Sacramento Region Health Care Partnership
Safety Net Learning Institute

Thursday, May 21, 2015
10:00 a.m. – 2:45 p.m.
Sierra Health Foundation – Bannon Island Room

AGENDA

10:00 a.m. Welcome and Introductions
Kaying Hang, Senior Program Officer, Sierra Health Foundation

10:15 a.m. Patient Portal
Charles Kitzman, MMI, Chief Information Officer
Shasta Community Health Center
• Setting the Stage
• Implementing Patient Portals
• Patient Portal and Population Health

12:15 p.m. Lunch

1:15 p.m. Patient Centered Medical Home 2.0: The Medical Neighborhood
Yali Bair, PhD
Ursa Consulting Group
• New Standards for Certification
• Care Transition and Referral
• Roundtable Discussion

2:40 p.m. Closing Remarks
Kaying Hang

2:45 p.m. Adjourn
**Patient Engagement.** People actively involved in their health and health care tend to have better outcomes—and, some evidence suggests, lower costs.

**WHAT’S THE ISSUE?**

A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs. As a result, many public and private health care organizations are employing strategies to better engage patients, such as educating them about their conditions and involving them more fully in making decisions about their care.

“Patient activation” refers to a patient’s knowledge, skills, ability, and willingness to manage his or her own health and care. “Patient engagement” is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. Patient engagement is one strategy to achieve the “triple aim” of improved health outcomes, better patient care, and lower costs.

This Health Policy Brief summarizes key findings on patient engagement published in the February 2013 issue of *Health Affairs*.

**WHAT’S THE BACKGROUND?**

Modern health care is complex, and many patients struggle to obtain, process, communicate, and understand even basic health information and services. Many patients lack health literacy, or a true understanding of their medical conditions. What’s more, the US health care system often has seemed indifferent to patients’ desires and needs. Many practitioners fail to provide the information that patients need to make the best decisions about their own care and treatment. And even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices. Those with low levels of health literacy find it difficult to follow instructions on how to care for themselves or to adhere to treatment regimens, such as taking their medicines.

Recognizing these problems, the 2001 Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, called for reforms to achieve a “patient-centered” health care system. The report envisioned a system that provides care that is “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Out of this recognition, in part, the field of patient engagement has emerged.

**FRAMEWORKS FOR ENGAGEMENT:** There are many aspects to patient engagement. Kristin Carman of the American Institutes for Research and coauthors propose a framework that conceptualizes patient engagement taking place on three main levels (Exhibit 1).

The first level is direct patient care, in which patients get information about a condition and
answer questions about their preferences for treatment. This form of engagement allows patients and providers to make decisions based on the medical evidence, patients’ preferences, and clinical judgment. In the second level of engagement, organizational design and governance, health care organizations reach out for consumer input to ensure that they will be as responsive as possible to patients’ needs. In the third level, policy making, consumers are involved in the decisions that communities and society make about policies, laws, and regulations in public health and health care.

**Shared Decision Making:** One strategy consistent with the first level of engagement described by Carman and coauthors is shared decision making, in which patients and providers together consider the patient’s condition, treatment options, the medical evidence behind the treatment options, the benefits and risks of treatment, and patients’ preferences, and then arrive at and execute a treatment plan. The strategy is often used with patients who have “preference-sensitive” conditions or treatment options—that is, they may or may not choose particular treatments, or to be treated at all, depending on their own feelings about the risks versus the benefits of treatment, their ability to live well with their conditions, or other factors.

For example, although one patient with knee pain may wish to have knee replacement surgery, another may worry about the risks that the surgery may not completely relieve pain or restore mobility and may choose to forgo it in favor of managing the pain with medication and weight loss. In such cases, there are multiple, reasonable treatment options, each with their own risks and benefits, and the “correct” path forward should be guided by a patient’s unique needs and circumstances.

France Légaré and Holly Witteman at the Université Laval in Quebec note that shared decision making involves several essential elements. First, providers and patients must recognize that a decision is required. Next, they must have at their disposal, and understand, the best available evidence. Finally, they must incorporate the patient’s preferences into treatment decisions.

There are various modalities through which shared decision making can be conducted. A typical process is to use decision aids—leaflets, books, videos, websites, and other interactive media—that give patients information on the risks and benefits of various treatment options and help them make the choice that most reflects their personal values. Some organizations, such as the Informed Medical Decisions Foundation and the private company Health Dialog, have developed balanced, expert-reviewed decision materials. Using these decision aids, shared decision making can be conducted in person between providers and patients, or remotely, as described below.

David Veroff at Health Dialog and coauthors conducted a large randomized study involving patients with one or more of six different preference-sensitive conditions: heart conditions, benign uterine conditions, benign prostatic hyperplasia, hip pain, knee pain, and back pain. One group of patients received enhanced decision-making support by trained...
Increased medical costs
Patients with the lowest activation scores—having the least skills and confidence to actively engage in their own health care—incurred costs up to 21 percent higher than patients with the highest activation levels.

Patients who received enhanced decision-making support ultimately had overall medical costs that were 5.3 percent lower than for those receiving only the usual support. They also had 12.5 percent fewer hospital admissions and 20.9 percent fewer preference-sensitive heart surgeries. The authors concluded that shared decision making through these relatively low-cost, remote models can extend the benefits of patient engagement to broad populations.

**PATIENT ACTIVATION:** Many studies have shown that patients who are “activated”—that is, have the skills, ability, and willingness to manage their own health and health care—experience better health outcomes at lower costs compared to less activated patients. In an effort to quantify levels of patient engagement, Judith Hibbard of the University of Oregon has developed a “patient activation measure”—a validated survey that scores the degree to which someone sees himself or herself as a manager of his or her health and care.

Hibbard and coauthors studied the relationship between patients’ activation scores and their health care costs at Fairview Health Services, a large health care delivery system in Minnesota. In an analysis of more than 30,000 patients, they found that those with the lowest activation scores, that is, people with the least skills and confidence to actively engage in their own health care, incurred costs that averaged 8 to 21 percent higher than patients with the highest activation levels, even after adjusting for health status and other factors (Exhibit 2). And patient activation scores were shown to be significant predictors of health care costs.

**BROADER PATIENT ENGAGEMENT:** Consistent with the second and third levels of engagement that Carman and coauthors describe are programs in which health care organizations structure themselves to meet patients’ needs and preferences—and in which those preferences help to shape broader responses on a societal scale. An example is the Conversation Project and the Conversation Ready Project—two efforts to elicit patients’ attitudes and choices about end-of-life care and predispose providers to give care consistent with those choices.

The Conversation Project, initiated by Boston-based journalist Ellen Goodman and colleagues, is a grassroots public campaign that encourages people to think about how they want to spend their last days and to have open and honest discussions with their families and health care providers. By having these important conversations before a crisis occurs, patients can consider and clearly communicate their wishes and forestall situations in which those decisions are made by others and not fully aware.

The Conversation Ready project, initiated by Maureen Bisognano, president and chief executive of the Institute for Healthcare Improvement, and IHI colleagues, is an effort to make certain that the nation’s health systems and providers have the skills to elicit and receive patients’ and families’ views about end-of-life care, document them, and carry them out. Ten “pioneer” health care organizations working with the institute have committed to being “Conversation Ready” within one year—and to developing replicable and scalable models of change that others can adopt as well.

For example, one of the systems, Gundersen Lutheran, which is based in LaCrosse, Wisconsin, has created Respecting Choices—a 501(c)3 not-for-profit aimed at engaging individuals in end-of-life decision making. Among other actions, the health care system prompts all patients at the age of 55 to discuss their wishes with their primary care provider.

**EXHIBIT 2**

Predicted Per Capita Costs of Patients by Patient Activation Level

<table>
<thead>
<tr>
<th>2010 patient activation level</th>
<th>Predicted per capita billed costs ($)</th>
<th>Ratio of predicted costs relative to level 4 PAM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 (lowest)</td>
<td>966**</td>
<td>1.21**</td>
</tr>
<tr>
<td>Level 2</td>
<td>840</td>
<td>1.05</td>
</tr>
<tr>
<td>Level 3</td>
<td>783</td>
<td>0.97</td>
</tr>
<tr>
<td>Level 4 (highest)</td>
<td>799</td>
<td>1.00</td>
</tr>
</tbody>
</table>


**Notes:** Authors’ analysis of Fairview Health Services billing and electronic health record data, January–June 2011. Inpatient and pharmacy costs were not included. PAM is Patient Activation Measure. **p < 0.05
WHAT ARE THE ISSUES?

Researchers have identified a number of common factors and obstacles that may need to be overcome to carry out effective patient engagement and activation strategies. Some are attributable to patients and their characteristics and proclivities and others to those of providers.

FACTORS INVOLVING PATIENTS: For patients to engage effectively in shared decision making, they must have a certain degree of health literacy. Howard Koh, assistant secretary for health at the Department of Health and Human Services, and his coauthors propose a new Health Literate Care Model that assumes that all patients are at risk of not understanding their health conditions or how to deal with them. Health care organizations adopting this model would work to increase health literacy and patient engagement over the entire care span.

Koh and colleagues propose, for example, that health care organizations first adopt the Care Model, formerly known as the Chronic Care Model, a mode of delivering health care that draws on clinical information systems, decision support, and self-management support to provide comprehensive care for chronically ill patients. Then, health literacy strategies would be incorporated into the model, such as the “teach-back” method, in which providers ask patients to explain back to them what the patients have learned, their own understanding of their condition, the options available to them, and their intentions to act on the information.

DIVERSE BACKGROUNDS: Elizabeth Bernabeo and Eric Holmboe of the American Board of Internal Medicine examined shared decision making and concluded that it is “patient specific.” Specifically, they said, a patient’s degree of engagement may be affected by such factors as cultural differences, sex, age, and education, among others. As a result, specific competencies, such as language skills or an awareness and understanding of religious beliefs, may be required on the part of clinicians and delivery systems to effectively engage patients with diverse cultural backgrounds and socioeconomic status.

COGNITIVE ISSUES: Robert Nease and colleagues of Express Scripts have noted that there are well-known limitations to human decision-making skills and the ability to maintain attention that serve as barriers to patient engagement. They argue that there may be better ways to influence patients’ decision making, such as through “choice architecture,” in which decisions to be made are structured so as to “nudge” a patient toward a particular choice. For example, in a pilot study by Express Scripts, patients were required to use preferred, lower-cost drugs before they could “step up” to other options. They were given information about the step-therapy program and given 60 days in which to “opt out” if they wanted to switch to a nonpreferred medication. The opt-out rate was only 1.5 percent, indicating that choice architecture is a potential alternative to other patient engagement approaches.

AVersion to considering costs: One area in which it may be especially hard to engage patients is considering costs in the context of making decisions about their health care. Roseanna Sommers, a Yale Law School student, and coauthors convened 22 focus groups of insured people and asked them about their willingness to weigh costs when deciding among nearly comparable clinical options—for example, to receive a computed tomography scan or undergo a more expensive magnetic resonance imaging after having had a severe headache for three months. Most participants were unwilling to consider costs and generally resisted the less expensive inferior options.

The authors identified a number of factors that lead patients to ignore cost. These factors include patients’ preference for care they perceive to be the best, regardless of expense; an inclination to equate cost with quality; inexperience in considering trade-offs among cost and quality; disregard for costs borne by insurers or society as a whole; and the impulse to act in one’s own self-interest even though resources are limited.

One antidote to consumers’ aversion to considering costs might be giving them cost and quality information that they find most useful and relevant to their concerns. Jill Matthews Yegian of the American Institutes for Research and coauthors found that consumers want to be able to compare information about individual physicians and to obtain cost data that reflect their own out-of-pocket expenses for an entire episode of care, not for individual procedures and services. Therefore, the authors contend, state and federal policy makers should look for ways to assemble such infor-
Barriers to shared decision making
Overworked physicians, insufficient provider training, and clinical information systems that failed to adequately track patients.

“More research will be needed to determine best practices for engaging patients.”

In one study, Grace Lin of the University of California, San Francisco, and coauthors explored the use of decision aids—DVDs and booklets about colorectal cancer screening and treatment for back pain—at five primary care clinics in Northern California that expressed a willingness to use them. Despite that support, the actual distribution rates for these items remained low, even after staff training sessions and other promotional activities. Some physicians felt that patient input was not warranted, although others had difficulty moving away from traditional physician-directed decision making. Most physicians cited a lack of time as a major barrier.

That perspective echoed a finding in the systematic review of 38 studies by Légaré and Witteman, which was that clinicians pointed most frequently to time constraints as the primary barrier, even though there was “no robust evidence that more time is required to engage in shared decision making in clinical practice than to offer usual care.”

Mark Friedberg of the RAND Corporation and coauthors evaluated a three-year demonstration project on shared decision making conducted at eight primary care sites in different parts of the United States. They discovered three main barriers to implementing shared decision making: overworked physicians, insufficient provider training, and clinical information systems that failed to track patients throughout the decision-making process. The researchers note that payment reforms and incentives may be needed for shared decision making to take hold.

WHAT ARE THE POLICY IMPLICATIONS?

Federal and state policy makers have embraced patient engagement as a strategy to address health care costs and improve quality. Here are some of the ways.

The Affordable Care Act identifies patient engagement as an integral component of quality in accountable care organizations (ACOs) and in patient-centered medical homes. Shared decision making is so valued in the law that a separate section (3506) calls for new Shared Decision-Making Resource Centers to help integrate the approach into clinical practice. No funds have yet been appropriated to implement this section, however.

Patient engagement is also central to Section 3021 of the law, which creates the Center for Medicare and Medicaid Innovation. Under the law, the center is to examine how support tools can be used to improve patients’ understanding of their medical treatment options. The health care law also created the Patient-Centered Outcomes Research Institute, charged with funding research that will assist patients, caregivers, clinicians, payers, and policy makers in making informed health decisions.

Because patient activation can be directly linked to improved outcomes, a measurement of patients’ level of activation could be adopted as an intermediate measure for ACOs, patient-centered medical homes, and other new and emerging delivery and payment structures, Hibbard and her coauthors observe. The need for additional measures of patient engagement is discussed further below.

STATE POLICY: In 2007 Washington became the first state to enact legislation encouraging shared decision making and decision aids to address deficiencies in the informed consent process. The legislation also required a pilot project to study shared decision making in clinical practice. Massachusetts is also incorporating patient engagement into its health policies. Now, to be certified by the state, ACOs and medical homes must include shared decision making. Patient engagement and consumer choice will also be fundamental to health insurance exchanges, where as of October 2014 people and small businesses will be able to shop for coverage.

So-called “navigators” and federally supported, state-run consumer assistance agencies will be able to assist consumers with their purchasing, as well as with issues that arise with their health coverage. Rachel Grob of National Initiatives and coauthors reviewed state efforts to meet the law’s consumer assistance goals and found that in fewer than half the states, consumers are getting the assistance they need to navigate a rapidly chang-
HEALTH POLICY BRIEF

PATIENT ENGAGEMENT

Despite evidence that has been compiled to date of the importance of patient engagement, experts in the field agree that more research will be needed to determine best practices for engaging patients, as well as to more fully demonstrate the relationship of patient engagement to cost savings. In the meantime, considerable efforts are under way to hold health care organizations accountable for engaging patients.

WHAT’S NEXT?

For example, the National Committee for Quality Assurance, a nonprofit organization that tracks the quality of care provided by health plans and health care organizations, requires a variety of assessments to determine how actively patients are being engaged in their health and care. Organizations wishing to be certified as meeting requirements for patient-centered medical homes, for example, must undertake surveys of patients that ask about whether clinicians engage them in shared decision making or provide support for them to manage their conditions. But there is wide agreement that even more could be done to measure how and how well health care organizations engage patients, and help to realize individuals’ full potential to maintain and improve their health.

RESOURCES


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How outcomes are achieved through patient portals: a realist review

Terese Otte-Trojel,1 Antoinette de Bont,1 Thomas G Rundall,2 Joris van de Klundert1

ABSTRACT
Objective To examine how patient portals contribute to health service delivery and patient outcomes. The specific aims were to examine how outcomes are produced, and how variations in outcomes can be explained.

Methods We used a realist review method, which aims to describe how ‘an intervention works, for whom, and in what circumstances’ by analyzing patterns between context, mechanism, and outcomes. We reviewed 32 evaluation studies of patient portals published since 2003.

Results The reviewed evaluations indicate that as a complement to existing health services, patient portals can lead to improvements in clinical outcomes, patient behavior, and experiences. Four different mechanisms are reported to yield the reported outcome improvements. These are patient insight into personal health information, activation of information, interpersonal continuity of care, and service convenience. The vast majority of evaluations were conducted in integrated health service networks in the USA, and we detected no substantial variation in outcomes across these networks.

Discussion and conclusions Patient portals may impact clinical outcomes and health service delivery through multiple mechanisms. Given the relative uniformity of evaluation contexts, we were not able to detect patterns in how patient portals work in different contexts. Nonetheless, it appears from the overwhelming proportion of patient portal evaluations coming from integrated health service networks, that these networks provide more fertile contexts for patient portals to be effective. To improve the understanding of how patient portals work, future evaluations of patient portals should capture information about mechanisms and context that influence their outcomes.

BACKGROUND AND SIGNIFICANCE
Health service organizations increasingly implement patient portals based on the belief that patient portals will enhance patient engagement, health outcomes, service efficiency, and convenience.1 A patient portal is a ‘secure website for patients, typically provided by primary care practices, that offers access to a variety of functions linked to a physician’s EHR [electronic health record] including secure messaging, protected health information (eg, lab results, medication lists, and immunizations), appointment scheduling, and tethered PHRs [personal health records]; more advanced portals may offer programs for self-management or patient questionnaires’.1 In 2012, Ammenwerth et al2 published a meta-analysis of the impact of patient portals, identifying six types of outcomes or processes to which patient portals can contribute. These include clinical outcomes, health resource consumption, patient adherence, patient–provider communication, patient empowerment, and patient satisfaction. Although providing a synthesis of the contribution of patient portals to these six outcomes and processes, the review method used by Ammenwerth et al does not explain how patient portals contribute to these outcomes and processes, nor does it explain why some patient portals are successful in doing so while others fail. The variation in outcomes reported by Ammenwerth et al, as well as by others, calls for a scientific analysis to provide explanations for variation in patient portal outcomes. This study seeks to provide such explanations using a so-called realist review method.

A realist review seeks to describe how ‘an intervention works, for whom, and in what circumstances’.3 It does so by analyzing the relationships between context, mechanism, and outcomes.4 In adhering to this terminology, we use the word outcome to refer to the six outcome and process measures defined by Ammenwerth.2 Mechanisms are the often hidden workings of the intervention that cause outcomes.5 Context refers to the conditions in the environment where the intervention works that activate the mechanisms.6 Contrary to more traditional literature synthesis methods, the realist approach does not aim to assess the outcomes of interventions, but rather to explain them. This aim allows for including diverse study designs, since each may help explain how the intervention works.7 A realist approach unravels the workings of complex interventions in their specific contexts.8 As such, the approach has recently been used on complex and diverse interventions such as joint health and safety committees,7 school feeding programs,8 culturally appropriate diabetes education programs,9 and internet-based medical education.10 Patient portals are also complex interventions and often continuously adapted to meet the needs of the users and the healthcare organizations involved.11 Given such idiosyncratic conditions, the effects of a patient portal may not be replicated from one context to another.12 As the number of patient portal implementations increases across a variety of settings, understanding the mechanisms that explain the results achieved in different contexts gains importance.

OBJECTIVE
Based on the realist line of thinking, the review aims to synthesize and analyze evaluations of patient portals to explain the reported outcomes. Our two main research questions are:
1. By what mechanism(s) do patient portals contribute to outcomes?
2. How can variations in outcomes across different contexts be explained?

MATERIALS AND METHODS
We adhered to the realist review method described in the RAMESES publication standards, published in 2013. The reporting of our methods and results follows these standards.

Exploratory review of how patient portals work
We started with an exploratory review of background documents and research studies to identify ways in which patient portals may contribute to health service delivery and patient outcomes. Based on this review, we identified six main ways in which patient portals may affect service delivery and outcomes. These include improving: patient access to information and services; patient decision-support; coordination of care around the patient; interpersonal continuity of care; health services efficiency; and service convenience to patients and caregivers. The aim of a realist review is to test and refine such ‘educated guesses’ against the data in the evaluation studies included in the realist review. In the following we describe how these studies were selected.

Searching process
We searched PubMed, LISTA, PsycINFO, and Scopus for peer-reviewed literature in English published between January 2003 and August 2013 (see table 1 for search queries). Assisted by a librarian, we searched for literature on both patient portals and electronic personal health records (PHRs). We included both these terms, since they are so related that literature often addresses them interchangeably. Given the definition of patient portals presented in the introduction, both entities are relevant to our review: when logged into a patient portal, patients may see their PHR, which stores data from information exchanges (such as secure messaging) made available via the portal.

Selection and appraisal of documents
Two reviewers selected the articles to be included in the review through a two-step process. First, each article’s title and abstract were reviewed, and articles were excluded if they did not present evaluations of electronic health record (EHR)-linked patient portals. The primary reviewer (TOT) reviewed all articles, while the second reviewer (AdB) reviewed a random sample of 10%.

Table 1 Search queries

<table>
<thead>
<tr>
<th>Search terms in title/abstract</th>
<th>Restrictions</th>
<th>Hits from combined search with all terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient web portal*</td>
<td></td>
<td>PsycINFO: 53</td>
</tr>
<tr>
<td>Patient online portal*</td>
<td>Language: English</td>
<td>LISTA: 48</td>
</tr>
<tr>
<td>Patient internet portal*</td>
<td></td>
<td>Scopus: 279</td>
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<tr>
<td>Personal health record (PHR)*</td>
<td>Type of publication: Peer-reviewed</td>
<td>Total: 530</td>
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<tr>
<td>AND electronic PRR* AND online</td>
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<td>Electronic PRR*</td>
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The asterisk (*) after a search term indicates that we searched for variations of the truncated term. In the displayed search queries, that enabled us to capture both the singular and the plural form of a term, eg ‘patient portal’ and ‘patient portals’.

The agreement rate was 97.4%, and disagreement was resolved through discussion. In the second round, we read the full text to determine whether our extended set of inclusion criteria was met. Building on Ammenwerth et al’s review, we included only evaluations addressing the six outcome or process categories classified in that review. In addition, we based our appraisal on whether the studies identified mechanisms by which the interventions were expected to work. The second reviewer received a random sample of 16%, and the agreement rate between reviewers about whether the inclusion criteria were met was 86%. Agreement was reached through discussion and 25 articles were selected. Through snowballing, an additional seven studies were identified, bringing the number to 32.

Data extraction
We extracted data from the articles and created six data tables, one for each outcome category. The data used to populate the cells included: article information; study objective; intervention description; patient portal characteristics; outcomes; contextual factors; proposed mechanisms; evaluation characteristics; and finally, study characteristics. For the studies that reported multiple outcomes, we posted relevant information into multiple outcome tables. However, we did not include information regarding second or tertiary outcomes that were only superficially reported, thus disregarding mechanisms linked to weaker or coincidental outcomes.

Analysis and synthesis processes
For each outcome category, we organized information to bring forward by what mechanism patient portals contribute to outcomes and the variation in outcomes across different contexts.

First, we identified the outcomes reported in each study, and organized outcome data according to intervention type and study design (randomized controlled trials (RCTs), observational, and qualitative). The organization of data in terms of intervention type was especially important, since we included evaluations of an entire patient portal, a patient portal module, or a program offered through a module. We reasoned that all interventions provide valuable information on the contribution of a patient portal, but were aware that the outcomes should be compared with caution. With respect to study design, we classified the strength of the patient portals’ effect on each outcome (see online supplementary appendix 1). For the RCTs, we separated the reported effects into studies reporting no statistically significant effect; those with some significant effect, but lacking consistency across different outcome measures and/or population subgroups; those with a significant effect not sustained over time; and finally those with significant effects across multiple outcome measures and sustained over time.

Second, for each outcome category, we identified the mechanisms mentioned by the authors. Most of the studies did not describe in detail the mechanisms believed to be in play, and careful reading of the text was required to identify the mechanisms proposed to link the patient portal intervention to an outcome. Moreover, we assessed whether these mechanisms were empirically tested; that is, whether the key concepts of the mechanism were operationalized in the studies.

Finally, we gathered information on the organizational and healthcare system context in which the evaluated patient portals operated. Unfortunately, the influence of context on the intervention was rarely described in detail at the service unit level (culture, working relationships, operational policies and procedures, incentive systems) or the personal patient–provider level (guidelines, communication, relationship). Most studies
contained some large-scale information, such as the type of organization, the number of providers and patients using the patient portal, the comprehensiveness of the EHR, and existing disease management efforts within the organization. User characteristics such as age distribution, ethnicity, language proficiency, and gender distribution were well described in the studies.

RESULTS

Document flow diagram

Figure 1 illustrates the paper selection flow that led to a total of 32 evaluation studies.

Document characteristics

Eleven studies evaluated the effect of a patient portal, portal module, or program offered through a patient portal on clinical outcomes. Eight studies examined the impact on healthcare utilization, and six looked into the effect on patient adherence. Patient–provider communication was an end-point in five evaluations, patient empowerment in eight, and patient satisfaction in five. Eighteen of the studies were RCTs, 11 were observational studies, three were qualitative studies using focus groups or interviews, and one used mixed methods (see online supplementary appendix 1). Thirty studies were from the USA, one was from Canada, and one from the Netherlands. Eleven articles were published before 2010 and 21 after 2010, indicating a recent and steady increase in the evaluations of patient portals and electronic PHRs. (See online supplementary appendix 2 for tables with article information and excerpts from the data about study objective, methods, context, mechanisms, and outcomes.)

Main findings

Outcomes

The evaluations indicated that patient portals could lead to improvements in clinical outcomes, patient adherence, patient–provider communication, patient empowerment, and patient satisfaction with health services. In total, 15 of the 18 RCTs demonstrated significant positive effects on these outcomes, albeit in some studies the effects were not strong or consistent over time. The majority of observational and qualitative studies provided indications consistent with these demonstrated effects. No studies found serious adverse consequences of patient portal implementations. However, interestingly, an often-hypothesized potential of patient portals to lower health resource consumption through substitution of services was not validated. On the contrary, of the eight studies that addressed healthcare utilization, five concluded that higher health resource consumption occurred after the implementation of a patient portal, and two found no change. Only one of the eight studies documented lower healthcare utilization due to a patient portal.22 However, this finding has been contradicted by a more recent study conducted within the same integrated delivery system.23 These results suggest that patient portals became complements rather than substitutes to existing health services.

More than half of the patient portal evaluations were targeted at chronic disease patients. This was particularly the case in the clinical outcome category, where all 11 evaluations focused on management of diabetes, hypertension, depression, chronic musculoskeletal pain, or mobility difficulty. This focus on chronic conditions is not surprising since several studies mentioned that the patient portal supported comprehensive self-disease management programs.24–29 Interestingly, several studies mentioned a ‘ceiling effect’ due to the breadth and quality of these existing disease management programs, which could explain why their results were often not strong or consistent. As one study concludes: ‘As control approaches the upper end of feasibility, further improvements may be limited’.24

Furthermore, several evaluations suffered from inadequate study samples, relatively short follow-up periods, and used different instruments to assess outcomes. These methodological problems may also have inhibited the strength of results and suggest that caution be taken in generalizing the findings from the studies. However, although the outcomes are important to understanding patient portals’ contributions to healthcare systems and the patients they serve, as noted earlier, assessments and comparisons of outcomes are not key to realist reviews. Rather, the focus is on explaining how and why the identified outcomes occur. In the sections below, we attempt to provide answers to those questions.

Mechanisms

By classifying and aggregating authors’ hypothesized mechanisms by which patient portals affect outcomes, we identified four such mechanisms. We recognized a mechanism if it was mentioned in at least half of the evaluations within a certain outcome category. Importantly, it should be noted that none of the studies described their hypothesized mechanisms in detail, nor did they empirically test whether these mechanisms did in fact lead to the reported outcomes. Further, as a consequence of the research designs used in the respective studies, data were not collected on the actual operationalization of these mechanisms. Hence, the mechanisms we identified are based are solely on researchers’ hypotheses about the patient portal workings, provided that these were not counter to the corresponding study outcomes. There were no correlations across mechanisms, study designs, or intervention type (whole portal, module, or a program). Below, we describe the four identified mechanisms and provide examples from the data.

Worth noting is that the four identified mechanisms do not include care coordination or provider efficiency, which we had identified as possible mechanisms in our exploratory review.

1. Patient insight into information: Several studies highlighted that having access to personal information will enable and motivate patients and their caregivers to be involved in its application and in ensuring its accuracy and comprehensiveness. This mechanism was mentioned in more than 50% of evaluations of patient empowerment, clinical outcomes, and patient adherence.
Patient empowerment: ‘Making electronic health records available across the Internet is viewed as an important step toward consumer empowerment, because without adequate information patients are not able to achieve sufficient levels of desired autonomy and self-efficacy’.30

Clinical outcomes: ‘Access to effective and tailored patient education, electronic patient–provider communication, and tailored patient education, electronic patient–provider communication, and the wealth of clinical information and web-based resources contained within modern PHRs could lead to improvements in chronic disease outcomes through improved patient-centered care and self-management’.31

Patient adherence: ‘The use of a secure, interactive personal health record (PHR) tethered to an EHR can provide an avenue for patients to review and update health information and has the potential to improve adherence to guidelines’.32

2. Activation of information: Several authors described how decision-support tools provide new and effective ways of using and presenting information. Primarily reminders sent to patients through patient portals were reported to increase the effectiveness and targetability of information. This mechanism was mentioned as being important for achieving patient adherence in more than half of the evaluations.

Patient adherence: ‘To act on their choices, patients need written plans and logistical details. They need reminders when services are due, guidance to deal with inconsistent recommendations, and access to decision aids for choices that require shared decision-making’.33

3. Interpersonal continuity of care: Easier and improved access for patients to contact their providers was proposed to enhance interpersonal continuity of care. As several studies mentioned, patient portals allow patients to communicate asynchronously with a preferred provider, enabling them to build an ongoing, personal relationship that includes mutual trust and responsibility.34 Interpersonal continuity of care was suggested to improve clinical outcomes and patient satisfaction in some studies, whereas patient–provider communication alone was linked to interpersonal continuity of care in more than 50% of the studies.

Patient–provider communication: ‘Our examples illustrate the cases in which patients and providers establish social bonds during the interactions facilitated by the patient portal system. As well, accumulated messages in the portal system about the same patient can provide rich trajectory information that help providers and the patient better understand her illness management from a long-term perspective’.35

4. Service convenience: Finally, patient portal services that ease the navigation of the health system, facilitate contact, and decrease patient costs, were believed to bring added service convenience to patients. This mechanism was hypothesized in more than 50% of the studies to impact health resource consumption and patient satisfaction by making it easier to acquire services.

Health resource consumption: ‘Internet portals may improve patient health and well-being by providing reliable and trusted MS [multiple sclerosis]-related information and resources, providing easy and reliable methods for patients to navigate an increasingly complex medical healthcare system, and providing a secure avenue for patients to communicate electronically with their MS provider regarding symptoms and disease management’.36

Patient satisfaction: ‘The portal was convenient: 81% believed that the portal saved them a telephone call, and 33% believed it saved them a visit to the clinic. The portal allowed patients to send messages at all hours; indeed, 73% of incoming messages were sent during non-clinic hours’.37

Authors regularly reported socio-demographic differences in achieving the outcomes. One study, for example, noted that ‘users were demographically different from nonusers (eg, fewer minorities and higher education), had more chronic illnesses, and were more up-to-date with care at baseline’.3.13 This may suggest a refinement to some or all of the proposed mechanisms. The refinement could point to variations in how mechanisms are triggered in individuals based on their race/ethnicity, geographical location, health and online literacy, and health consciousness.

As indicated above, the hypothesized significance of these mechanisms differs per outcome. This is illustrated in figure 2. The arrows signify that a least 50% (thin arrows) and 75% (thick arrows) of authors hypothesized that a particular mechanism was in play to produce the expected or observed outcome.

Context
The vast majority of evaluated patient portals included in our review operated within health service networks in the USA. These health service networks were integrated delivery networks, academic hospitals providing integrated care, and multi-specialty group practices. Although some of these were indeed truly integrated delivery networks, we refer to the three types of networks as ‘organised’. (See online supplementary appendix 3 for a list of these networks.) Only two patient portals were from outside the USA (Netherlands and Canada) and both distinguished themselves by operating independently within a hospital clinic or a hospital network.

The organized health service networks appeared to share some large-scale contextual characteristics, including the presence of comprehensively used EHRs and a focus on chronic disease management. The influence of the network configuration on patient portals received some attention in the material, as several research teams noted the impact of integration on the outcomes. One team remarked: ‘this study was conducted in an integrated health care system with shared records of medical and mental health care as well as established collaborative relationships between primary care and mental health providers’. Moreover, ‘the efficiency and clinical benefit of this program might be difficult to replicate outside of an integrated system’.38

Context–mechanism–outcomes patterns
From a realist perspective, patterns between context, mechanisms, and outcomes of an intervention are central to understanding how and why the intervention had an effect. Based on such patterns, reviewers can explore the impact of the particular context on the mechanisms that were suggested to produce the outcomes. We did not identify context–mechanism–outcome patterns based on the reviewed literature, as we were unable to detect consistent differences regarding the outcomes or proposed mechanisms across contexts. Nor did study design, intervention type, or evaluation methods differ notably across contexts.

DISCUSSION
Summary of findings
Using a realist lens, we set out to answer (1) by what mechanism (s) patient portals contribute to outcomes, and (2) how variations in outcome across different contexts can be explained.

To the first question, although not empirically tested, patient portal evaluators suggest at least four mechanisms to influence clinical outcomes, health service utilization, patient adherence, patient–provider communication, patient empowerment, and
satisfaction. This supports our premise that patient portals are complex interventions that work through multiple pathways to generate multiple outcomes. The most frequently reported mechanisms were patient insight into information and interpersonal continuity of care. Seventy-five per cent of authors hypothesized that patient insight was in play to enhance patient empowerment. Similarly, 75% of authors hypothesized that interpersonal continuity of care was a mechanism that explains how patient portals improve patient–provider communication.

Lack of variability in outcomes and mechanisms across relatively uniform contexts hinders a response to our second question. We give three possible explanations for this lack of detectable context–mechanism–outcome patterns in the included studies. First, as indicated above, conditions for patient portals in organized health service networks may be relatively similar, and consequently, the uniformity of evaluation contexts may have inhibited significant differences in mechanisms and outcomes. Second, the effect of a patient portal on outcomes may be limited because of a ceiling effect produced by existing disease management programs. Third, the study designs and evaluation methods did not allow for surfaced measurable differences, especially if these would be marginal due to the ceiling effect.

Nevertheless, the striking tendency of evaluated patient portals to operate within organized health service networks can provide some insights into the contextual characteristics conducive to patient portals. Large and organized health service networks with shared EHRs are well equipped to make the investment to establish high-functional patient portals that integrate information from the continuum of care. The probability that this investment will be returned is high since their large scale facilitates patient traffic, which is necessary to generate outcomes. Moreover, the business care for patient portals remains strong in organized networks, even if costs and benefits appear in different network components. Likewise, organized health service networks suffer less from internal operational barriers which hinder reaping joint benefits as attainable through the higher levels of collaboration and communication enabled by patient portals. These attributes are likely to support a culture with a focus on quality improvement and patient-centered care, which may positively affect the application of patient portals across the care continuum. In addition, existing research and quality improvement traditions incite and permit scientific evaluations of these technologies.

This examination of the impact of organizational aspects on patient portals prompts two reflections. First, the modest outcomes produced by most of the studies may be explained by the fact that the organized health service networks already provide well established patient-centered health services. As many of the reviewed studies noted, due to existing disease management and patient-engagement programs, the effect of adding a patient portal was only incremental. Furthermore, the high degree of interorganizational coordination found in organized health service networks could explain why the potential of patient portals to improve care coordination did not surface as an important mechanism in the reviewed studies. As care coordination commonly underlies the existing disease management programs, evaluators may have overlooked care coordination as a relevant contextual factor.

Second, the above-mentioned ceiling effect may not apply to fragmented contexts, which may therefore derive higher value from patient portals. In fragmented contexts, patient portals may become a means to achieving a discontinuous improvement, for example towards care coordination, and thus to generating desired effects. However, it appears from the lack of reported outcomes from fragmented healthcare systems that these systems are less conducive to achieving such improvements. Patient portals seem to struggle in contexts that need them most.

**Strengths and limitations**
We found that the studies rarely detail the mechanisms by which an intervention is expected to work. Consequently, the studies are not designed to empirically test the mechanisms that could

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**Figure 2** Hypothesized links between mechanisms and outcomes. The thin arrows signify that at least 50% of authors hypothesized that a given mechanism produced a given outcome. The thick arrows indicate that this was the case for at least 75% of authors.
explain how patient portals improve outcomes. Combined with a scarcity of small-scale contextual information, individual studies tell us little of how and why patient portals create outcomes in different contexts. Thus, our ability to identify and aggregate the proposed mechanisms underlying each intervention is an important step in establishing the evidence base for the implementation of patient portals, and a major contribution of this realist review.

There are a number of limitations to the study. First, we only included evaluations with the six process and outcome measures identified by Ammenwerth et al, and may thus have excluded evaluations of other end-points. The lack of cost evaluations could, for example, explain why provider efficiency and productivity was not mentioned as an important mechanism in the reviewed studies. Second, we acknowledge a possible publication bias towards successful implementations, potentially having led to an omission of information regarding patient portal implementations from less effective contexts.49

Future research directions
The reviewed evaluations are likely to be forerunners to a larger body of evaluations that may confirm our preliminary results. Future evaluations should describe the small- and large-scale contexts impacting the intervention to make apparent why an intervention may or may not have worked. Furthermore, our understanding of how and why patient portals work will benefit from more attention to the proposed mechanisms underlying patient portal interventions; for example, by empirically measuring whether key concepts to an given intervention mechanism have actually been operationalized as intended.

This review has indicated that patient portals may have even higher value propositions in more fragmented contexts, but that these contexts may be less favorable to patient portals. Therefore, a topic that deserves further exploration is how to implement and derive outcomes from patient portals in healthcare systems that are more fragmented than the ones captured in this review.

CONCLUSION
Patient portals affect clinical outcomes, health service utilization, patient adherence, patient–provider communication, patient empowerment, and patient satisfaction with health services by four mechanisms. These mechanisms are: patient insight into information, activation of information, interpersonal continuity of care, and service convenience. The significance of these mechanisms differs per outcome. Reported outcomes of patient portals derive mostly from large and organized health service networks. In highly organized health service networks, patient portals appear to be complements to disease management programs rather than substitutes for these services. Paradoxically, patient portals may have higher impact in more fragmented contexts that are less conducive to patient portal implementation and use.

The complexity of deriving outcomes from patient portals emphasizes the necessity of research that disentangles the mechanisms by which outcomes are produced in relation to their context. Research designs and evaluations reported to date are insufficient for this purpose. Moreover, reports on unsuccessful patient portals, which are equally important for such disentanglement, are lacking.

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Contributors TO-T made substantial contributions to study conception and design, acquisition of data, data analysis, and interpretation of data, drafted the article and revised it critically for important intellectual content, and provided final approval of the version published. ADtB made substantial contributions to study conception and design, data analysis, and interpretation of data, revised the article critically for important intellectual content, and provided final approval of the version published. JvdK made substantial contributions to study conception and design as well as interpretation of data, revised the article critically for important intellectual content, and provided final approval of the version published. TGR made final approval of the version published.

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Competing interests None.

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Applying the Care Transitions Framework: A Case Study

Below is an adapted version of a case study from the Robert Wood Johnson Foundation's Aligning Forces for Quality program.32 We use this modified example to illustrate how the Care Transitions Framework may be used.

Applying the Care Transitions Framework

Below, we apply the flowchart to the case study, selecting a few constructs as examples for each step.

Step 1. Define the Intervention Characteristics

- What is the intervention designed to achieve?

The goal of this intervention is to reduce heart failure readmissions. In a broader sense, the intervention is building a collaborative and working to coordinate care across disparate organizations.

- What are the features of the intervention?

The intervention for this case has five key elements, all adapted from established care transitions programs but rebundled for this collaborative:

1. Implement a heart failure readmission risk assessment tool.
2. Use the teach-back method during key clinical interventions.
3. Provide real-time handover communications.
4. Address timely physician followup.
5. Follow up with the patient or primary caregiver after discharge.

Relevant constructs may include feasibility (e.g., whether all these elements can realistically be carried out at all hospitals, including issues of cost-effectiveness), complexity (e.g., difficulty of implementing five disparate elements of the intervention, which will require involvement of a number of providers, including training), and the workflows and task/process standardization that will be needed to incorporate tasks such as teach-back into daily care. See Table 18.

- Who is the intended target group?

The ultimate beneficiary of the changes in practices is the patient, who is thus a primary stakeholder. However, much of the intervention is focused on changes in processes and workflows within and between hospitals, so other targeted entities include providers and staff, units, and hospitals. See Table 18.

Step 2. Define the External Context

- What components of the environment will impact the implementation?

Key constructs for external context may include external networks, or existing relationships with outpatient providers who will need to see the patient in a timely way to achieve timely physician followup (element #4), and the external pressure and policy incentives to reduce heart failure readmissions. See Table 19.
Step 3. Define the Organizations Involved and Their Characteristics

- Which organizations are directly involved in the intervention?

For this case, the 19 hospitals and health systems are included, as well as community and national organizations: the Health Improvement Collaborative of Greater Cincinnati, Greater Cincinnati Health Council (hospital organization), and the Robert Wood Johnson Foundation.

- Which components of structure and process within and between these organizations will impact the implementation?

Key structural characteristics may include the size and organizational resources of the various 19 hospitals, which could influence their capacity, internal support, and ability to be flexible enough to make the multiple changes needed. The implementation climate could affect how willing the individual organizations are to change care processes to improve care transitions. Other important constructs include individual organizational accountability for reducing heart failure readmissions in the larger collaborative, relative priority within the organizations to dedicate to the elements of the intervention as compared to other priorities, and leadership engagement to support the organizations and staff in implementing the intervention. See Table 20.

Step 4. Define the Characteristics and Roles of the Providers

- What are the characteristics of individuals who are engaged in the provision of care or treatment?

For this intervention, provider roles may be particularly important, as new roles (especially discharge followup) need to be developed within each organization. Collective efficacy, belief that the intervention can be achieved, is needed at the individual and organizational as well as the collaborative level. See Table 21.

Step 5. Define the Characteristics and Roles of Patients and Caregivers

- What are the characteristics and roles of patients and caregivers that will impact their ability to engage in the intervention or to benefit from it?

The importance of patient goals, needs, preferences, and resources is reflected in the first element of the intervention—risk assessment for readmission, including social factors—and these factors may affect the implementation of the intervention and readmission outcomes. Knowledge and beliefs and skills and competencies are important for the effectiveness of the teach-back method and phone followup, and social factors such as access to transportation and a telephone could affect physician followup. See Table 21.

Step 6. Define the Processes Required To Achieve Desired Level of Use

- What are the implementation processes applied to achieve individual- and organizational-level use of the intervention?
For this case, planning is important, with the elements of the intervention chosen from existing programs and rebundled for this collaborative. Engaging patients and caregivers and providers is also critical, with important information exchange in teach-back and postdischarge phone calls for patients/caregivers, and effective handoff communication with providers. Measurement capability and data availability are particularly important for care transitions interventions; in this case, outcomes could not be evaluated due to issues with accessing data from the various organizations involved. See Table 22. This step does not cover how completely an intervention was used; this concept is covered under the Measures of Implementation domain.
Learning Institute
PCMH 2.0 Roundtable Exercise

Step 1: Choose a Topic
1. Behavioral health referrals and/or integration
2. Specialty referrals
3. ER transitions of care/avoidance
4. Inpatient visit transitions of care/avoidance

Step 2: Design an Intervention

Step 3: Answer 3 Questions
1. What is the intervention designed to achieve?
2. Who needs to be involved for the intervention to be successful?
3. What are the major steps to implement the intervention?
Sacramento Region Health Care Partnership
Safety Net Learning Institute
May 21, 2015

Speaker Bio

Charles Kitzman, MMI
Chief Information Officer, Shasta Community Health Center

Charles Kitzman joined SCHC in 2006 when he was hired to manage the organization's EHR implementation. Afterward, he was asked to remain with the organization and did so as Director of Informatics until January of 2010 when he accepted the CIO position.

Mr. Kitzman has an extensive background in education specializing in technology and the humanities. He is an active member of HIMSS (Healthcare Information and Management Systems Society) and CHIME (College of Health Information Management Executives). He has presented on many topics related to Health IT in various forums including the Western Clinician's Network and the California Primary Care Association HIT Summits. Mr. Kitzman holds a Master's degree in Medical Informatics (MS-MMI) from Northwestern University.

Mr. Kitzman is a recent graduate of the Clinic Leadership Institute Emerging Leaders program and is the current Chair of the CPCA HIT Task Force. When he isn't geeking out, he enjoys spending time with his children and playing guitar and mandolin.

Yali Bair, PhD
President and CEO of Ursa Consulting Group

Yali Bair, PhD is President and CEO of Ursa Consulting Group. For more than two decades, she has been at the forefront of health system change and has worked collaboratively with health care providers, businesses, foundations and universities throughout the United States. Dr. Bair is a primary care practice coach and NCQA Patient Centered Medical Home Certified Content Expert. She is the author of “What’s In It For Me? Health Care Reform. Explained.”, a brief, easy-to-read overview of the Affordable Care Act.

Yali completed her undergraduate training in biological science at the University of California, San Diego and earned a PhD in epidemiology, with an emphasis on health services research, from the University of California, Davis. Dr. Bair is a graduate of HOPE Latina Leadership Institute and received an NIH minority dissertation fellowship for her work on the Study of Women’s Health Across the Nation. (www.ursaconsultinggroup.com)
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Sacramento Safety Net Learning Institute
Improving the Health of Communities
Meeting Evaluation Form
May 21, 2015

1. Using the following scale, please share your opinions about this session:

<table>
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<tr>
<th>1 = Not at all</th>
<th>2 = A Little</th>
<th>3 = Some</th>
<th>4 = A Lot</th>
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To what extent, if any, did today’s session:
- Increase your knowledge of potential strategies for engaging patients in their care.
- Increase your understanding of how to use patient portal as a tool for improved population health.
- Increase your awareness of the requirements for obtaining a patient centered medical home 2.0 designation.

2. Please state the extent to which you agree or disagree with the following statements:

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<tr>
<th>1 = Strongly Disagree</th>
<th>2 = Disagree</th>
<th>3 = No Opinion</th>
<th>4 = Agree</th>
<th>5 = Strongly Agree</th>
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<td>In general, the presentations were clear and effective.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Presentation content was useful.</td>
<td>1</td>
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<td>Presentation materials were easy to understand and use.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

3. Did the advanced reading increase your knowledge of patient engagement?
   __Yes  __ No  __ Did not read the articles

4. Please rate the following:
   Level of the quality of discussion during the session was:
   __Too low  __ About right  __ Too high
   Amount of participant involvement was:
   __ Too little  __ About right  __ Too much
   Length of the learning session was:
   __ Too short  __ About right  __ Too long
5. Additional Feedback

How do you expect to use the information in your job?

What was the most valuable part of the session today?

What training needs were identified for you or your staff today?

Do you have overall suggestions to improve future sessions?

6. Optional Information

Name:
Organization:
Job title or primary role:

Thank you!