (OHITs) that provide information, enhance information exchange, or promote self-management on immediate, intermediate, and long-term outcomes among patients ages 65 and older</p>	<p><b>Date range:</b> January 2006 – September 4, 2013</p> <p><b>Inclusion criteria:</b> Study described OHITs designed to provide information on an illness for general audiences, studied effects on a sample or subgroup with a mean age of 65 years or older, used a quantitative design, and was published in English in a peer-reviewed journal.</p> <p><b>Exclusion criteria:</b> Did not meet inclusion criteria, full text could not be retrieved, or no mean age reported and author did not respond to reviewers' inquiries.</p>	<p><b>Studies included:</b> 25 studies: three pre-post, two nonclinical RCTs, 13 RCTs, six surveys, and one quasi-experimental design. Only RCTs were included in the reviewers' Best Evidence Synthesis (BES).</p> <p><b>High-level findings:</b> OHITs seem promising in facilitating immediate, intermediate, and long-term outcomes in older patients. The reviewers' BES analysis of RCTs provides evidence that OHITs improve self-efficacy, blood pressure, hemoglobin levels, and cholesterol levels. They find limited evidence to support OHIT's effects on knowledge, perceived social support, health service utilization, glycemic control, self-care adherence, exercise performance, endurance, and quality of life.</p>	<p>The reviewers used 11 criteria of internal validity to rate only the 13 RCTs. They rated 12 RCTs as high quality and one as low quality.</p>	<p>The reviewers are based at the University of Amsterdam.</p>
<p>Horey D et al. Interventions for Supporting Pregnant Women's Decision-making</p>	<p>To examine the effectiveness of interventions to support decision-making about vaginal</p>	<p><b>Date range:</b> Not provided, though searches were conducted in June and July of 2013.</p>	<p><b>Studies included.</b> Three RCTs involving 2,270 women eligible for inclusion. The studies were conducted in the U.K., Canada, and Australia and examined the effectiveness of decision support tools to be used independently by</p>	<p>The reviewers judged the overall risk of bias for included studies to be low for the primary outcomes (planned mode of birth,</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
<p>about Mode of Birth after a Caesarean. Cochrane Database of Systematic Reviews. 2013, Issue 7. Art. No. CD010041</p>	<p>birth after a caesarean birth and to identify issues related to the acceptability of any inventions to parents and the feasibility of their implementation</p>	<p><b>Inclusion criteria:</b> Published, unpublished, and ongoing RCTs and quasi-RCTs with published data with participants who are pregnant women who previously had a caesarean birth. Secondary participants include health professionals or partners of pregnant women with a previous caesarean birth. Interventions designed to support these women decide among birth options – independent (e.g. web-based decision aids), shared (e.g. decision coaching with care provider), and mediated (e.g. telephone decision-coaching). Controls are usual care or no formal decision tool. No language restrictions.</p> <p><b>Exclusion criteria:</b> Studies of women with known multiple pregnancies as well as</p>	<p>women or mediated through the involvement of someone not associated with their care support. No studies looked at shared medical decision-making.</p> <p><b>High-level findings:</b> The decision support tools studied made no difference on the type of birth women planned, how women actually gave birth, or on the number of women and babies who experienced their planned typed of birth. There were no differences between intervention and control groups in adverse outcomes in the one study reporting them, in the proportion of women who were unsure about what they wanted, or in the proportion who achieved their preferred mode of birth. Overall, nearly 65% of women who wanted a vaginal birth achieved this, while 97% of women who wanted a caesarean birth had one.</p> <p>Research is needed on the effectiveness of shared decision supports designed to be used by women together with the health professionals caring for them.</p>	<p>adverse outcomes, and congruence between planned and actual mode of birth). Lower quality evidence was provided for some secondary outcomes (decisional conflict, knowledge, and satisfaction with decision-making) due to moderate to high attrition in one small study for all of these outcomes and moderate attrition for one outcome in another study.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p>studies that included women who were not pregnant or had not experienced a previous caesarean. Studies were also excluded if the intervention did not support decisions about mode of birth.</p>			
<p>Kopke S et al. Information Provision for People with Multiple Sclerosis. Cochrane Database of Systematic Reviews. 2014, Issue 4. Art. No. CD008757</p>	<p>Effectiveness of information provision interventions for people with multiple sclerosis (MS) that aim to promote informed choice and improve patient-relevant outcomes</p>	<p><b>Date range:</b> No date range provided, but search occurred in June 2013.</p> <p><b>Inclusion criteria:</b> RCTs, cluster RCTs, quasi-RCTs of information provision interventions with intention of improving patient outcomes compared to optimized standard care. Trials with these designs that compare two such strategies were also included. Participants of all ages with a diagnosis of MS or in the process of being diagnosed were included. All languages eligible.</p>	<p><b>Included studies:</b> 10 RCTs involving 1,314 participants. Seven studies were hospital-based (mainly in outpatient departments), one recruited patients from regional MS societies, one recruited from the national MS society and treating neurologists, and one recruited from multiple locations including primary care settings and hospitals. Three studies were carried out in Germany; the remaining studies took place in the U.K. (2), the U.S. (2), Australia (1), Belgium (1), and Italy (1).</p> <p>Interventions included provision of written information or decision aids, educational programs, and personalized information. Topics of information provided included disease-modifying therapy, relapse management, self-care strategies, fatigue management, family planning, and general health promotion.</p> <p><b>High-level findings:</b> Information provision for people with MS appears to increase disease-related knowledge (moderate quality evidence)</p>	<p>The reviewers deemed two studies to be of high methodological quality. All other studies had at least some risk of bias (selection bias, performance bias, or attrition bias).</p> <p>Interpretation of study results remains challenging due to the significant heterogeneity of studied interventions, the outcome measures used, and the quality of the evidence.</p>	

Citation	Focus of review	Methods	Relevant findings	Limitations and quality of the evidence as reported by the author	Notes
		<p><b>Exclusion criteria:</b> Studies not fitting inclusion criteria—in particular, intervention not primarily about information provision or only optional; no MS patients or sub-analysis of MS patients provided; not randomized.</p>	<p>with mixed results on decision-making (low quality evidence) and quality of life (low quality evidence). There seem to be no negative side effects to informing patients.</p>		
<p>Cranley NM et al. Influential Factors on Treatment Decision Making Among Patients with Colorectal Cancer: A Scoping Review. Support Care Cancer. 2017 Sep;25(9):2943-2951.</p>	<p>Scoping review to evaluate the state of the literature on factors influential in treatment decision-making among patients with colorectal cancer (CRC)</p>	<p><b>Date range:</b> January 1999 – December 2015</p> <p><b>Inclusion criteria:</b> Study population comprises adults ages 18 years and older with CRC. Studies of patients with other cancers included if sufficient subgroup information for CRC patients is provided. Quantitative and qualitative designs included. Studies from any country included if in English or translations are available.</p> <p><b>Exclusion criteria:</b> Topic did not match inclusion criteria; focus was on one</p>	<p><b>Studies included:</b> 13 studies involving 2,237 participants. Nearly half used cross-sectional designs; five studies were qualitative.</p> <p><b>High-level findings:</b> Providers who initiate a dialog to better understand patients' treatment goals can establish rapport, increase patient understanding of treatment options, and help patients assume their desired role in their decision-making.</p> <p>Influences fell into four categories: informational, patient treatment goals, patient role preferences, and relationship with provider. Quality of life and trust in physician were rated a high priority among patients when making decisions between therapeutic options. Several studies found that patients wanted to be informed and involved but did not necessarily want to make autonomous treatment choices, with many preferring a more passive role.</p>	<p>There were a small number of studies that met all inclusion criteria, with most using cross-sectional designs.</p> <p>The reviewers identified four intertwined themes that can move together, but each still uniquely contributes to patient decisions.</p> <p>The majority of included studies were from outside the U.S., suggesting varying cultural norms, standards of practice, and medical care systems.</p> <p>Older studies may be less relevant as developments in shared medical</p>	

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		therapeutic method versus another.		decision-making and consumer-based medicine could affect influences on patient decisions.	

## Appendix B: Selected Robert Wood Johnson Foundation Investments Relevant to Consumer Engagement in Health Care

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
Can We Talk?		Avalere Health; Joshua Seidman	2016	This initiative seeks to facilitate conversations between patients and providers about the costs and affordability of care by: (1) conducting research on best practices, particularly on unintended consequences; (2) conducting a scan of decision-support tools; (3) creating a training guide of best practices that can inform those conversations; and (4) executing communications efforts with both patients and providers to encourage these types of conversations.	<a href="http://go.avalere.com/action/attachment/12909/f-041a/1/-/-/-/Avalere%20-%20RWJF%20Cost%20of%20Care%20Table.pdf">http://go.avalere.com/action/attachment/12909/f-041a/1/-/-/-/Avalere%20-%20RWJF%20Cost%20of%20Care%20Table.pdf</a>
	Exploring the nuances of cost-of-care conversations between providers and patients in low-income Latino communities near Denver	Colorado Coalition for the Medically Underserved; Joe Sammen and Jack Westfall	2016	This project examines how cost-of-care conversations impact satisfaction and perceived quality of care among provider-patient dyads in three settings serving low-income Latinos in southwest Adams County, Colorado.	
	Engaging vulnerable patients and their physicians in creating communication strategies and messages for	Consumers Union; Stephen Alexander Martin and Doris Peter	2016	This project tests the use of patient workshops, physician feedback, clinical simulations, social media feedback, and particular messages to support patient-provider cost conversations in Spanish and in English.	

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	discussing health care costs				
	Creating a clinical atmosphere that facilitates productive cost-of-care conversations between providers and vulnerable patients	Migrant Clinicians Network; Deliana Garcia and Douglas D. Bradham	2016	This mixed methods study examined best practices for conducting cost-of-care conversations and training physicians to discuss costs with unauthorized Latino immigrants at federally-qualified health centers.	
	Providing patients and families with understandable and useful information on the total and out-of-pocket costs of cancer care	University of Alabama, Birmingham; Maria Pisu	2016	This project is developing a decision-support system to communicate costs of care to white and African American cancer patients informed by preferences and needs of patients and care providers.	
	Documenting and improving the delivery of clinical services related to cost-of-care conversations	Kaiser Foundation Health Plan of Washington; Nora Henrikson	2016	This human-centered design study aims to understand and improve clinical workflows related to cost-of-care conversations. The project tests a financial navigator program and an EHR-based tool to discuss the cost of cancer chemotherapy.	
	Integrating a user-centered tool to facilitate provider/patient cost-of-care conversations	Sinai Urban Health Institute; Kim Erwin and Veronica Fitzpatrick	2016	This project is developing a tool that fits into usual care to enable clinician/patient cost-of-care conversations among underinsured,	

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	throughout the birthing and post-delivery process			high-risk patients at an OB/GYN clinic on Chicago's Southside.	
	Assessing the feasibility and impact of a team-based approach to integrating cost-of-medication conversations into primary care	University of Rochester; Kevin Fiscella	2016	This project is testing the feasibility and impact of a team-based approach to promoting cost-of-medication conversations through screening questions embedded in primary care clinic workflows.	
	Enhancing clinical cost-of-care conversations to help patients understand the cost/value equation and inform their choice of treatment options	University of Southern Maine; Kimberley S. Fox and Carolyn Gray	2016	This project is a study of cost-of-care tools related to diagnosis and treatment of low-back pain at 12 primary care sites. The focus is on implementation, impact on patient engagement in decision making, and implications for public cost information reporting.	
Choosing Wisely		ABIM Foundation; Daniel B. Wolfson	Multiple grants since 2012 to ABIM Foundation and other organizations to support the Choosing Wisely initiative. However, RWJF is not credited with funding the survey	Choosing Wisely encourages provider-patient discussions of overused procedures identified by medical specialties. See article in <i>Journal of General Internal Medicine</i> and accompanying commentary report from survey of primary care physicians on feasibility of following Choosing Wisely recommendations and potential barriers to their uptake.	<a href="https://link.springer.com/content/pdf/10.1007%2Fs11606-016-3853-5.pdf">https://link.springer.com/content/pdf/10.1007%2Fs11606-016-3853-5.pdf</a> and <a href="https://link.springer.com/content/pdf/10.1007%2Fs11606-016-3916-7.pdf">https://link.springer.com/content/pdf/10.1007%2Fs11606-016-3916-7.pdf</a>

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
			discussed in the linked article.		
Health Reform Monitoring Survey		Urban Institute	Multiple grants starting in 2013	Analysis of data from the ongoing Health Reform Monitoring Survey (HRMS) has resulted in several Policy Briefs and Quick Take reports in 2017 on topics relevant to consumer engagement and trust in the health care system. HRMS is an Internet-based survey of the non-elderly population that provides data relevant to Affordable Care Act implementation before data from federal government surveys are available.	<a href="http://hrms.urban.org/">http://hrms.urban.org/</a>
OpenNotes		Beth Israel Deaconess Medical Center; Thomas Delbanco and Janice Walker	Multiple grants starting with a planning grant in 2008	This project has supported the spread of the practice of providing patients with access to physicians' medical notes and has studied its impacts.	<a href="https://www.opennotes.org/">https://www.opennotes.org/</a>
Open Research Exchange		Patients Like Me	Multiple grants starting in 2013	Multiple grants to establish and sustain an online, open-source platform for creation, deployment, and analysis of patient-reported outcomes data, to develop the methods for creation and validation of patient-reported outcome measures (PROMs), and to support the development of PROMs for submission to the National Quality Forum for endorsement.	<a href="https://www.rwif.org/en/how-we-work/grants-explorer/featured-programs/open-research-exchange.html">https://www.rwif.org/en/how-we-work/grants-explorer/featured-programs/open-research-exchange.html</a>
Optimizing Value in Health Care:		AcademyHealth	2015	Solicitation to fund research to better understand consumer perceptions of value in the current and emerging health care	<a href="http://www.academyhealth.org/node/6521">http://www.academyhealth.org/node/6521</a>

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
Consumer-focused Trends from the Field				landscape and to allow for rapid learning from the field on this topic. Funded 11 grants relevant to consumer engagement.	
	Consumer Valuation of Providers, Services and Venues in Three Complex Care Situations	Public Agenda; David Schleifer	2015	Mixed methods research (literature review expert interviews, focus groups, national survey) to understand consumers' valuation practices, information needs, and decision-making in three complex care situations for which price and quality vary: (1) pregnancy care/childbirth; (2) joint replacement; (3) type 2 diabetes management.	
	Mental Health Care Consumer Values and Preferences Regarding the Use of Provider Performance Data	SUNY, University of Albany; James Boswell	2015	Examines community mental health center consumers' attitudes about provider outcome/performance information through interviews, focus groups, and a survey that integrates a delay-discounting paradigm to better understand consumer and patient preferences and decision making.	
	Understanding the Value of Community Care: Can Consumer Decision-Making Be a Tool for Cost Containment	Massachusetts Health Policy Commission; David Auerbach	2015	Project employs hospital discharge and claims data, focus groups, an online survey using unfolding choice scenario methodology, and key informant interviews to examine consumer perspectives on the value of different care settings (most notably, community health systems versus academically affiliated systems) for planned services that are high volume and may be performed in multiple care settings.	

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	Rationally Choosing the Emergency Department over Primary Care for Non-Urgent Conditions: Valuing Consumer Benefits	University of Colorado Denver; Anne Libby	2015	Through interviews and survey methods, project measures how adult Medicaid enrollees seeking non-urgent care at a Colorado emergency department (ED) perceive and value health care services in four key domains: (1) costs to the patient for ED and primary care services; (2) value of health services; (3) quality of care; and (4) socio-cultural perceptions of care.	
	Fee-For-Service or Managed Care? An Investigation of Dual Eligible Consumer Preferences for Health Care Delivery	University of California, Los Angeles; Kathryn Kietzman	2015	Through interviews and focus groups, project examines how California dual eligibles (1) make decisions about health care coverage; (2) access and incorporate different information sources into their decision making; and (3) perceive the value of receiving health care through fee-for-service or managed care.	
	Understanding Consumers' Health Care Preferences and Values	University of California, Irvine; Dana B. Mukamel	2015	Through a survey, project examines preferences of UC Irvine faculty, staff, student employees and retirees around various health care settings, comparing new modalities, like retail clinics and telehealth, to traditional settings, such as physician offices or emergency departments, to identify factors that influence setting choice.	
	A National Survey of Value-Promoting Consumer Behaviors	University of Michigan; Jeffrey Kullgren	2015	Using a nationally representative survey, project examines the extent to which consumers who are in high-deductible	

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	in High-Deductible Health Plans			health plans engage in behaviors that help them optimize value.	
	Perceptions of Telemental Health among Adolescents and Young Adults	Parkview Health; Tammy Toscos	2015	In collaboration with community partners, project uses a Delphi study, focus groups, and surveys to examine the role, benefits, and disadvantages of telehealth in addressing mental health needs in adolescents and young adults.	
	Opportunities and Trade-offs Due to Patent Expirations and Health Reform: Estimating HIV Patients' Treatment Preferences to Inform Treatment Decisions	Duke University; Jan Ostermann	2015	Through interviews, focus groups, and a discrete choice experiment with HIV-infected patients, project identifies and quantifies patient tradeoffs among characteristics of antiviral therapy and develops a tool to help patients and providers make treatment choices.	
	Understanding Consumers' Views of Cost Sharing, Quality and Network Choice	University of California; Patrick Romano	2015	Project employs focus groups and surveys to explore the opportunities and challenges facing individuals newly enrolled in the California insurance marketplace, as compared with individuals who have had coverage for at least five years.	

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	Measuring Consumer Value of Telehealth Services	American Academy of Family Physicians Foundation; Winston Liaw	2015	Through a survey of Anthem consumers in California and Ohio with access to telehealth services, project explores consumers' awareness, perception, and value of telehealth in primary care and uses claims data to explore the characteristics of telehealth users and nonusers.	
Developing Principles for Making Measurement of Health Care Performance Patient-centered		American Institutes for Research; Pam Dardess	2015	As part of RWJF's Measuring What Matters initiative, this project developed five principles for patient-centered measurement with input from a multidisciplinary group of stakeholders. The five principles are that such measures be: patient-driven, holistic, transparent, comprehensible and timely, and co-created with patients	<a href="http://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf">http://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf</a>
Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care		National Academy of Medicine, Leadership Consortium for a Value & Science-Driven Health System; J. Michael McGinnis and Susan B. Frampton	Funded as part of RWJF's sponsorship of the Leadership Consortium; discussion paper issued in 2017.	The Leadership Consortium convened a scientific advisory panel to compile evidence-based strategies that facilitate patient and family engaged care (PFEC) and are tied to research findings documenting improved patient care and outcomes. Discussion paper presents results and lays out a framework of elements necessary to create a culture of PFEC.	<a href="https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/">https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/</a>
Right Place, Right Time		Oliver Wyman (with Altarum Institute); Jim Fields and Helen Leis	2016	This project involves focus groups, interviews, and surveys to understand vulnerable individuals' health care	<a href="https://altarum.org/sites/default/files/uploaded-publication-files/USE_RPRT_Cons">https://altarum.org/sites/default/files/uploaded-publication-files/USE_RPRT_Cons</a>

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
				information needs and how market stakeholders are addressing those needs.	<a href="http://www.oliverwyman.com/content/dam/oliver-wyman/v2/publications/2017/jan/right-place-right-time/Oliver%20Wyman%20Right%20Place%20Right%20Time.pdf">umer_Perspectives_Final.pdf</a> and <a href="http://www.oliverwyman.com/content/dam/oliver-wyman/v2/publications/2017/jan/right-place-right-time/Oliver%20Wyman%20Right%20Place%20Right%20Time.pdf">http://www.oliverwyman.com/content/dam/oliver-wyman/v2/publications/2017/jan/right-place-right-time/Oliver%20Wyman%20Right%20Place%20Right%20Time.pdf</a>
Roadmap to Consumer Clarity in Decision-Making		Patient Advocate Foundation; Alan Blach	2016	This white paper proposes actionable models to drive person-centered care at key decision milestones in the health care system.	<a href="https://www.npaf.org/wp-content/uploads/2017/07/RoadmapWhitePaper_ecopy.pdf">https://www.npaf.org/wp-content/uploads/2017/07/RoadmapWhitePaper_ecopy.pdf</a>
Understanding the Use and Impact of Price Transparency in Health Care		AcademyHealth; Bonnie Austin Cluxton and Megan Collado	2013	This solicitation funded empirical research contributing to our understanding of the use and impact of price data in health care to inform policymakers and other stakeholders and accelerate the pace of efforts to use price information effectively. Five of the six grants awarded are relevant to consumer engagement.	<a href="http://hcfo.org/files/hcfo/HCFOPriceTransparencyBrief2016.Final.pdf">http://hcfo.org/files/hcfo/HCFOPriceTransparencyBrief2016.Final.pdf</a>
	The Impact of a Customized Price Transparency Tool on Consumer Behavior,	George Mason University; Alison Cuellar	2013	This project evaluated a price transparency tool offered by a large national insurer to identify salient characteristics of users and estimate impact on provider choice, utilization, and costs.	<a href="http://hcfo.org/grants/price-data-solicitation-impact-customized-price-transparency-tool-consumer-behavior.html">http://hcfo.org/grants/price-data-solicitation-impact-customized-price-transparency-tool-consumer-behavior.html</a>

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	Patterns of Use, Perceived Abilities and Broader Attitudes	Public Agenda; Carolin Hagelskamp and David Schleifer	2013	This project used a national survey, interviews, and focus groups to examine consumer opinions, preferences, current habits, barriers, and needs related to price data and price data tools. In 2016, RWJF funded a follow-up survey to measure trends.	<a href="http://hcfo.org/grants/price-data-solicitation-public-perspectives-price-data-patterns-use-perceived-abilities-and-b.html">http://hcfo.org/grants/price-data-solicitation-public-perspectives-price-data-patterns-use-perceived-abilities-and-b.html</a>
	Impact of Price Transparency Tools on Consumer Behavior	Harvard School of Public Health; Anna Sinaiko	2013	Evaluated web-based tool, Aetna Member Payment Estimator (MPE). Used enrollment, eligibility, other MPE and Area Resource File to analyze characteristics of users and non-users, impact on provider choice and spending patient, plan, and identified health care service characteristics associated with greater MPE use.	<a href="http://hcfo.org/grants/price-data-solicitation-grant-impact-price-transparency-tools-consumer-behavior.html">http://hcfo.org/grants/price-data-solicitation-grant-impact-price-transparency-tools-consumer-behavior.html</a>
	Can a Pricing Tool + Customized Messages Lead to Consumer Choice of Less Costly Health Care? A High Deductible Health Plan as an Experiment	NORC; Elaine Swift and Jon Gabel	2013	This project studied an e-tool for Cerner Corp employees with high-deductible health plans that sends customized price and quality messages. Used claims, survey, and utilization data to compare cost savings, employee characteristics, and quality of care for message recipients and non-recipients.	<a href="http://hcfo.org/grants/price-data-solicitation-grant-can-pricing-tool-customized-messages-lead-consumer-choice-less-.html">http://hcfo.org/grants/price-data-solicitation-grant-can-pricing-tool-customized-messages-lead-consumer-choice-less-.html</a>
	The Effect of Point-of-Care Information on Physician Ordering Behavior	Boston Children's Hospital; Alyna Chien	2013	This project conducted a randomized controlled trial at a large multispecialty group practice in which physicians in two intervention arms received varying types of	<a href="http://hcfo.org/grants/price-data-solicitation-grant-effect-point-care-information-physician-">http://hcfo.org/grants/price-data-solicitation-grant-effect-point-care-information-physician-</a>

Project	Grants Awarded as Part of a Solicitation	Organization & Principal Investigator/Project Director	Year Awarded	Description/Notes	Links
	and Clinical Decision-Making			price information via EHR when ordering tests.	<a href="#">ordering-behavior-and-c.html</a>
Importing an Interactive Disease Registry to the United States		Dartmouth College; Eugene C. Nelson	Multiple grants starting in 2013	RWJF provided two planning grants to Dartmouth College and the Karolinska Institute in Sweden to assess the feasibility of adapting the Swedish Rheumatology Quality Register (SRQ) for use the United States, with results published in <i>BMJ</i> and in a RWJF report. SRQ is an interactive registry intended to support shared medical decision-making between patients and physicians. In 2014, RWJF provided funding for development of such a registry for chronic illness management starting with cystic fibrosis.	<a href="https://www.rwjf.org/content/dam/farm/reports/program_results_reports/2015/rwjf418349">https://www.rwjf.org/content/dam/farm/reports/program_results_reports/2015/rwjf418349</a> and <a href="http://www.bmj.com/content/bmj/354/bmj.i3319.full.pdf">http://www.bmj.com/content/bmj/354/bmj.i3319.full.pdf</a>