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Routine patient-reported experience measurement of shared decision-making in the US: a qualitative study of the current state according to frontrunners

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ABSTRACT

Objectives: To identify and describe instances of routine patient-reported SDM measurement in the US, and to explore barriers and facilitators of routine patient-reported SDM measurement for quality improvement.

Setting: Payer and provider healthcare organizations in the United States.

Participants: Ten current or former adult employees of healthcare organizations with prior SDM activity and that may be conducting routine SDM measurement.

Outcomes: Qualitative interview and survey data collected through snowball sampling recruitment strategy to inform barriers and facilitators of routine patient-reported SDM measurement.

Results: Three participating sites (out of 26 sites approached) routinely measured SDM from patients' perspectives, including one payer organization and two provider organizations - with the largest measurement effort taking place in the payer organization. Facilitators of SDM measurement included SDM as a core organizational value or strategic priority, trialability of SDM measurement programs, flexibility in how measures can be administered, and existing momentum from payer-mandated measurement programs. Barriers included competing organizational priorities with regard to patient-reported measurement and lack of perceived comparative advantage of patient-reported SDM measurement.

Conclusions: Payers have a unique opportunity to encourage emphasis on SDM within healthcare organizations, including routine patient-reported measurement of SDM; however, provider organizations are currently best placed to make effective use of this type of data.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Shared decision-making (SDM) is a growing policy interest in the United States, with measurement efforts also increasing to meet demand from quality improvement and performance incentivization perspectives.
- This study gathered insight from organizations on the leading edge of shared decision-making practice.
- The snowball sampling recruitment methodology identified previously unknown examples of routine patient-reported SDM measurement, though it may have omitted relevant cases.

INTRODUCTION

Policy interest in shared decision-making (SDM) is growing internationally, leading to calls for increased measurement and feedback efforts. Underlying these efforts is preliminary evidence that audit and feedback can improve the quality of health care, particularly related to provider behaviors,[1] despite some reports that feedback is not always effective in improving clinician performance.[2,3] Additional interest in measurement relates to its potential to motivate and monitor focused efforts at multiple levels, from clinic quality improvement initiatives to system-level performance incentivization programs.[4,5] This policy interest, while drawing to some extent on academic research, is not necessarily led by clinician or researcher efforts. Additionally, time-delimited research and quality improvement projects in healthcare settings often do not lead to sustained initiatives. Prior research on widespread use of patient experience data for quality improvement (QI) purposes found "no single best way to collect or use [patient-reported experience] data for QI."[6]

Patient-reported experience measures are questionnaires that "gather information on patients' views of their experience [of] receiving care."[7] The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys are in widespread use in the United States, measuring diverse aspects of the patient experience.[8] However, CAHPS lacks a measure that captures the three core dimensions of SDM: 1) information provision; 2) preference elicitation; and 3) preference integration.[9–11]

While measures of SDM have been described in detail elsewhere,[12] existing studies do not adequately examine these patient-reported experience measures in the specific context of quality improvement. Identifying sites at varying stages of implementing SDM measurement and feedback and seeking in-depth insight into their experiences will allow us to learn what differentiates organizations that conduct small-scale SDM measurement projects in research and/or quality improvement contexts from those that implement widespread SDM measurement programs. Understanding their experiences within a US context can inform strategies at other organizations, both domestic and international, that seek to implement SDM measurement and feedback. Therefore, in this study we differentiate routine patient-reported SDM measurement, i.e. an ongoing SDM measurement program not tied to a specific project and generally internally funded as part of routine operations, from patient-reported SDM measurement as part of research or quality improvement projects that are often time-delimited, smaller in scale, and externally sponsored.

In this study, we aim to 1) identify and describe instances of routine patient-reported SDM measurement in the US; and 2) explore barriers and facilitators of routine patient-reported SDM measurement for quality improvement using the Greenhalgh et al. diffusion of innovations theoretical framework.[13]

METHODS

Given the orientation of the study to explore how and why patient-reported SDM measurement and feedback were undertaken, we adopted a descriptive multiple case study research design.[14] We conducted a qualitative survey of leading SDM centers to identify examples of patient-reported SDM measurement, paired with in-depth interviews of representatives from included sites. This study was reviewed and approved by Dartmouth College's Committee for the Protection of Human Subjects (CPHS

#31002). Participants received an information sheet describing the research study (survey participants) and/or verbally reviewed the information sheet with the interviewer (interview participants) immediately prior to participation in the survey or interview components of the study. With participants' verbal permission, interviews were audio-recorded.

Inclusion criteria

Sites included healthcare organizations in which the research team was aware of ongoing SDM research or quality improvement efforts. Sites were identified through the research team's professional network, drawing on prior knowledge of SDM activity in the US.

Interview and survey participants were current or former adult employees of healthcare organizations that may be conducting routine SDM measurement. Inclusion criteria did not specify job titles of eligible individuals; instead, any staff with knowledge of a relevant SDM measurement program were eligible for participation.

Recruitment

We adopted a snowball sampling approach to participant recruitment. A snowball sampling approach has the benefit of identifying previously unknown or hidden populations,[15] and SDM researchers and practitioners are well-placed to be aware of peers active in routine patient-reported SDM measurement. Through their professional networks and drawing on more than two decades of experience in SDM research, the research team initially made email contact with 32 individuals from 23 US centers known to be active in either conducting research on SDM or implementing SDM to participate in a survey and/or telephone interview. At the conclusion of each interview, the interviewer (RF) requested that the participant identify other knowledgeable individuals at his or her site or related sites for possible interview participation.

Data

We conducted a 12-item open-ended survey hosted by Qualtrics online survey software. Participants were asked to provide information on which SDM measures were in routine use at their organizations, how the measures were selected, details on measurement volume, what concerns are voiced in their organizations about SDM measurement, and how the organizations use the SDM data they collect for quality improvement.

One member of the research team (RF) also conducted semi-structured interviews with key informants at a sample of sites with ongoing SDM measurement programs. The interview guide was developed to investigate several core components of Greenhalgh's diffusion of innovations model, namely: 1) the innovation; 2) adoption by individuals; and 3) system readiness for innovation.[13] (See Appendix 1 for the full interview guide.)

Participants were asked to describe patient-reported SDM measurement and feedback within their organizations, including decision-making processes to establish measurement, dedicated resources, and related processes while differentiating between individual-level and system-level adoption.[13] Interview questions sought to understand the purpose of SDM measurement and feedback in these organizations, as well as who initiated the work and why. Audio-recordings were transcribed verbatim

for analysis. Where interviews could not be audio-recorded, as was the case in one interview, the interviewer (RF) took detailed field notes.

Patient and public involvement

Patients and the public were not involved in the conduct or reporting of this research.

Analysis

A single coder (RF) reviewed survey responses to identify instances of routine SDM measurement. Two coders (RF and JE) conducted thematic analysis[16,17] of interview transcripts and/or field notes with specific reference to relevant domains of Greenhalgh's diffusion of innovations model[13] using Atlas.ti version 8.4.4 software. After detailed review of the data, initial codes were independently generated. The coders then identified, discussed, and iteratively refined themes across the coded data.[16,17] Figures were generated using the R visNetwork and tidyverse software packages.[18,19]

RESULTS

Of 42 people referred to the research team through our snowball sampling approach, 36 people from 26 organizations were contacted for survey and interview recruitment. Eleven people reported no knowledge of routine patient-reported SDM measurement, three reported only CAHPS surveys in use for routine patient-reported measurement, three reported proxy measurement of SDM through a non-patient reported channel, four reported additional routine patient-reported SDM measurement, six acknowledged receipt of the email invitation but did not provide measurement details, and nine did not respond. The recruitment process and full snowball sample referral network is depicted in Figure 1 and Figure 2.

Figure 1. Recruitment process and snowball sample referral network, colored by organization[a, b]

Figure 2. Recruitment process and snowball sample referral network, colored by organization's SDM measurement status[a, c]

[a] Nodes represent individuals working within healthcare organizations; each individual's referrals to the study team for potential participation are indicated by directed edges. [b] Each color represents a unique organization. [c] Grey: organization has no routine SDM measurement; Yellow: organization has routine non-patient-reported SDM measurement; Green: organization has routine patient-reported SDM measurement.

Table 1. Participant and organizational characteristics where SDM measurement is occurring

	Measurement type(s)	**Organization description**	**Participant profile(s)**
Site 1	**Routine patient-reported SDM measurement.**	A nonprofit organization providing health insurance coverage to California residents.	• Administrator; 5-10 years experience in current organization. (P01) • Clinical administrator; 2-4 years experience in current organization. (P02)

Site 2	**Routine patient-reported SDM measurement;** Routine CAHPS-based communication measurement.	A large health system in northern California.	• Administrator and researcher; 5-10 years experience in current organization. (P03)
Site 3	**Routine patient-reported SDM measurement.**	A large not-for-profit healthcare system.	• Researcher; 15-20 years experience in current organization. (P04)
Site 4	Project-based patient-reported SDM measurement; Routine CAHPS-based communication measurement.	A United States Department of Veterans Affairs medical center. The Department of Veterans Affairs operates 172 medical centers offering services to military veterans.	• Researcher; 25+ years experience in current organization. (P05) • Researcher/Administrator; 25+ years experience in current organization. (P06)
Site 5	Routine CAHPS-based communication measurement.	A health care system affiliated with an academic institution.	• Faculty researcher; 5-10 years experience in current organization. (P07)
Site 6	Routine CAHPS-based communication measurement.	A midwestern academic medical center.	• No demographic data available. (P08)
Site 7	Routine measurement focused on uptake of patient decision aids.	A regional integrated health care payer and provider organization.	• Clinical administrator; 25+ years experience in current organization. (P09)
Site 8	Routine measurement focused on uptake of patient decision aids.	A regional integrated health care payer and provider organization.	• Clinician; 20-25 years experience in current organization. (P10)

Measurement summary: routine patient-reported SDM measurement

Table 1 summarizes SDM measurement at each included site. One health insurance company (site 1) and two provider organizations (sites 2 and 3) routinely measure SDM from patients' perspectives.

Site 1 collects patient-reported SDM measures in selected clinical areas including orthopedics, gynecology, bariatrics, and cardiology. For several elective procedures, this payer organization requires in-network healthcare providers to collect a set of patient-reported SDM measures in order for the procedures to be pre-authorized for payment. Measures include collaboRATE,[9,20] SDM-Q-9,[21] and an internally-developed measure asking whether patients 1) have enough information, 2) are clear about which benefits and side effects matter most to them, and 3) understand the options available to them (see Table 2 for collaboRATE and SDM-Q-9 items). Across the organization, approximately 10,000 patient reports are collected annually. At this site, the potential for waste reduction, i.e. patients

receiving only the most appropriate services for them, was the impetus behind the measurement program.

Site 2 collects the collaboRATE patient-reported measure of SDM[9,20] in orthopedics and urology clinics from all patients making total joint replacement and prostate cancer treatment decisions. The purpose of measurement was initially to meet payer requirements for elective orthopedic procedures, but then expanded to include other non-mandatory clinical areas.

Site 3 collects the Shared Decision Making Process measure[22] along with the Hip Osteoarthritis Decision Quality Instrument,[23] Knee Osteoarthritis Decision Quality Instrument,[23] Herniated Disc Decision Quality Instrument,[23,24] and the Spinal Stenosis Decision Quality Instrument from patients with relevant health conditions (see Table 2 for detail on included measures). The measures are administered through the health system's electronic medical record as part of the organization's patient-reported outcomes measurement system, collecting approximately 1,800 patient reports of SDM experience per year for benchmarking and performance improvement purposes.

Table 2. Patient-reported SDM measures used in this sample

SDM-Q-9	**collaboRATE**	**Decision Quality Instrument** [a]
My doctor made clear that a decision needs to be made. My doctor wanted to know exactly how I want to be involved in making the decision. My doctor told me that there are different options for treating my medical condition. My doctor precisely explained the advantages and disadvantages of the treatment options. My doctor helped me understand all the information. My doctor asked me which treatment option I prefer.	How much effort was made to help you understand your health issues? How much effort was made to listen to the things that matter most to you about your health issues? How much effort was made to include what matters most to you in choosing what to do next?	How important is it to you to… - relieve your [specific type of] pain? - not be limited in what you can do because of your [specific type of] pain? - avoid a treatment with a long recovery time? - avoid having [specific type of] surgery? - avoid taking pain medicine for a long time? Which treatment do you want to do to treat your [condition]? [Five knowledge items specific to the patient's health condition and possible treatment options] Did any of your health care providers talk about [specific type of] surgery as an option for you? How much did you and your health care providers talk about the reasons to have [specific type of] surgery?

My doctor and I thoroughly weighed the different treatment options. My doctor and I selected a treatment option together. My doctor and I reached an agreement on how to proceed.		How much did you and your health care providers talk about the reasons **not** to have [specific type of] surgery? Did any of your health care providers talk about non-surgical treatments as something that you should seriously consider? Did any of your health care providers ask you whether you wanted to have [specific type of] surgery or not?

[a] See [23] and [24] for full condition-specific instruments.

Measurement summary: other measurement cases

While routine patient-reported measurement at site 4 is largely limited to CAHPS-based patient questionnaires (see Table 3 for relevant CAHPS items), a pilot project within the organization utilizes the collaboRATE measure[9,20] to assess patients' SDM experience in primary care settings. As part of the pilot, patient responses are collected by a researcher in the clinic setting. The purpose of SDM measurement at site 4 is to support local quality improvement efforts. Sites 5 and 6 report only CAHPS-based routine patient-reported measurement, with no items specific to SDM.

Table 3. CAHPS items related to SDM and clinical communication

CAHPS SDM Measure	**CAHPS Communication Measure**
Did you and this doctor talk about the reasons you might want to take medicine?	How often did this doctor explain things in a way that was easy to understand?
Did you and this doctor talk about the reasons you might not want to take medicine?	How often did this doctor listen carefully to you?
When you and this doctor talked about starting or stopping a prescription medicine, did this doctor ask what you thought was best for you?	How often did this doctor show respect for what you had to say?
	How often did this doctor spend enough time with you?

Sites 7 and 8 take a similar, non-patient-reported approach to routine SDM measurement. Rather than collecting patient reports of SDM experience, these organizations designate the use of patient decision aids, which are shared through the electronic health record and accessed digitally, as a proxy for SDM. Prevalence of patient decision aid use is then tracked through electronic health record reporting functionality. The stated aim of site 7's SDM measurement program is to promote SDM as an effective quality improvement model.

Barriers and facilitators of routine patient-reported SDM measurement

Various barriers and facilitators were identified by participants both in organizations that do and do not yet conduct routine patient-reported SDM measurement. Greenhalgh's diffusion of innovations model offers a framework for these barriers and facilitators, summarized in Table 4.[13]

Table 4. Barrier and facilitator summary

	Attributes	Specific factors	Illustrative quotations
Facilitators			
The innovation	Compatibility	• SDM as core organizational value and/or strategic priority: sites 1, 3 and 7 • Healthcare environment has recently shifted toward SDM: site 2 • Continuous quality improvement as core organizational value: site 7	"In 2009, it was an uphill battle. Now there's general acknowledgement and agreement that SDM is how care should be delivered." (P03, site 2)
	Complexity	• Brevity of collaboRATE measure: site 2	"...it's only three questions. People recoil at a long survey." (P03, site 2)
	Trialability	• Measurement began in single clinical context, then spread: sites 1 and 2 • Pilot project: site 4	"We had such great success with [data collection] that we extended it into other policies like, for example, hysterectomy for benign conditions… We also extended it into our bariatric surgery. We extended it into cardiovascular disease." (P01, site 1)
	Observability	• Keen tracking helps maintain focus/attention: site 7	"I don't know if there's a formal protocol [for feedback of patient-reported data] so much as there is keen institutional focus."

	Attributes	Specific factors	Illustrative quotations
			(P09, site 7)
	Fuzzy boundaries	• Flexibility in how measures can be implemented, e.g. electronic data collection (sites 2, 3, 7, 8) vs. paper data collection (site 4)	
Adoption by individuals	Meaning	• SDM is an important addition to other ongoing patient-reported measurement: sites 5, 6, and 7	"We recognize that things like [CAHPS] don't do a good job of helping us understand shared decision-making." (P09, site 7)
	The adoption decision	• Rank-and-file clinicians involved in adoption decision: site 2	"We asked orthopedic surgeons if we should collect collaboRATE from everyone or just [from a subset of] patients [for whom SDM measurement is required by a payer]; surgeons said everyone." (P03, site 2)
System readiness for innovation	Innovation-system fit	• Payers have started to require patient-reported SDM measurement: sites 1 and 2 • Capacity for electronic data collection: sites 2, 3, 7, and 8	"We have an electronic [survey] platform… In the EMR, you can invite [patients] to a website [where] you can post questions for them to answer." (P10, site 8)
	Support and advocacy	• Involvement of clinical and/or administrative champions: sites 1, 2, 4, 7, and 8	"I was the one that decided this needs to be done." (P01, site 1) "Some [other clinicians] championed it within their networks [but] more it's me trying to get people to use the tools." (P10, site 8)
	Dedicated time and resources	• Dedicated personnel to design the measurement program and/or process SDM data: sites 1, 2, 4, 7, and 8	"There are a lot of people involved in data/analytics and reporting, [both] in departments and in units separate from departments that send data back to departments." (P03, site 2)

	Attributes	Specific factors	Illustrative quotations
Barriers			
The innovation	Relative advantage	• Relative advantage of patient-reported SDM measurement over proxy measurement (e.g. decision aid uptake) not yet sufficient to spur adoption: sites 7 and 8	
	Observability	• Other organizational priorities precede SDM performance monitoring: site 7	"And then the biggest thing is competing priorities…if you were to talk to one of the chiefs, they would say, 'that's fine, but [CAHPS] is what I need to focus on.'" (P09, site 7)
	Assessment of implications	• Patient burden perceived as a barrier to patient-reported measurement; however, adopters find that patients are willing to complete the measures: sites 2 and 4	"Operational leadership believes [that patients]...won't be happy with them if they send long surveys." (P03, site 2)
System readiness for innovation	Dedicated time and resources	• Lack of availability of pragmatic SDM measures at the time of program design: site 7	"It wasn't until recently that there were clearly very pragmatic tools for measuring patients' perceptions of shared decision-making." (P09, site 7)

Facilitators

The innovation

Facilitators of SDM measurement in this sample were predominantly related to the nature of the innovation itself.

SDM as a core organizational value or strategic priority was mentioned multiple times as a facilitator (sites 1, 2, 3, and 7), while an organizational culture of continuous quality improvement was mentioned once (site 7). One participant cited a broader shift in the healthcare environment toward SDM as helpful to SDM measurement efforts, explaining that ten years ago (in 2009), "it was an uphill battle," but "now there's general acknowledgement and agreement that SDM is how care should be delivered" (P03, site 2).

Practical aspects of measurement were also important. The brevity of the collaboRATE measure facilitates its use (site 2). In addition, the trialability of patient-reported SDM measurement is an evident facilitator (sites 1 and 2), with measurement beginning in a single clinical context then spreading. Similarly, in one instance, the patient-reported SDM measurement is occurring within the context of a pilot project (site 4). Where routine measurement has been trialed, flexibility in how measures can be collected, i.e. electronic data collection (sites 2, 3, 7, and 8) compared to paper data collection (site 4), lends itself to successful implementation. Finally, the ability for SDM outcomes to be tracked over time demonstrates the high observability of SDM measurement and facilitates its implementation (site 7).

Adoption by individuals

Adoption-related facilitators of SDM measurement focused on meaning and the adoption decision itself. This includes acknowledgement of SDM as an important addition to other ongoing patient-reported measurement — "recogniz[ing] that things like [CAHPS] don't do a good job of helping us understand shared decision-making" (P09, site 7). At another site (site 2), initial routine patient-reported SDM measurement was originally mandated by a payer organization (site 1). In debating whether or not to expand the measurement program beyond the minimum scope required to meet payer requirements, that site actively engaged the clinicians whose performance was being measured, who supported the program's expansion.

System readiness for innovation

System readiness for routine patient-reported SDM measurement involved innovation-system fit, support and advocacy within the organizations, and dedicated time and resources for building and maintaining routine measurement. With regard to innovation-system fit, payers have started to require patient-reported SDM measurement for preauthorization of payment for elective procedures (sites 1 and 3). Further, the capacity for electronic data collection was a system-level factor that fit the demands of routine SDM measurement (site 2, 3, 7, and 8).

Pertaining to support and advocacy for routine SDM measurement, clinical and/or administrative champion involvement was critical (sites 1, 2, 4, 7, and 8). It was also important for operational leadership to recognize SDM as an important issue (P03).

Finally, the availability of material support was a critical facilitator of SDM measurement, including dedicated personnel to design SDM measurement programs and/or process SDM data (sites 1, 2, 4, 7, and 8).

Barriers

Several key barriers to routine patient-reported SDM measurement were identified.

The innovation

In settings where SDM measurement relies on a proxy measure of patient decision aid use, the relative advantage of patient-reported measurement is not yet sufficient to spur adoption (sites 7 and 8). Other organizational priorities, particularly those aspects of care assessed by the CAHPS patient experience survey, resulted in less attention being available among organizational leadership for SDM performance

management (site 7). Another barrier is the perceived patient burden of patient-reported SDM measurement; however, as patient-reported SDM measurement was adopted, those involved found that patients were willing and able to complete the measures without substantial burden (sites 2 and 4).

System readiness for innovation

Finally, a lack of availability of pragmatic patient-reported SDM measures was identified as a barrier to patient-reported SDM measurement, as "it wasn't until recently that there were clearly very pragmatic tools for measuring patients' perceptions of shared decision-making" (P09, site 7).

Use of SDM data

Of the eight organizations reporting routine SDM measurement, four describe subsequent use of the data for benchmarking and internal performance improvement purposes (sites 2, 3, 4, 7). This takes the form of routine reporting of SDM data to heads of relevant clinical departments, including graphics depicting comparative performance and with subsequent feedback to individual clinicians. Site 2 reports substantial and productive clinic-level engagement with this feedback.

One site, however, struggles to find a use for its extensive SDM data that is deemed acceptable by its community of clinicians (site 1). As a payer organization, site 1 finds that its collection of SDM data has "created a little bit of trepidation" within the clinician community due to a perception that they could "weaponize this information" to "steer patients away and send them to higher performers" (P01). They aspire to "use the information to try to educate" and offer training to lower-performing clinicians (P01). However, they "haven't quite gone there yet" (P01).

DISCUSSION

Key findings

Three of the eight organizations in this sample conduct routine patient-reported SDM measurement. Other organizations under study (4 of 8) rely on proxies of SDM; two organizations use related constructs measured in the widespread CAHPS patient experience survey and two others track patients' use of decision aids. A single organization in this sample uses a CAHPS-like patient experience survey throughout the organization paired with a pilot project in which they administer SDM-specific patient-reported measures to a selected group of patients. The most common stated purpose for SDM measurement was local quality improvement, while one site specifically targeted system-level waste reduction in its measurement efforts.

In organizations where patient-reported SDM measurement is routine, facilitators include: compatibility of SDM measurement with core organizational values; brevity of the collaboRATE patient-reported SDM measure; trialability (and potential for subsequent expansion) of patient-reported SDM measurement within the organization; flexibility in how measures can be implemented; involvement of both clinical champions and rank-and-file clinicians in the decision to measure SDM performance; an environment in which payers (e.g., health insurance companies) have begun to require provider organizations to measure patients' experiences of SDM; and dedicated resources (i.e. personnel) within the organizations to design and maintain their SDM measurement programs.

Several barriers to patient-reported SDM measurement were identified in this sample of organizations. These include inadequate perceived relative advantage of patient-reported SDM measurement over proxy measures, a paucity of patient-reported SDM measures that are sufficiently pragmatic for routine and widespread use, and the existence of competing priorities for organizational leadership when it comes to patient experience.

Finally, the few organizations we identified with routine patient-reported SDM measurement tend to use the resulting information for internal benchmarking and quality improvement initiatives. However, site 1, due to constraints unique to payer-only organizations, is still in the process of developing a tenable use of the extensive patient-reported SDM data it collects.

Results in context

Despite policy momentum, routine patient-reported SDM measurement is rare in the US. While it occurs in three of the eight organizations in this rarefied sample, there remains an enormous silent denominator — most of which has yet to consider routine patient-reported SDM measurement. The study team contacted 32 individuals affiliated with the US research and clinical centers known to be active in SDM; this population of active SDM sites is an extremely small subset of the more than 600 health systems and hundreds of additional standalone hospitals and private practices in the US.[25] When routine patient-reported measurement of SDM spreads beyond the small number of organizations identified in this study, future research employing network analysis would be helpful to track patterns of diffusion.

This study is the first, to our knowledge, to examine routine patient-reported SDM measurement use cases within the US. Organizations with routine patient-reported SDM measurement programs use a variety of measures, including the SDM Process measure, Decision Quality Instrument, SDM-Q-9, and collaboRATE. The use of patient decision aid access data as a proxy for SDM, adopted by two organizations within this sample, is consistent with proxy measures described by Durand and colleagues as part of recent US healthcare policy related to SDM.[26] However, while “decision and conversation aids can be valuable in facilitating SDM...they are neither necessary nor sufficient for choosing an approach to address each patient’s situation.”[27] Although decision aid use has been associated with improved decisional outcomes such as reduced uncertainty and higher satisfaction with the decision-making process,[28] direct comparisons of proxy measures to patient-reported and observer-rated SDM in a future study would further elucidate their validity. A recent systematic review assessing the quality of SDM measurement instruments finds generally limited available information on measurement quality of SDM measurement instruments, including for the SDM Process measure, SDM-Q-9, and collaboRATE.[12] More research is needed to critically appraise the psychometric properties of these instruments.

While most uses of patient-reported experience data do not broach the subject of clinician behavior change,[6] some organizations in this sample that conduct SDM measurement provide feedback directly to clinical teams with the intent to enhance clinician skills and modify behavior. Despite systematic review evidence of a positive effect of audit and feedback on clinician performance,[1] recent commentaries have called this relationship into question.[3] Implementation science can inform optimal operationalization of audit and feedback for performance improvement, including pairing feedback with clinician training in SDM, as well as structuring clinical timelines to allow healthcare professionals to address the varied priorities for which they are accountable.[29]

While site 1 appears to benefit from its leverage as a payer organization to facilitate the largest and most robust patient-reported SDM measurement program in this sample, its use of the data is constrained by its role as a payer organization. These constraints relate to perceived distrust between provider organizations and health insurance companies, including a fear that health insurance companies may weaponize performance data to drive patients away from low-performing professionals. Among managed care health plan members, prior research has demonstrated a sense of vulnerability, worry, and fear in relation to health insurance plans[30] — consistent with our current findings focused on healthcare providers. Overcoming this distrust is critical for health insurance companies to make effective quality improvement use of the data they are well-positioned to collect.

Strengths and limitations

Through the authors' professional networks and a snowball sampling approach, recruitment efforts for this study involved a near-census of major SDM initiatives in the United States. However, while our snowball sampling recruitment method allowed for insight into organizations on the leading edge of SDM measurement, this sampling strategy may have inadvertently omitted relevant cases.

Conclusion

Payers have a unique opportunity to encourage emphasis on SDM within healthcare organizations, including routine patient-reported measurement of SDM; however, provider organizations are currently best placed to make effective use of this type of data. Next steps for organizations that choose to pursue routine patient-reported SDM measurement, particularly payer organizations with potential for broad impact, include implementing data use that drives widespread SDM quality improvement.

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Competing interests statement
Glyn Elwyn has edited and published books that provide royalties on sales by the publishers: the books include Shared Decision Making (Oxford University Press) and Groups (Radcliffe Press).
Glyn Elwyn's academic interests are focused on shared decision making and coproduction. He owns copyright in measures of shared decision making and care integration, namely collaboRATE, integRATE (measure of care integration, consideRATE (patient experience of care in serious illness), coopeRATE (measure of goal setting), toleRATE (clinician attitude to shared decision making, Observer OPTION-5 and Observer OPTION-12 (observer measures of shared decision making).
Glyn Elwyn has in the past provided consultancy for organizations, including: 1) Emmi Solutions LLC who developed patient decision support tools; 2) National Quality Forum on the certification of decision support tools; 3) Washington State Health Department on the certification of decision support tools; 4) SciMentum LLC, Amsterdam (workshops for shared decision making).
Glyn Elwyn is the Founder and Director of &think LLC which owns the registered trademark for Option Grids TM patient decision aids; Founder and Director of SHARPNETWORK LLC, a provider of training for shared decision making. He provides advice in the domain of shared decision making and patient decision aids to: 1) Access Community Health Network, Chicago (Adviser to Federally Qualified Medical Centers); 2) EBSCO Health for Option Grids TM patient decision aids (Consultant); 3) Bind On Demand Health Insurance (Consultant), 4) PatientWisdom Inc (Adviser); 5) abridge AI Inc (Chief Clinical Research Scientist).
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To protect the confidentiality of research participants, interview and survey data will not be made publicly available.

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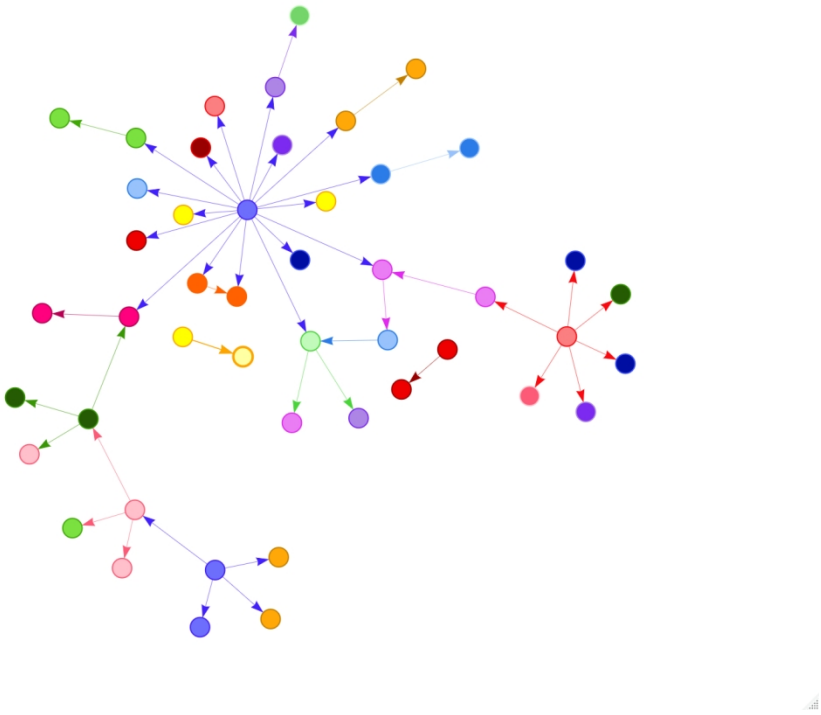
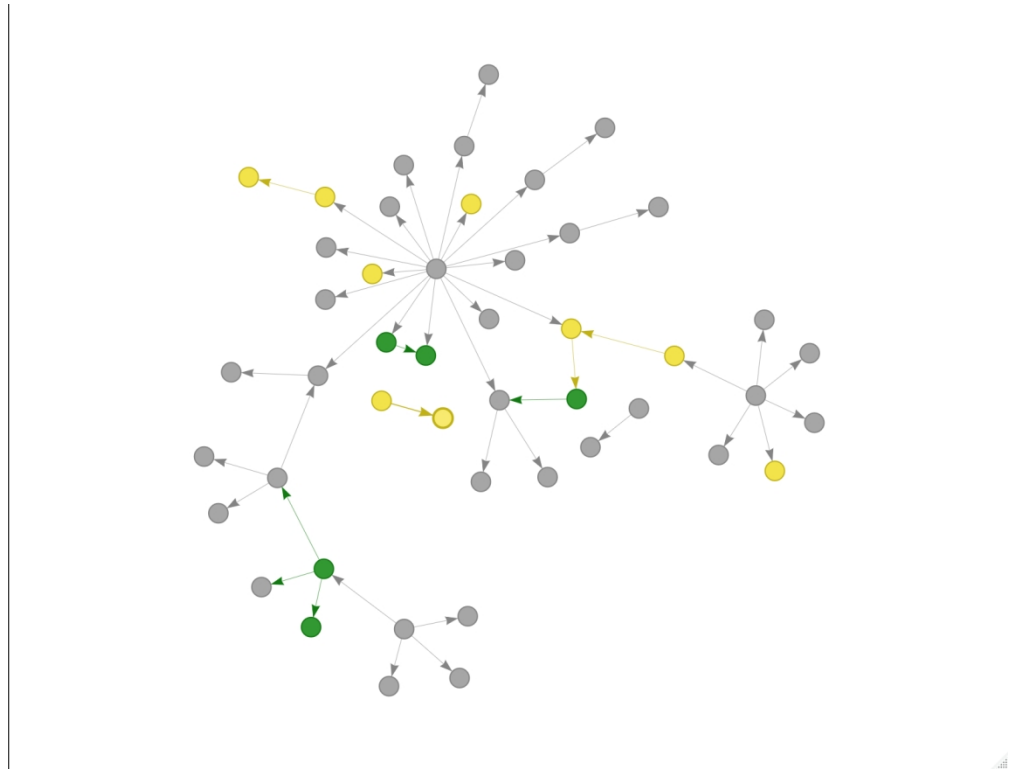


Figure 1. Recruitment process and snowball sample referral network, colored by organization [a, b]



Recruitment process and snowball sample referral network, colored by organization's SDM measurement status [a, c]

APPENDIX 1. Interview guide

ORGANIZATION'S CURRENT DATA COLLECTION

- To start, could you tell me about patient experience measurement in general in your organization?
    - Which patient-reported experience measures does your organization collect?
        - What constructs are measured?
        - How were those measures decided upon?
    - Can you provide a little background on your organization?

- Which patient-reported measures specific to shared decision-making does your organization collect?
    - Does this vary within your organization?
    - How was/were the measure(s) selected?
        - Who chose the measures? What criteria did they consider?
        - What advantages do they convey?
        - Are there any disadvantages to consider?

- Why did your organization decide to measure SDM?
    - What need does it fill?
    - What advantages does it convey?
    - What prompted the decision?
    - What was the original intended use of this data? Why?
    - Do you have a formal logic model?

- Please describe the process by which your organization administers SDM measures.
    - Is there a formal protocol/SOP for SDM measurement?
    - Does this vary within your organization?
        - Is there opting in/out? Are there differences between those who participate and those who do not?
        - How are opt-in/out decisions made?

- Do you consider patient-reported SDM measurement to be a routine part of healthcare operations in your organization?
    - Does this vary by department/area?
    - If not, what would it take for your organization to routinely measure SDM?
    - If so, how did SDM measurement get to be routine?
    - What in your organization is a barrier or challenge to routine patient-reported SDM measurement?
    - What in your organization facilitates routine patient-reported SDM measurement?

- How often does your organization conduct SDM measurement? Is it ongoing?
    - How often are data collected? E.g. monthly sampling, annual sampling.

- Approximately how many [annual/monthly/other] patient responses do you/your organization gather for each SDM measure we've discussed?
    - How do you decide how many responses to collect?

- What resources go into SDM measurement in your organization? [Financial, human, other]

- Where do these resources come from?
- How does the organization decide to use them in this way?

- What concerns about SDM measurement have you heard in your organization? Who voices these concerns?
  - In early stages?
  - In later stages?

- Does SDM measurement have a 'champion' within your organization?
  - How did this champion emerge? What motivates him/her?
  - Does this person have dedicated time/resources for SDM measurement within his or her official role?

- Are there any efforts to evaluate the SDM measurement process within your organization?
  - What would be considered a successful outcome of SDM measurement?

USE OF DATA COLLECTED

- How does your organization use the data it collects about shared decision-making performance?
  - Are the data fed back or disseminated in some way?
    - To whom? Clinicians? Managers? Patients? Administrators? Insurers?
    - Are any interventions offered where low performance is identified?
  - Is there a formal protocol/SOP for feedback of SDM data?
  - How long has your organization been using SDM performance data in this way?
  - Is this use of SDM performance data uniform across your organization, or do different departments/areas use the data differently?
  - Did SDM measurement and feedback begin at the same time, or did it happen in stages?
  - What resources go into this use of SDM performance data? [Financial, human, other.]
    - Where do these resources come from? How does the organization decide to spend them in this way?
  - How did the organization come to use the data this way?
    - Whose idea was it?
    - How did they make it happen?
    - Was [or is] organizational leadership involved?
      - At what level/stage and in what capacity?
    - Who is involved in implementation?
  - What in your organization is a barrier or challenge to feeding back patient-reported SDM data for performance improvement?
  - What in your organization facilitates feeding back patient-reported SDM data for performance improvement?

[IF DATA ARE FED BACK:]

- What does the feedback look like?
  - How often is feedback provided/to whom?
  - Is it a report? A single number? Graphics? Text?
  - How is it delivered? Email? Online? Paper format? Phone?
  - Who designed the feedback's format?
  - Who generates the feedback?
    - Is it automated?

- Why did your organization decide to start providing feedback?
  - What need does it fill?
  - What advantages does it convey?

- When your organization first started providing patient experience/SDM feedback, how did recipients of the data initially react to it?
  - Have their reactions changed since you started providing feedback?

- Did feedback recipients receive any priming or training prior to starting to receive the feedback?
  - Is SDM training/resources available to recipients after they receive feedback?

- Has your organization seen changes in SDM performance since it started feeding back data on patient experience of SDM?

- Has your organization seen changes on any [other] quality or health outcomes since they started feeding back data on patient experience of SDM?
  - Have you seen changes resulting from any non-SDM related patient feedback?

RECRUITMENT

- I'm hoping to get perspectives on patient-reported SDM measurement from clinicians, clinical staff, administrators, and researchers. Are there others in or outside your organization who you'd suggest I speak with about patient-reported measurement of shared decision-making?
  - What is the best way for me to get in touch with them?

DEMOGRAPHICS

Before we wrap up, I'd like to get some background information about you and your organization.

- What is your job title?
  - In a sentence or two, how would you describe your role as it relates to patient experience measurement in your organization?

- What is your educational background?
  - When did you finish your terminal [and/or most recent] degree?

- How long have you worked at your current organization?
  - How long have you been in your current position?

- I won't use your name in any reports or presentations about this project. How would you like me to refer to your organization? [By name, by description - looking for specific wording.]
- How large is your organization? [Beds, employees]
- How would you describe your patient population?

OTHER

- Is there anything else you'd like to share about patient experience measurement at your organization?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
Purpose or research question - Purpose of the study and specific objectives or questions	3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	3-4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	3-4
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4-5

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4, 18-21
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	13-14
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	9-13

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	13-14
Limitations - Trustworthiness and limitations of findings	15

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	17
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	17

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Routine patient-reported experience measurement of shared decision-making in the US: a qualitative study of the current state according to frontrunners

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Routine patient-reported experience measurement of shared decision-making in the US: a qualitative study of the current state according to frontrunners

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ABSTRACT

Objectives: To identify and describe instances of routine patient-reported shared decision-making (SDM) measurement in the US, and to explore barriers and facilitators of routine patient-reported SDM measurement for quality improvement.

Setting: Payer and provider healthcare organizations in the United States.

Participants: Current or former adult employees of healthcare organizations with prior SDM activity and that may be conducting routine SDM measurement.

Outcomes: Qualitative interview and survey data collected through snowball sampling recruitment strategy to inform barriers and facilitators of routine patient-reported SDM measurement.

Results: Three participating sites (out of 26 sites approached) routinely measured SDM from patients' perspectives, including one payer organization and two provider organizations - with the largest measurement effort taking place in the payer organization. Facilitators of SDM measurement included SDM as a core organizational value or strategic priority, trialability of SDM measurement programs, flexibility in how measures can be administered, and existing momentum from payer-mandated measurement programs. Barriers included competing organizational priorities with regard to patient-reported measurement and lack of perceived comparative advantage of patient-reported SDM measurement.

Conclusions: Payers have a unique opportunity to encourage emphasis on SDM within healthcare organizations, including routine patient-reported measurement of SDM; however, provider organizations are currently best placed to make effective use of this type of data.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Recruitment for this study involved a near-census of major SDM initiatives in the United States.
- This study gathered insight from organizations on the leading edge of shared decision-making practice.
- The snowball sampling recruitment methodology identified previously unknown examples of routine patient-reported SDM measurement.
- Data derived from this small but heterogeneous group of institutions did not reach thematic saturation.
- The multi-modal data collection approach (interviews and surveys) led to varying levels of detail available across included participants and sites.

INTRODUCTION

Policy interest in shared decision-making (SDM) is growing internationally, leading to calls for increased measurement and feedback efforts. Underlying these efforts is preliminary evidence that audit and feedback can improve the quality of health care, particularly related to provider behaviors,[1] despite some reports that feedback is not always effective in improving clinician performance.[2,3] Additional interest in measurement relates to its potential to motivate and monitor focused efforts at multiple levels, from clinic quality improvement initiatives to system-level performance incentivization programs.[4,5] This policy interest, while drawing to some extent on academic research, is not necessarily led by clinician or researcher efforts. Additionally, time-delimited research and quality improvement projects in healthcare settings often do not lead to sustained initiatives. Prior research on widespread use of patient experience data for quality improvement (QI) purposes found "no single best way to collect or use [patient-reported experience] data for QI."[6]

Patient-reported experience measures are questionnaires that "gather information on patients' views of their experience [of] receiving care."[7] The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys are in widespread use in the United States, measuring diverse aspects of the patient experience.[8] However, CAHPS lacks a measure that captures the three core dimensions of SDM: 1) information provision; 2) preference elicitation; and 3) preference integration.[9–11]

While measures of SDM have been described in detail elsewhere,[12] existing studies do not adequately examine these patient-reported experience measures in the specific context of quality improvement. We seek to identify sites at varying stages of implementing SDM measurement and feedback and gain in-depth insight into their experiences. This will allow us to learn what differentiates organizations that conduct small-scale SDM measurement projects in research and/or quality improvement contexts from those that implement widespread SDM measurement programs. Understanding their experiences within a US context can inform strategies at other organizations, both domestic and international, that seek to implement SDM measurement and feedback. Therefore, in this study we differentiate routine patient-reported SDM measurement, i.e. an ongoing SDM measurement program not tied to a specific project and generally internally funded as part of routine operations, from patient-reported SDM measurement as part of research or quality improvement projects. These research or quality improvement projects are often time-delimited, smaller in scale, and externally sponsored.

In this study, we aim to 1) identify and describe instances of routine patient-reported SDM measurement in the US; and 2) explore barriers and facilitators of routine patient-reported SDM measurement for quality improvement using the Greenhalgh et al. diffusion of innovations theoretical framework.[13] Our primary research question was: what are the barriers and facilitators of routine patient-reported SDM measurement in the US?

METHODS

Given the orientation of the study to explore how and why patient-reported SDM measurement and feedback were undertaken, we adopted a descriptive multiple case study research design.[14]
To describe examples of patient-reported SDM measurement, we employed a multi-pronged data collection approach, including a survey of representatives from leading SDM centers, and, as available, in-depth interviews of representatives from relevant sites. This study, including all consent and data collection procedures, was reviewed and approved by Dartmouth College's Committee for the Protection of Human Subjects (CPHS #31002). Participants received an information sheet describing the research study (survey participants) and/or verbally reviewed the information sheet with the interviewer (interview participants) immediately prior to participation in the survey or interview components of the study. With participants' verbal permission, interviews were audio-recorded.

Inclusion criteria

Sites included healthcare organizations in which the research team was aware of ongoing SDM research or quality improvement efforts. Sites were identified through the research team's professional network, drawing on prior knowledge of SDM activity in the US.

Interview and survey participants were current or former adult employees of healthcare organizations that may be conducting routine SDM measurement. Inclusion criteria did not specify job titles of eligible individuals; instead, any staff with knowledge of a relevant SDM measurement program were eligible for participation.

Recruitment

We adopted a snowball sampling approach to participant recruitment. A snowball sampling approach has the benefit of identifying previously unknown or hidden populations,[15] and SDM researchers and practitioners are well-placed to be aware of peers active in routine patient-reported SDM measurement. Through their professional networks and drawing on more than two decades of experience in SDM research, the research team initially made email contact with 32 individuals from 23 US centers known to be active in either conducting research on SDM or implementing SDM to participate in a survey or telephone interview. The research team made initial contact by email, followed by either an emailed link to the survey or an interview invitation, depending on participant availability and preference. At the conclusion of each interview, the interviewer (RF) requested that the participant identify other knowledgeable individuals at his or her site or related sites for possible interview participation. Additional outreach resulting from the snowball sampling approach is described in the results section of this manuscript.

Data collection

One member of the research team (RF) also conducted semi-structured interviews with key informants at a sample of sites with ongoing SDM measurement programs. In-depth interviews were conducted by Zoom teleconference (audio only). The interview guide was developed to investigate several core components of Greenhalgh's diffusion of innovations model, namely: 1) the innovation; 2) adoption by individuals; and 3) system readiness for innovation.[13] (See Appendix 1 for the full interview guide.)

Where we were unable to conduct semi-structured interviews with relevant contacts, we conducted a 12-item open-ended survey hosted by Qualtrics online survey software to gain insight into routine SDM

measurement efforts. Participants were asked to provide information on 1) which SDM measures were in routine use at their organizations, 2) how the measures were selected, 3) details on measurement volume, 4) what concerns are voiced in their organizations about SDM measurement, and 5) how the organizations use the SDM data they collect for quality improvement (see Appendix 2).

Participants were asked to describe patient-reported SDM measurement and feedback within their organizations, including decision-making processes to establish measurement, dedicated resources, and related processes while differentiating between individual-level and system-level adoption.[13] Interview questions sought to understand the purpose of SDM measurement and feedback in these organizations, as well as who initiated the work and why. Audio-recordings were transcribed verbatim for analysis. Where interviews could not be audio-recorded, as was the case in one interview, the interviewer (RF) took detailed field notes.

Patient and public involvement

Patients and the public were not involved in the conduct or reporting of this research.

Analysis

A single coder (RF) reviewed survey responses to identify instances of routine SDM measurement. Two coders (RF and JE) conducted thematic analysis[16,17] of interview transcripts and/or field notes with specific reference to relevant domains of Greenhalgh's diffusion of innovations model[13] using Atlas.ti version 8.4.4 software. After detailed review of the data, initial codes were independently generated. The coders then identified, discussed, and iteratively refined themes across the coded data.[16,17] Figures were generated using the R visNetwork and tidyverse software packages.[18,19]

RESULTS

Of 42 people referred to the research team through our initial sample (32 people) and our snowball sampling approach (10 people), 36 people from 26 organizations were contacted for survey and interview recruitment. Eleven people reported no knowledge of routine patient-reported SDM measurement. Three reported only CAHPS surveys in use for routine patient-reported measurement. Three reported proxy measurement of SDM through a non-patient reported channel. Four reported additional routine patient-reported SDM measurement. Six acknowledged receipt of the email invitation but did not provide measurement details. Nine did not respond. Six participants completed semi-structured interviews, with an average interview duration of 40 minutes. The recruitment process and full snowball sample referral network is depicted in Figure 1 and Figure 2. Table 1 summarizes SDM measurement at each included site with active SDM measurement initiatives. One health insurance company (site 1) and two provider organizations (sites 2 and 3) routinely measure SDM from patients' perspectives.

Figure 1. Recruitment process and snowball sample referral network, colored by organization[a, b]

Figure 2. Recruitment process and snowball sample referral network, colored by organization's SDM measurement status[a, c]

[a] Nodes represent individuals working within healthcare organizations; each individual's referrals to the study team for potential participation are indicated by directed edges. [b] Each color represents a unique

organization. [c] Grey: organization has no routine SDM measurement; Yellow: organization has routine non-patient-reported SDM measurement; Green: organization has routine patient-reported SDM measurement.

Table 1. Participant and organizational characteristics where SDM measurement is occurring

	Measurement type(s)	**Organization description**	**Participant profile(s)**
Site 1	**Routine patient-reported SDM measurement.**	A nonprofit organization providing health insurance coverage to California residents.	• Administrator; 5-10 years experience in current organization. (P01) • Clinical administrator; 2-4 years experience in current organization. (P02)
Site 2	**Routine patient-reported SDM measurement;** Routine CAHPS-based communication measurement.	A large health system in northern California.	• Administrator and researcher; 5-10 years experience in current organization. (P03)
Site 3	**Routine patient-reported SDM measurement.**	A large not-for-profit healthcare system.	• Researcher; 15-20 years experience in current organization. (P04)
Site 4	Project-based patient-reported SDM measurement; Routine CAHPS-based communication measurement.	A United States Department of Veterans Affairs medical center. The Department of Veterans Affairs operates 172 medical centers offering services to military veterans.	• Researcher; 25+ years experience in current organization. (P05) • Researcher/Administrator; 25+ years experience in current organization. (P06)
Site 5	Routine CAHPS-based communication measurement.	A health care system affiliated with an academic institution.	• Faculty researcher; 5-10 years experience in current organization. (P07)
Site 6	Routine CAHPS-based communication measurement.	A midwestern academic medical center.	• No demographic data available. (P08)
Site 7	Routine measurement focused on uptake of patient decision aids.	A regional integrated health care payer and provider organization.	• Clinical administrator; 25+ years experience in current organization. (P09)
Site 8	Routine measurement focused on uptake of patient decision aids.	A regional integrated health care payer and provider organization.	• Clinician; 20-25 years experience in current organization. (P10)

Measurement summary: routine patient-reported SDM measurement

Site 1 collects patient-reported SDM measures in selected clinical areas including orthopedics, gynecology, bariatrics, and cardiology. For several elective procedures, this payer organization requires in-network healthcare providers to collect a set of patient-reported SDM measures in order for the procedures to be pre-authorized for payment. Measures include collaboRATE,[9,20] SDM-Q-9,[21] and an internally-developed measure asking whether patients 1) have enough information, 2) are clear about which benefits and side effects matter most to them, and 3) understand the options available to them (see Appendix 3 for collaboRATE and SDM-Q-9 items). Across the organization, approximately 10,000 patient reports are collected annually. At this site, the potential for waste reduction, i.e. patients receiving only the most appropriate services for them, was the impetus behind the measurement program.

Site 2 collects the collaboRATE patient-reported measure of SDM[9,20] in orthopedics and urology clinics from all patients making total joint replacement and prostate cancer treatment decisions. The purpose of measurement was initially to meet payer requirements for elective orthopedic procedures, but then expanded to include other non-mandatory clinical areas.

Site 3 collects the Shared Decision Making Process measure[22] along with the Hip Osteoarthritis Decision Quality Instrument,[23] Knee Osteoarthritis Decision Quality Instrument,[23] Herniated Disc Decision Quality Instrument,[23,24] and the Spinal Stenosis Decision Quality Instrument from patients with relevant health conditions (see Appendix 3 for detail on included measures). The measures are administered through the health system's electronic medical record as part of the organization's patient-reported outcomes measurement system, collecting approximately 1,800 patient reports of SDM experience per year for benchmarking and performance improvement purposes.

Measurement summary: other measurement cases

While routine patient-reported measurement at site 4 is largely limited to CAHPS-based patient questionnaires (see Table 2 for relevant CAHPS items), a pilot project within the organization utilizes the collaboRATE measure[9,20] to assess patients' SDM experience in primary care settings. As part of the pilot, patient responses are collected by a researcher in the clinic setting. The purpose of SDM measurement at site 4 is to support local quality improvement efforts. Sites 5 and 6 report only CAHPS-based routine patient-reported measurement, with no items specific to SDM.

Table 2. CAHPS items related to SDM and clinical communication

CAHPS SDM Measure	**CAHPS Communication Measure**
Did you and this doctor talk about the reasons you might want to take medicine?	How often did this doctor explain things in a way that was easy to understand?

Did you and this doctor talk about the reasons you might not want to take medicine?	How often did this doctor listen carefully to you?
When you and this doctor talked about starting or stopping a prescription medicine, did this doctor ask what you thought was best for you?	How often did this doctor show respect for what you had to say?
	How often did this doctor spend enough time with you?

Sites 7 and 8 take a similar, non-patient-reported approach to routine SDM measurement. Rather than collecting patient reports of SDM experience, these organizations designate the use of patient decision aids, which are shared through the electronic health record and accessed digitally, as a proxy for SDM. Prevalence of patient decision aid use is then tracked through electronic health record reporting functionality. The stated aim of site 7's SDM measurement program is to promote SDM as an effective quality improvement model.

Barriers and facilitators of routine patient-reported SDM measurement

Various barriers and facilitators were identified by participants both in organizations that do and do not yet conduct routine patient-reported SDM measurement. Greenhalgh's diffusion of innovations model offers a framework for these barriers and facilitators, summarized in Table 3.[13]

Table 3. Barrier and facilitator summary

	Attributes/Themes	**Specific factors/Codes**	**Illustrative quotations**
Facilitators			
The innovation	Compatibility	• SDM as core organizational value and/or strategic priority: sites 1, 3 and 7 • Healthcare environment has recently shifted toward SDM: site 2 • Continuous quality improvement as core organizational value: site 7	"SDM is seen as important component of patient engagement, which is core organizational value. (P04, site 3) "There's a big effort at [site] right now to change the way care is provided, take a more whole health approach, patient-centered approach to really provide care that starts with what matters most to the patients." (P05, site 4)

	Attributes/Themes	Specific factors/Codes	Illustrative quotations
	Complexity	• Brevity of collaboRATE measure: site 2	"...it's only three questions. People recoil at a long survey." (P03, site 2)
	Trialability	• Measurement began in single clinical context, then spread: sites 1 and 2 • Pilot project: site 4	"We had such great success with [data collection] that we extended it into other policies like, for example, hysterectomy for benign conditions… We also extended it into our bariatric surgery. We extended it into cardiovascular disease." (P01, site 1)
	Observability	• Keen tracking helps maintain focus/attention: site 7	"I don't know if there's a formal protocol [for feedback of patient-reported data] so much as there is keen institutional focus." (P09, site 7)
	Fuzzy boundaries	• Flexibility in how measures can be implemented, e.g. electronic data collection (sites 2, 3, 7, 8) vs. paper data collection (site 4)	"What we're doing is we're collecting it at point of care using our research assistant… We didn't have a whole lot of money to do it. One of our goals, really, with the pilot is usability so we get patients to do it, how long is it going to take." (P05, site 4)
Adoption by individuals	Meaning	• SDM is an important addition to other ongoing patient-reported measurement: sites 5, 6, and 7	"We recognize that things like [CAHPS] don't do a good job of helping us understand shared decision-making." (P09, site 7)
	The adoption decision	• Rank-and-file clinicians involved in adoption decision: site 2	"We asked orthopedic surgeons if we should collect collaboRATE from everyone or just [from a subset of] patients [for whom SDM measurement is required by a payer]; surgeons said everyone." (P03, site 2)

	Attributes/Themes	Specific factors/Codes	Illustrative quotations
System readiness for innovation	Innovation-system fit	• Payers have started to require patient-reported SDM measurement: sites 1 and 2 • Capacity for electronic data collection: sites 2, 3, 7, and 8	"We have an electronic [survey] platform… In the EMR, you can invite [patients] to a website [where] you can post questions for them to answer." (P10, site 8)
	Support and advocacy	• Involvement of clinical and/or administrative champions: sites 1, 2, 4, 7, and 8	"I was the one that decided this needs to be done." (P01, site 1) "Some [other clinicians] championed it within their networks [but] more it's me trying to get people to use the tools." (P10, site 8)
	Dedicated time and resources	• Dedicated personnel to design the measurement program and/or process SDM data: sites 1, 2, 4, 7, and 8	"There are a lot of people involved in data/analytics and reporting, [both] in departments and in units separate from departments that send data back to departments." (P03, site 2)
Barriers			
The innovation	Relative advantage	• Relative advantage of patient-reported SDM measurement over proxy measurement (e.g. decision aid uptake) not yet sufficient to spur adoption: sites 7 and 8	Interviewer: "Do you collect patient-reported measures specific to shared decision-making?" P09: "We do not, unfortunately. I've been trying to get collaboRATE in and I'm unsuccessful…" (P09, site 7)
	Observability	• Other organizational priorities precede SDM performance monitoring: site 7	"And then the biggest thing is competing priorities…if you were to talk to one of the chiefs, they would say, 'that's fine, but [CAHPS] is what I need to focus on.'" (P09, site 7)
	Assessment of implications	• Patient burden perceived as a barrier to patient-	"Operational leadership believes [that patients]...won't be happy

	Attributes/Themes	Specific factors/Codes	Illustrative quotations
		reported measurement; however, adopters find that patients are willing to complete the measures: sites 2 and 4	with them if they send long surveys." (P03, site 2)
System readiness for innovation	Dedicated time and resources	• Lack of availability of pragmatic SDM measures at the time of program design: site 7	"It wasn't until recently that there were clearly very pragmatic tools for measuring patients' perceptions of shared decision-making." (P09, site 7)

Facilitators

The innovation

Facilitators of SDM measurement in this sample were predominantly related to the nature of the innovation itself.

SDM as a core organizational value or strategic priority was mentioned multiple times as a facilitator (sites 1, 2, 3, and 7), while an organizational culture of continuous quality improvement was mentioned once (site 7). One participant cited a broader shift in the healthcare environment toward SDM as helpful to SDM measurement efforts, explaining that ten years ago (in 2009), "it was an uphill battle," but "now there's general acknowledgement and agreement that SDM is how care should be delivered" (P03, site 2).

Practical aspects of measurement were also important. The brevity of the collaboRATE measure facilitates its use (site 2). In addition, the trialability of patient-reported SDM measurement is an evident facilitator (sites 1 and 2), with measurement beginning in a single clinical context then spreading. Similarly, in one instance, the patient-reported SDM measurement is occurring within the context of a pilot project (site 4). Where routine measurement has been trialed, flexibility in how measures can be collected, i.e. electronic data collection (sites 2, 3, 7, and 8) compared to paper data collection (site 4), lends itself to successful implementation. Finally, the ability for SDM outcomes to be tracked over time demonstrates the high observability of SDM measurement and facilitates its implementation (site 7).

Adoption by individuals

Adoption-related facilitators of SDM measurement focused on meaning and the adoption decision itself. This includes acknowledgement of SDM as an important addition to other ongoing patient-reported measurement — "recogniz[ing] that things like [CAHPS] don't do a good job of helping us understand shared decision-making" (P09, site 7). At another site (site 2), initial routine patient-reported SDM measurement was originally mandated by a payer organization (site 1). In debating whether or not to expand the measurement program beyond the minimum scope required to meet payer requirements, that site actively engaged the clinicians whose performance was being measured, who supported the program's expansion.

System readiness for innovation

System readiness for routine patient-reported SDM measurement involved innovation-system fit, support and advocacy within the organizations, and dedicated time and resources for building and maintaining routine measurement. With regard to innovation-system fit, payers have started to require patient-reported SDM measurement for preauthorization of payment for elective procedures (sites 1 and 3). Further, the capacity for electronic data collection was a system-level factor that fit the demands of routine SDM measurement (site 2, 3, 7, and 8).

Pertaining to support and advocacy for routine SDM measurement, clinical and/or administrative champion involvement was critical (sites 1, 2, 4, 7, and 8). It was also important for operational leadership to recognize SDM as an important issue (P03).

Finally, the availability of material support was a critical facilitator of SDM measurement, including dedicated personnel to design SDM measurement programs and/or process SDM data (sites 1, 2, 4, 7, and 8).

Barriers

The innovation

In settings where SDM measurement relies on a proxy measure of patient decision aid use, the relative advantage of patient-reported measurement is not yet sufficient to spur adoption (sites 7 and 8). Other organizational priorities, particularly those aspects of care assessed by the CAHPS patient experience survey, resulted in less attention being available among organizational leadership for SDM performance management (site 7). The success of financial incentives for patient-reported SDM measurement at sites 1 and 2 suggests that relative advantage is associated with those activities that are rewarded by payers. Another barrier is the perceived patient burden of patient-reported SDM measurement; however, as patient-reported SDM measurement was adopted, those involved found that patients were willing and able to complete the measures without substantial burden (sites 2 and 4).

System readiness for innovation

Finally, a lack of availability of pragmatic patient-reported SDM measures was identified as a barrier to patient-reported SDM measurement, as “it wasn’t until recently that there were clearly very pragmatic tools for measuring patients’ perceptions of shared decision-making” (P09, site 7).

Use of SDM data

Of the organizations reporting routine SDM measurement, benchmarking and internal performance improvement purposes is a common stated use of the data (sites 2, 3, 4, 7). This takes the form of routine reporting of SDM data to heads of relevant clinical departments, including graphics depicting comparative performance and with subsequent feedback to individual clinicians. Site 2 reports substantial and productive clinic-level engagement with this feedback.

One site, however, struggles to find a use for its extensive SDM data that is deemed acceptable by its community of clinicians (site 1). As a payer organization, site 1 finds that its collection of SDM data has

"created a little bit of trepidation" within the clinician community due to a perception that they could "weaponize this information" (P01). The participant explains:

> [Low SDM scores] make the physician look bad and we, as a health plan, could frankly use that information to steer patients away from those kinds of doctors and towards the doctors that get better scores. That's part of the problem with anything when you're collecting data, any type of data. Whether it's shared decision-making data or efficacy data around quality scores or even around outcomes, the perception is that health plans can use that data against them to steer patients away and send them to higher performers. That's the concern from providers and so we have this data. We don't intend on doing that. We don't intend on using the scores in a way to punish or, right now, even provide benefit to those high scorers. We just want to collect the data to better understand shared decision-making. Is the process occurring? How the patients – how are they responding to it? (P01, site 1)

Site 1 aspires to "use the information to try to educate" and offer training to lower-performing clinicians (P01). However, despite a desire to "use it as a mechanism to help educate maybe the lower-scored folks versus the higher-scored folks…[site 1] haven't quite gone there yet" (P01) with regard to training low-scoring providers in SDM.

DISCUSSION

Key findings

In organizations where patient-reported SDM measurement is routine, facilitators include: 1) compatibility of SDM measurement with core organizational values; 2) brevity of the collaboRATE patient-reported SDM measure; 3) trialability (and potential for subsequent expansion) of patient-reported SDM measurement within the organization; 4) flexibility in how measures can be implemented; 5) involvement of both clinical champions and rank-and-file clinicians in the decision to measure SDM performance; 6) an environment in which payers (e.g., health insurance companies) have begun to require provider organizations to measure patients' experiences of SDM; and 7) dedicated resources (i.e. personnel) within the organizations to design and maintain their SDM measurement programs. Barriers include inadequate perceived relative advantage of patient-reported SDM measurement over proxy measures, a paucity of patient-reported SDM measures that are sufficiently pragmatic for routine and widespread use, and the existence of competing priorities for organizational leadership when it comes to patient experience. The few organizations we identified with routine patient-reported SDM measurement tend to use the resulting information for internal benchmarking and quality improvement initiatives. However, site 1, due to constraints unique to payer-only organizations, is still in the process of developing a tenable use of the extensive patient-reported SDM data it collects.

Results in context

Despite policy momentum, routine patient-reported SDM measurement is rare in the US. While it occurs in three of the eight organizations in this rarefied sample, there remains an enormous silent denominator — most of which has yet to consider routine patient-reported SDM measurement. The study team contacted 32 individuals affiliated with the US research and clinical centers known to be active in SDM; this population of active SDM sites is an extremely small subset of the more than 600

health systems and hundreds of additional standalone hospitals and private practices in the US.[25] Underlying the sparse routine use of patient-reported SDM measurement is a US context in which the SDM process is not yet widely rewarded by healthcare payers. There are a few emerging exceptions, including the Centers for Medicare and Medicaid Services requiring documentation of SDM for lung cancer screening.[26] However, such initiatives tend not to differentiate distribution of patient decision aids from an SDM process in which patients and clinicians share information about potential benefits and harms, engage in dialogue about preferences and values, and jointly decide on next steps. The relative advantage of a valid and reliable SDM measure, inclusive of potential data collection costs, over low-cost proxy measures such as extent of decision aid distribution, is therefore currently absent in sites 7 and 8. In settings where the SDM process is already routine, monitoring decision aid distribution can be a helpful proxy; however, measures of the SDM process itself are needed for patient-centered culture change and SDM skill-building. When routine patient-reported measurement of SDM spreads beyond the small number of organizations identified in this study, future research employing network analysis would be helpful to track patterns of diffusion.

This study is the first, to our knowledge, to examine routine patient-reported SDM measurement use cases within the US. Organizations with routine patient-reported SDM measurement programs use a variety of measures, including the SDM Process measure, Decision Quality Instrument, SDM-Q-9, and collaboRATE. The use of patient decision aid access data as a proxy for SDM, adopted by two organizations within this sample, is consistent with proxy measures described by Durand and colleagues as part of recent US healthcare policy related to SDM.[27] However, while "decision and conversation aids can be valuable in facilitating SDM...they are neither necessary nor sufficient for choosing an approach to address each patient's situation."[28] Although decision aid use has been associated with improved decisional outcomes such as reduced uncertainty and higher satisfaction with the decision-making process,[29] direct comparisons of proxy measures to patient-reported and observer-rated SDM in a future study would further elucidate their validity. A recent systematic review assessing the quality of SDM measurement instruments finds generally limited available information on measurement quality of SDM measurement instruments, including for the SDM Process measure, SDM-Q-9, and collaboRATE.[12] More research is needed to critically appraise the psychometric properties of these instruments.

While most uses of patient-reported experience data do not broach the subject of clinician behavior change,[6] some organizations in this sample that conduct SDM measurement provide feedback directly to clinical teams with the intent to enhance clinician skills and modify behavior. Despite systematic review evidence of a positive effect of audit and feedback on clinician performance,[1] recent commentaries have called this relationship into question.[3] Implementation science can inform optimal operationalization of audit and feedback for performance improvement, including pairing feedback with clinician training in SDM, as well as structuring clinical timelines to allow healthcare professionals to address the varied priorities for which they are accountable.[30]

While site 1 appears to benefit from its leverage as a payer organization to facilitate the largest and most robust patient-reported SDM measurement program in this sample, its use of the data is constrained by its role as a payer organization. These constraints relate to perceived distrust between provider organizations and health insurance companies, including a fear that health insurance companies may weaponize performance data to drive patients away from low-performing professionals. Among managed care health plan members, prior research has demonstrated a sense of vulnerability, worry, and fear in relation to health insurance plans[31] — consistent with our current findings focused

on healthcare providers. Overcoming this distrust is critical for health insurance companies to make effective quality improvement use of the data they are well-positioned to collect.

Strengths and limitations

Through the authors' professional networks and a snowball sampling approach, recruitment efforts for this study involved a near-census of major SDM initiatives in the United States. Our snowball sampling recruitment method allowed for insight into organizations on the leading edge of SDM measurement. Through our broad snowball sampling approach, we sought to conduct a thorough search of active SDM researchers and leading SDM practitioners in the US. Data derived from this small but heterogeneous group of institutions did not reach thematic saturation, though we observed several key commonalities as described in the key findings. As this study is an early exploration into routine SDM measurement, we found that the landscape is diverse and currently without consensus. This study therefore presents views of early adopters, relevant even without thematic saturation. However, the multi-modal data collection approach led to varying levels of detail available across included participants and sites, which is a limitation.

Conclusion

Payers have a unique opportunity to encourage emphasis on SDM within healthcare organizations, including routine patient-reported measurement of SDM; however, provider organizations are currently best placed to make effective use of this type of data. Next steps for organizations that choose to pursue routine patient-reported SDM measurement, particularly payer organizations with potential for broad impact, include implementing data use that drives widespread SDM quality improvement.

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Competing interests statement
Glyn Elwyn has edited and published books that provide royalties on sales by the publishers: the books include Shared Decision Making (Oxford University Press) and Groups (Radcliffe Press).
Glyn Elwyn's academic interests are focused on shared decision making and coproduction. He owns copyright in measures of shared decision making and care integration, namely collaboRATE, integRATE (measure of care integration, consideRATE (patient experience of care in serious illness), coopeRATE (measure of goal setting), toleRATE (clinician attitude to shared decision making, Observer OPTION-5 and Observer OPTION-12 (observer measures of shared decision making).
Glyn Elwyn has in the past provided consultancy for organizations, including: 1) Emmi Solutions LLC who developed patient decision support tools; 2) National Quality Forum on the certification of decision support tools; 3) Washington State Health Department on the certification of decision support tools; 4) SciMentum LLC, Amsterdam (workshops for shared decision making).
Glyn Elwyn is the Founder and Director of &think LLC which owns the registered trademark for Option Grids TM patient decision aids; Founder and Director of SHARPNETWORK LLC, a provider of training for shared decision making. He provides advice in the domain of shared decision making and patient decision aids to: 1) Access Community Health Network, Chicago (Adviser to Federally Qualified Medical Centers); 2) EBSCO Health for Option Grids TM patient decision aids (Consultant); 3) Bind On Demand Health Insurance (Consultant), 4) PatientWisdom Inc (Adviser); 5) abridge AI Inc (Chief Clinical Research Scientist).
No other authors declare competing interests.

Data sharing statement
To protect the confidentiality of research participants, interview and survey data will not be made publicly available.

Author contributions
Conception or design of the work: RCF, MJM, AJO, GE
Acquisition, analysis, or interpretation of data: RCF, JAE
Drafting the work: RCF
Critically revising the work: JAE, MJM, AJO, GE
Final approval of submitted version: RCF, JAE, MJM, AJO, GE

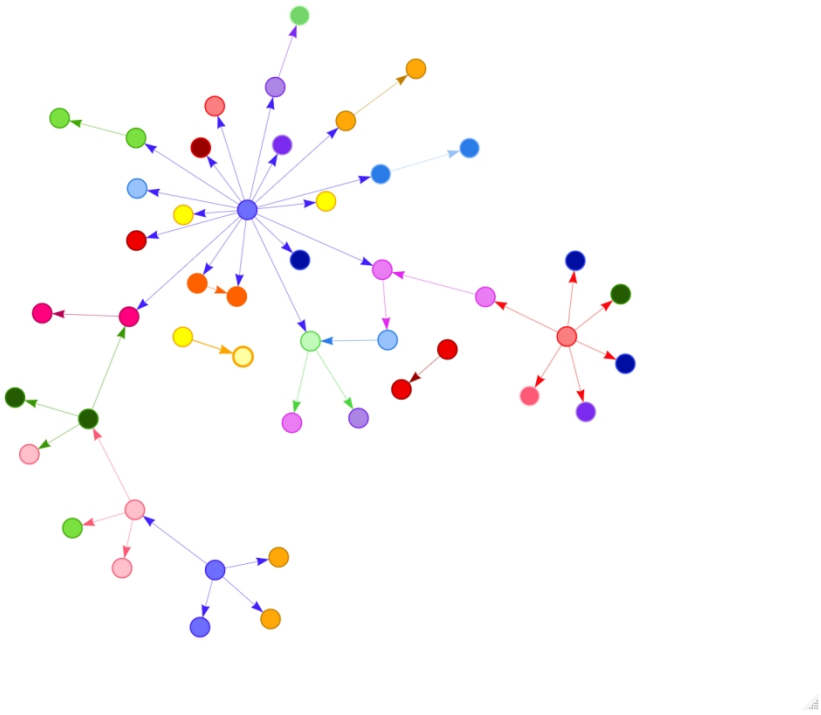

Figure 1. Recruitment process and snowball sample referral network, colored by organization [a, b]

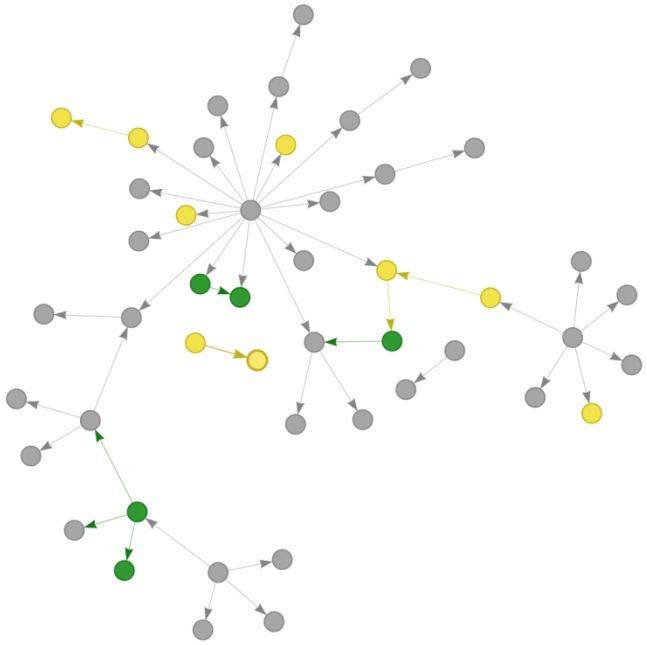

Figure 2. Recruitment process and snowball sample referral network, colored by organization's SDM measurement status [a, c]

APPENDIX 1. Interview guide

ORGANIZATION'S CURRENT DATA COLLECTION

- To start, could you tell me about patient experience measurement in general in your organization?
    - Which patient-reported experience measures does your organization collect?
        - What constructs are measured?
        - How were those measures decided upon?
    - Can you provide a little background on your organization?

- Which patient-reported measures specific to shared decision-making does your organization collect?
    - Does this vary within your organization?
    - How was/were the measure(s) selected?
        - Who chose the measures? What criteria did they consider?
        - What advantages do they convey?
        - Are there any disadvantages to consider?

- Why did your organization decide to measure SDM?
    - What need does it fill?
    - What advantages does it convey?
    - What prompted the decision?
    - What was the original intended use of this data? Why?
    - Do you have a formal logic model?

- Please describe the process by which your organization administers SDM measures.
    - Is there a formal protocol/SOP for SDM measurement?
    - Does this vary within your organization?
        - Is there opting in/out? Are there differences between those who participate and those who do not?
        - How are opt-in/out decisions made?

- Do you consider patient-reported SDM measurement to be a routine part of healthcare operations in your organization?
    - Does this vary by department/area?
    - If not, what would it take for your organization to routinely measure SDM?
    - If so, how did SDM measurement get to be routine?
    - What in your organization is a barrier or challenge to routine patient-reported SDM measurement?
    - What in your organization facilitates routine patient-reported SDM measurement?

- How often does your organization conduct SDM measurement? Is it ongoing?
    - How often are data collected? E.g. monthly sampling, annual sampling.

- Approximately how many [annual/monthly/other] patient responses do you/your organization gather for each SDM measure we've discussed?
    - How do you decide how many responses to collect?

- What resources go into SDM measurement in your organization? [Financial, human, other]

- Where do these resources come from?
- How does the organization decide to use them in this way?

- What concerns about SDM measurement have you heard in your organization? Who voices these concerns?
  - In early stages?
  - In later stages?

- Does SDM measurement have a 'champion' within your organization?
  - How did this champion emerge? What motivates him/her?
  - Does this person have dedicated time/resources for SDM measurement within his or her official role?

- Are there any efforts to evaluate the SDM measurement process within your organization?
  - What would be considered a successful outcome of SDM measurement?

USE OF DATA COLLECTED

- How does your organization use the data it collects about shared decision-making performance?
  - Are the data fed back or disseminated in some way?
    - To whom? Clinicians? Managers? Patients? Administrators? Insurers?
    - Are any interventions offered where low performance is identified?
  - Is there a formal protocol/SOP for feedback of SDM data?
  - How long has your organization been using SDM performance data in this way?
  - Is this use of SDM performance data uniform across your organization, or do different departments/areas use the data differently?
  - Did SDM measurement and feedback begin at the same time, or did it happen in stages?
  - What resources go into this use of SDM performance data? [Financial, human, other.]
    - Where do these resources come from? How does the organization decide to spend them in this way?
  - How did the organization come to use the data this way?
    - Whose idea was it?
    - How did they make it happen?
    - Was [or is] organizational leadership involved?
      - At what level/stage and in what capacity?
    - Who is involved in implementation?
  - What in your organization is a barrier or challenge to feeding back patient-reported SDM data for performance improvement?
  - What in your organization facilitates feeding back patient-reported SDM data for performance improvement?

[IF DATA ARE FED BACK:]

- What does the feedback look like?
  - How often is feedback provided/to whom?
  - Is it a report? A single number? Graphics? Text?
  - How is it delivered? Email? Online? Paper format? Phone?
  - Who designed the feedback's format?
  - Who generates the feedback?
    - Is it automated?

- Why did your organization decide to start providing feedback?
  - What need does it fill?
  - What advantages does it convey?

- When your organization first started providing patient experience/SDM feedback, how did recipients of the data initially react to it?
  - Have their reactions changed since you started providing feedback?

- Did feedback recipients receive any priming or training prior to starting to receive the feedback?
  - Is SDM training/resources available to recipients after they receive feedback?

- Has your organization seen changes in SDM performance since it started feeding back data on patient experience of SDM?

- Has your organization seen changes on any [other] quality or health outcomes since they started feeding back data on patient experience of SDM?
  - Have you seen changes resulting from any non-SDM related patient feedback?

RECRUITMENT

- I'm hoping to get perspectives on patient-reported SDM measurement from clinicians, clinical staff, administrators, and researchers. Are there others in or outside your organization who you'd suggest I speak with about patient-reported measurement of shared decision-making?
  - What is the best way for me to get in touch with them?

DEMOGRAPHICS

Before we wrap up, I'd like to get some background information about you and your organization.

- What is your job title?
  - In a sentence or two, how would you describe your role as it relates to patient experience measurement in your organization?

- What is your educational background?
  - When did you finish your terminal [and/or most recent] degree?

- How long have you worked at your current organization?
  - How long have you been in your current position?

- I won't use your name in any reports or presentations about this project. How would you like me to refer to your organization? [By name, by description - looking for specific wording.]

- How large is your organization? [Beds, employees]

- How would you describe your patient population?

OTHER

- Is there anything else you'd like to share about patient experience measurement at your organization?

Your organization's SDM measurement:

Which patient-reported measures specific to shared decision-making does your organization collect? How are they administered?

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_____

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How were the measures selected?

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Why did your organization decide to measure shared decision-making?

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_____

Approximately how many patient reports about shared decision-making does your organization gather each month/year?

_____

What, if any, concerns about shared decision-making measurement have you heard within your organization? Who voices these concerns?

_____

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How does your organization use the data it collects about shared decision-making performance?

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What is the name of your organization?

_____

How may I refer to your organization in reports about this research? (E.g. by name, a brief description, etc.)

_____

_____

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Appendix 3. Patient-reported SDM measures used in this sample

SDM-Q-9	**collaboRATE**	**Decision Quality Instrument** [a]
My doctor made clear that a decision needs to be made. My doctor wanted to know exactly how I want to be involved in making the decision. My doctor told me that there are different options for treating my medical condition. My doctor precisely explained the advantages and disadvantages of the treatment options. My doctor helped me understand all the information. My doctor asked me which treatment option I prefer. My doctor and I thoroughly weighed the different treatment options. My doctor and I selected a treatment option together. My doctor and I reached an agreement on how to proceed.	How much effort was made to help you understand your health issues? How much effort was made to listen to the things that matter most to you about your health issues? How much effort was made to include what matters most to you in choosing what to do next?	How important is it to you to… - relieve your [specific type of] pain? - not be limited in what you can do because of your [specific type of] pain? - avoid a treatment with a long recovery time? - avoid having [specific type of] surgery? - avoid taking pain medicine for a long time? Which treatment do you want to do to treat your [condition]? [Five knowledge items specific to the patient's health condition and possible treatment options] Did any of your health care providers talk about [specific type of] surgery as an option for you? How much did you and your health care providers talk about the reasons to have [specific type of] surgery? How much did you and your health care providers talk about the reasons **not** to have [specific type of] surgery? Did any of your health care providers talk about non-surgical treatments as something that you should seriously consider? Did any of your health care providers ask you whether you wanted to have [specific type of] surgery or not?

[a] See [23] and [24] for full condition-specific instruments.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3
Purpose or research question - Purpose of the study and specific objectives or questions	3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	3-4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4
Context - Setting/site and salient contextual factors; rationale**	4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	3-4
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4-5

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4, 18-21
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	4

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	13-14
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	9-13

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	13-14
Limitations - Trustworthiness and limitations of findings	15

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	17
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	17