

Challenges to Engaging Patients in Healthcare Implementation and Promising Solutions: An Environmental Scan

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Abstract

Background: Inequities exist in delivery of helpful, effective healthcare interventions. One emerging paradigm to address these inequities is to engage consumers of healthcare (e.g., patients, families, caregivers) in the implementation process. There are not enough examples or standards of successful consumer engagement in implementation, which limits clarity on processes other implementers could be using. Implementation scientists need a clear foundation from which to build processes or strategies with more specificity to engage consumers in healthcare settings.

Methods: We conducted an environmental scan of three data sources: archived webinars, literature review articles, and interviews/observations with implementers who engaged consumers in efforts to introduce new programs and practices in healthcare settings. We described examples of consumer engagement in implementation efforts, categorized recurring challenges, and identified promising solutions to those challenges. We extracted and categorized data using a coding template informed by frameworks from implementation science and stakeholder engagement literature.

Results: We found 26 examples of consumer engagement in implementation of healthcare service delivery (through research or clinical practice), mostly in the United States. Most implementers engaged consumers using a medium level of intensity. These projects described nine recurring challenges; the three most frequently identified were: 1) recruiting consumers representative of actual patients served in the healthcare system; 2) ensuring processes that allow for equitable communication among all stakeholders; and 3) retaining consumers in implementation efforts. We also matched promising solutions described by implementers to recurring challenges in consumer engagement in implementation.

Conclusion: We clarified the foundation of who, how, and where a sample of implementers are engaging consumers in healthcare implementation initiatives. A notable finding is implementers rarely specified if they were targeting a patient population experiencing healthcare inequities.

Contributions To The Literature

- Sampled a variety of data sources to identify 26 examples of who, how, and where implementers are engaging consumers in healthcare implementation initiatives (a topic gaining interest in implementation science)
- Clarified nine recurring challenges to consumer engagement in implementation, matched with promising solutions from implementers, which is useful to implementation scientists and practitioners
- Most implementers are using a medium level of intensity to engage consumers / patients—soliciting their feedback, perhaps repeatedly, yet not establishing collaborations

Introduction

Background

Healthcare disparities in the United States (U.S.) are significant differences in access to, receipt of, or quality of healthcare interventions between groups, not due to selection bias and rooted in social injustice.[1, 2] Healthcare disparities occur when one group, who typically experiences societal disadvantage, receives an effective healthcare intervention at lower rates or with poorer quality compared with another group. One example concerns implementation of HIV prevention medicine among Black and African American individuals. Black and African American individuals with certain risk factors (e.g., multiple sex partners) are at increased risk of acquiring HIV.[3] However, HIV prevention medicine[4] is delivered less often to Black and African American individuals compared to White people.[5]

There are many proposed solutions to reducing healthcare disparities, including using implementation science to increase equitable delivery of effective healthcare interventions.[6] In implementation science, scientists and practitioners use and/or study multilevel strategies to overcome barriers to uptake of an intervention in provider, clinic, hospital, or organizational

domains.[7] Implementation scientists recently have begun to elucidate purposeful ways to understand[8] and intervene upon healthcare disparities.[9] One emerging paradigm to reduce healthcare disparities within implementation science is to engage communities and consumers in the implementation process.[10] Consumers are end-users or recipients of a healthcare intervention, including patients, caregivers, or families. This study documents examples of, challenges of, and solutions to consumer engagement in implementation efforts, with an additional focus on those who experience disparities in a certain area of health care.

Consumer Engagement in Implementation Science

Some studies have demonstrated how engaging consumers who experience health disparities in participatory research approaches, such as community-based participatory research (CBPR), may lead to improved health at individual and population levels.[11–13] Implementation scientists have roles to play in using participatory approaches to reduce healthcare disparities.[14] Within implementation science, however, there are not many well-documented examples of how consumer engagement might change implementation strategies or outcomes. Consumers have been engaged in quality improvement initiatives or in the health promotion field for much longer,[15, 16] although these types of consumer engagement have not yet “translated” robustly to implementation science yet. Consumer engagement in implementation strategies might involve consumers serving on quality improvement advisory boards, consulting on intervention marketing, or participating in practice “walk throughs” of an intervention to troubleshoot service delivery issues. A variety of implementers—researchers, quality improvement personnel, facilitators—select and tailor implementation strategies, but rarely are consumers involved in this important process.[17]

Existing research on engaging consumers in the implementation process is limited, and is also known as co-created integrated knowledge translation,[18, 19] participatory implementation science,[20] or community engaged dissemination and implementation.[10] The limited work on this topic shows preliminary benefits: a better intervention fit for the patient population,[9] systems redesign that is more patient-centered,[21] greater use of effective healthcare interventions in community settings,[22] improved patient health behaviors and outcomes, [23] and increased sustainment of an intervention.[24] The intensity and process of engaging consumers falls on a continuum,[25] from implementers reaching out to share information with consumers (outreach is unidirectional) to shared power or decision making between consumers and implementers based on mutual benefit, longer-term commitments, and trust (engagement is bidirectional). [26] A recent systematic review identified consumer engagement to improve quality of health care.[27] Authors concluded that unidirectional consumer engagement (e.g., consultation) usually led to more discrete products, like a toolkit, whereas collaborative and co-created consumer engagement usually led to changes in care process or structural outcomes.[27]

Delafield and colleagues also used consumer engagement principles to implement an intervention, but main stakeholders were not patients or end users, rather, they were representatives from community-based organizations.[28] Other researchers evaluated a national effort in Ireland to engage consumers in primary care, and concluded that one major barrier to consumer engagement was “confusion and debate among stakeholders about what this ‘thing’ is exactly.”[29] Authors reported limited understanding for stakeholders on what consumer engagement meant or why it was important. They found limited understanding was partially because of varied terminology regarding consumer engagement, which was complicated by different cultures of healthcare disciplines and settings. Clearly, there are not enough examples or standards of successful consumer engagement in implementation, which limits clarity on processes other implementers could be using.

One logical next step in this work is to provide more clarity and guidance to facilitate consumer engagement in implementation initiatives and research, specifically what, when, where, how, and why an implementer might engage consumers who experience healthcare disparities in implementing or redesigning services.[30] To provide clearer standards for consumer engagement in implementation, we must first systematically document existing work to create a foundation on what exists and works already, especially for consumers experiencing healthcare disparities.

Current Study

Lack of synthesis and standards makes it difficult to engage consumers in implementation initiatives and evaluate impact of consumer engagement on reducing healthcare disparities. We conducted an environmental scan of various data sources to identify consumer engagement in implementation initiatives and research, document challenges and solutions related to its use, and plan for developing guidance for implementers to engage consumers.

Methods

Design and Procedures

Environmental scanning is an assessment method to document a phenomenon of interest and can assist in data-driven planning, making it a good fit for the nascent state of science on consumer engagement in implementation initiatives.[31, 32] Such scans involves using a single data source [e.g., literature review[33] or survey[34]] or multiple data sources using a variety of methods [e.g., review by advisory committees, analysis of existing datasets, physical observations [35]]. In this scan, we collected data from these sources: published literature, webinars, and interviews with or observations of workgroups of implementers who were researchers or professionals who included consumers in healthcare implementation, quality improvement, or systems redesign.

Choo [36] described categories of environmental scanning; we used “searching” and “conditioned viewing.” Searching involves using well-defined search goals to “actively intrud[e] into the environment to collect an accurate set of facts.”[36] In searching, we actively sought out certain environments to gather data (i.e., interviewing or observing implementation experts). Conditioned viewing represents a “passive” approach to data gathering, with less intrusion on the environment than searching,[36] using methods “based on widely-accepted industry assumptions and norms.”[36] The data gathered through viewing are “conditioned” because they derive from existing procedural archives. Our conditioned viewing data sources were data representing health research standards (i.e., literature reviews, archived webinars). Our approach to data synthesis was open, anticipating newly identified gaps, and willing to revise existing knowledge.[36]

Inclusion and exclusion criteria

We conducted our search May 2019 - May 2020. We set these *a priori* parameters as inclusion criteria for data sources: 1) consumers were engaged in implementation, service delivery, systems redesign, or quality improvement of an intervention, and could be engaged in dissemination if it was used as an implementation strategy; 2) the implementation activity focused on a health problem (e.g., diabetes prevention, behavioral health care); 3) service delivery was conducted partially or completely in a healthcare setting (e.g., hospital, private practice); and 4) the study or activity used descriptive, qualitative, quantitative, or mixed-methods research. A case was excluded if: 1) the study or activity engaged consumers only in research, not in any implementation or quality improvement activity; 2) the focus of the study or activity was on individual or direct care that may only result in changes for that individual's health or health care; 3) the study or activity focused on guideline development, instrument development, or broader organizational issues (e.g., theoretical or conceptual articles, protocol papers); or 4) the study was a literature review.

Data Sources and Theoretical Frameworks

From each case that met inclusion criteria, we extracted and categorized data using a coding template. We created our coding template using domains from two theoretical frameworks—one from stakeholder engagement literature[25] and one from implementation science and health equity research.[8] The stakeholder engagement framework depicts the continuum of levels at which researchers engage consumers, including methods that are not truly engagement, to symbolic participation, to engaged participation, as described in Table 1.[25] We slightly adapted the framework to be about implementers and consumers rather than researchers and community stakeholders, and the activities to be about implementation rather than research.

Table 1

Classifications of intensity of consumer engagement in implementation initiatives adapted from Goodman and Sanders Thompson (2017)

Non-Participation	<p>Outreach: Implementers develop, implement, and evaluate strategies to reach target populations. Consumers of target population (gatekeepers) can be engaged as advisors and make key connections.</p>
	<p>Education: Implementers try to educate consumers about a topic (e.g., gain audiences for education sessions).</p>
Symbolic Participation	<p>Coordination: Implementers gather consumers to inform elements of a study or activity. Consumers give feedback, which informs implementers' decisions, but it is the implementers' responsibility to design and implement the study with no help expected from consumers. Implementation activities are strengthened through community outreach, and results are disseminated through community groups and gatekeepers.</p>
	<p>Cooperation: Implementers ask consumers for help, instead of just asking for advice. There is some activity on the part of consumers in defined aspects of the project, including recruitment, implementation of interventions, measurement, and interpretation of outcomes. Consumers are ongoing partners in decision-making. Consumer understanding of implementation and its potential importance is enhanced through participation in activities.</p>
Engaged Participation	<p>Collaboration: Implementers and consumers are actively involved in the design and implementation of a study or activity and interpretation of findings. All stakeholders benefit from working together, including increased capacity of consumers to engage in implementation activities. Consumers collaborate in decision-making and resource allocation with an equitable balance of power that values their input.</p>
	<p>Patient-Centered: Patients, caregivers, or advocacy groups assume responsibility for priority setting for research or activities, control design and implementation of activities, and manage interpretation and dissemination of findings. Implementers use expertise to move these things along, but consumers make all major decisions. Systems are in place for patient participation at all engagement levels. Consumers can engage in collaborations with equitable balance of power for governance and strong level of accountability to public/ community.</p>
	<p>CBPR: CBPR is the population health approach to the patient-centered engagement level. The principles of CBPR are applied to implementation, highlighting trust among partners, respect for each partner's expertise and contributions, mutual benefit among all partners, and a community-driven collaboration with equitable and shared decision-making.</p>

The Health Equity Implementation Framework highlights domains relevant to implementation and healthcare disparities. The innovation, or the intervention being implemented, is delivered in the clinical encounter, which is the interaction between recipients (e.g., patient and provider) and the intervention (e.g., HIV prevention medication). Healthcare settings include inner context (local—clinic or unit or ward, and organizational—hospital) and outer context (network or entire system). Societal influence includes, but is not limited to, economies, sociopolitical forces, and physical structures. Economic factors include how goods and services are exchanged (e.g., insurance, cost of services); sociopolitical forces include policies and social norms affecting implementation (e.g., Black Lives Matter, policy mandates); and physical structures include the built environment (e.g., proximity to clinic, safe walking paths). Implementation facilitation, or facilitation, is an essential active process to ignite change in any domain.[37, 38]

We used the coding template in Additional File 1 to extract information on examples of consumer engagement in implementation, challenges, and solutions, and Health Equity Implementation Framework domains (e.g., which innovation was being implemented? What sociopolitical forces were relevant?). We used the coding template to classify each example according to Goodman and Sanders Thompson's (2017) levels described in Table 1.

Literature Review

For one data source in this environmental scan, we conducted a narrow, systematic literature review on consumer engagement in implementation activities. We did not complete a full systematic review because 1) our goal was to scan the environment, rather than be exhaustive in identifying every possible data source, and 2) a review on consumer engagement in quality improvement of health care had recently been published by Bombard and colleagues in 2018.[27] Therefore, we

narrowed our literature search to two databases not explicitly searched by Bombard and colleagues: The Patient-Centered Outcomes Research Institute (PCORI) Health Research Literature Explorer[39] and the Veteran's Health Administration (VHA) Behavioral Health QUERI Implementation Facilitation Scoping Review. The latter scoping review was conducted by Smith and colleagues[40] of published articles on implementation facilitation. We chose to use the scoping review database as one source because, in our future work, we will specifically incorporate consumer engagement into implementation facilitation methods.

From the PCORI literature explorer tool online, we expanded on the Bombard and colleagues[27] review by including articles through May 2019. We screened articles under the categories "dissemination" or "translation" for phases of research; then, we screened articles under the categories "patients" and/or "caregivers" for stakeholder involvement. The search process PCORI used to identify articles in the literature explorer is available online.[39] From the VHA Behavioral Health QUERI Implementation Facilitation Scoping Review, we screened every article and did not use search terms to narrow the sample.

Per Fig. 1, Coder 1 (ENW) searched the QUERI review, and Coder 2 (AMC) searched the PCORI literature explorer. Before screening, Coders 1 and 2 practiced screening random samples from both databases until reaching 80% consensus. First, we screened titles and abstracts and imported selected articles into *Covidence*. [41] Next, coders screened full texts and simultaneously extracted data from included articles. Both coded separately using the template described above.

Webinars

We also searched VHA Health Services Research and Development archived webinars. We selected this data source in VHA because our work is predominantly within this healthcare system. We followed a similar systematic search strategy as used in the literature review. We search these terms in webinar titles:

1. "patient", "user", "client", "consumer", "veteran", "caregiver", "partner", OR "family" AND
2. "engag*", "participat*", "involv*", OR "consult*".

We searched webinars archived from the earliest possible date (January 1, 2015) through May 28, 2019. Prior to screening, Coders 1 and 2 independently screened a random sample for practice until 80% consensus was met. Using the inclusion/exclusion criteria as in the literature review, there were 115 webinars. Coder 1 screened 30% and Coder 2 screened 70% of 112 webinar titles and identified 32 webinars for possible inclusion. Coders screened those 32 webinar abstracts, reduced the sample to 12 webinars and reviewed their verbatim transcripts. Coders included four webinars in the final sample and extracted data using the coding template.

Implementers

Implementers were researchers or healthcare professionals who engaged consumers in implementation activities. We recruited from professional organizations with an implementation science affiliation in the U.S where we undertake much of our work (e.g., the Implementation Research Institute, Mentored Training for Dissemination and Implementation in Cancer) and solicited implementers recruitment using Twitter. Some individuals responded to this solicitation to declare interest in participation, or to notify us of another person that might be important to sample. Using snowball sampling, we reached out to those additional individuals. We also solicited workgroups that focused on consumer engagement in implementation efforts. After one round of interviews and data analysis, we did not feel we had saturated results, so we conducted a second round of recruitment until we interviewed enough implementers to saturate qualitative results.

We sent implementers an electronic survey about engaging consumers in implementation activities. Sample questions included: "What were the roles of patients or other consumers in implementation? What problems did you encounter and how did you solve them?" (see Additional File 2 for survey). Coders 1 and 2 reviewed completed surveys, and when there were follow up questions, they scheduled a 30- to 45-minute telephone interview. Some implementers opted to complete the survey; a telephone interview; or both. Thirteen implementers contacted us, four were lost to follow-up, one declined

participation, and one was not eligible. We reached out to three workgroups of implementers, one declined to participate, and one was not eligible. We included one workgroup observation and seven individual surveys/interviews in our final sample, counting as eight total implementer cases. Coders used interview or observation notes and surveys from each case to populate a coding template.

Data Integration and Analysis

Once cases from all data sources were extracted into coding templates, Coders 1 and 2 discussed each example to organize them by consumer engagement level and a third coder (JEK or CW) resolved disagreements. Coders synthesized data in two matrices: a descriptive matrix and a consumer engagement categorization matrix. The descriptive matrix delineated Health Equity Implementation Framework domains (e.g., inner and outer contexts in which implementation took place, whether populations experiencing health disparities were engaged). The consumer engagement categorization matrix organized all examples identified by consumer engagement level from Goodman and Sanders Thompson, e.g., outreach, cooperation, patient-centered.[25] In the final step, Coders 1 and 2 reviewed extracted data for recurring challenges, grouping them into themes, with 100% agreement. They extracted every potential solution and resource for engaging consumers in implementation efforts.

Results

Description of Data Sources of Consumer Engagement in Implementation

All data sources originated in the past decade—see Table 2. For We included seven literature articles, published between 2009 and 2017. We included four webinars, presented between 2016 and 2018. We surveyed eight implementers (including one workgroup) across healthcare settings.

Table 2

Descriptions of all Consumer Engagement in Implementation Initiatives Examples from Environmental Scan, Described Using Health Equity Implementation Framework Domains^a

Data Source	Innovation	Consumer Recipients	Provider/ Staff Recipients	Inner Context and Outer Context	Societal Influences ^b	Population with Health Disparity? ^c
Articles from Literature Review						
Absolom 2015	Electronic medical record tool	Cancer patients (outpatient)	Cancer care providers	Unspecified clinics in UK National Health Service ^c	Sociopolitical: (+) UK policy essentially required consumer engagement for funded research	Not specified
Angstman 2009	Several	Primary care patients or parents of patients	Primary care providers and staff	One primary care clinic; Network of clinics in Minnesota	Not specified	Not specified
Duong 2015; Eriksson 2013	Bundle of prenatal and neonatal survival interventions	Pregnant women and their newborn infants	Healthcare providers and staff including midwives	Health centers in eight geographic districts with 90 communes in Quang Ninh province, northern Vietnam	Sociopolitical: (-) Seen as "women's" issues not warranting assistance from men; Economic: (-) Inadequate health care coverage; Physical structures: (-) Topographical challenges in route to care e.g., poor roads, mountains	Extremely rural dwelling, low income, and some ethnic minority consumers
Norman 2013	Several	Several	Healthcare providers	Unspecified clinics in Colorado; Single U.S. healthcare system	Not specified	Rural and frontier communities

Note. *a.* Domains are from the Health Equity Implementation Framework (e.g., innovation, societal influences), although one domain, the clinical encounter, is omitted because no factors in this domain were identified in data collection. *b.* Societal influences could include: Sociopolitical factors (e.g., laws, policies), Economic factors (e.g., insurance), or Physical Structures (e.g., the built environment, signs, location of health care). (+) = this factor was a facilitator or strength for implementation. (-) = this factor was a barrier or deterrent for implementation. *c.* Health disparity population is defined as a group that experiences disparities in health outcomes or access to or quality of health care in within a certain health condition (e.g., HIV). *d.* All locations based in the United States unless noted otherwise. UK = United Kingdom. VHA = Veterans Health Administration in the United States.

Data Source	Innovation	Consumer Recipients	Provider/ Staff Recipients	Inner Context and Outer Context	Societal Influences ^b	Population with Health Disparity? ^c
Pérez Jolles 2017	Mental health services for youth	Parents of youth with mental health needs	Mental health care staff and directors	One mental health clinic in North Carolina	Sociopolitical: (+/-) Values of immigrant cultures affect perception of U.S. health care	Latino families who were less likely to access mental health services. Spanish speaking (some bilingual)
Tapp 2017	Shared decision-making toolkit	Patients with asthma	Healthcare providers	Many types of clinics; Practice based research network and advanced Medicaid network in North Carolina	Not specified	Yes, not specified
Webinars						
Asch 2018	HIV testing	Patients at high risk for HIV	Primary care providers in VHA	Primary care clinics in selected regions in VHA healthcare system	Sociopolitical: (-) Stigma about HIV risk behavior makes it harder to reach people at high HIV risk	Not specified
Elwy 2018	Several	Several	Several	Implementation research centers; VHA healthcare system	Not specified	Not specified
LaChappelle et al., 2017	Several	VHA patients	VHA providers	Geographic regions: Denver, Houston, Iowa City catchment areas; VHA healthcare system	Sociopolitical: (-) Unsure how to disseminate information to policymakers	Yes, several
Fehling et al., 2016	Several	VHA patients	Not specified	Research Centers of Innovation; VHA healthcare system	Not specified	Yes, several
Implementer Interviews / Observations						

Note. *a.* Domains are from the Health Equity Implementation Framework (e.g., innovation, societal influences), although one domain, the clinical encounter, is omitted because no factors in this domain were identified in data collection. *b.* Societal influences could include: Sociopolitical factors (e.g., laws, policies), Economic factors (e.g., insurance), or Physical Structures (e.g., the built environment, signs, location of health care). (+) = this factor was a facilitator or strength for implementation. (-) = this factor was a barrier or deterrent for implementation. *c.* Health disparity population is defined as a group that experiences disparities in health outcomes or access to or quality of health care in within a certain health condition (e.g., HIV). *d.* All locations based in the United States unless noted otherwise. UK = United Kingdom. VHA = Veterans Health Administration in the United States.

Data Source	Innovation	Consumer Recipients	Provider/ Staff Recipients	Inner Context and Outer Context	Societal Influences ^b	Population with Health Disparity? ^c
Implementer 1	Health communication and information tools	Patients and/or their caregivers	Clinicians; clinician researchers; health managers	Unspecified clinics; Single Canadian healthcare system	Economic: (-) Financial honorariums needed for immigrant consumers	Recent immigrants
Implementer 2	Several	Several	Clinic and quality improvement leaders; Community health advocates	12–26 clinics in in Washington, California, Oregon; Single U.S. integrated health care system, Federally Qualified Health Center system, or two Medicaid managed care insurance plans	Economic: (-) Challenges working with insurance payers	Low income
Implementer 3	Evidence based psychotherapy	VHA patients exposed to traumatic events	Mental health providers, clinic administrators	Several mental health clinics in one VHA hospital in Massachusetts	Not specified	Not specified
Implementer 4	Notification letter informing parents their children were being placed on a treatment waitlist	Parents of children with mental health concerns (children were patients)	Mental health providers, administrative assistant	One outpatient mental health clinic; Private university hospital in New York	Economic: (-) Having public insurance made it hard to find other providers, so waitlist notification was even more upsetting to families because they did not have other options. (+) Implementation initiative funded by a health foundation because it would not otherwise be billable by insurance	People of color

Note. *a.* Domains are from the Health Equity Implementation Framework (e.g., innovation, societal influences), although one domain, the clinical encounter, is omitted because no factors in this domain were identified in data collection. *b.* Societal influences could include: Sociopolitical factors (e.g., laws, policies), Economic factors (e.g., insurance), or Physical Structures (e.g., the built environment, signs, location of health care). (+) = this factor was a facilitator or strength for implementation. (-) = this factor was a barrier or deterrent for implementation. *c.* Health disparity population is defined as a group that experiences disparities in health outcomes or access to or quality of health care in within a certain health condition (e.g., HIV). *d.* All locations based in the United States unless noted otherwise. UK = United Kingdom. VHA = Veterans Health Administration in the United States.

Data Source	Innovation	Consumer Recipients	Provider/ Staff Recipients	Inner Context and Outer Context	Societal Influences ^b	Population with Health Disparity? ^c
Implementer 5	Diabetes self-management program	Latino diabetes patients or those at risk for diabetes	Clinic managers, community health worker, providers	One community clinic in New Mexico; No larger healthcare system	Economic: (+) external funder that valued community engagement	Immigrants, Latino ethnicity, mainly Spanish speaking, mainly low income
Implementer 6	Several	VHA patients	VHA providers and staff	Seven community clinics and three larger hospitals in California; VHA healthcare system	Physical structures: (-) difficult for some to get to meetings due to lack of affordable or easy transport	People of color
Implementer 7	Several (substance use or mental health focus)	VHA patients in recovery who used VHA addiction and/or mental health services	VHA providers and staff	Selected clinics in VHA healthcare system	Not specified	Primarily Black and Latino
Implementer 8	Several	VHA patients	Not specified	Hospitals and clinics; VHA healthcare system	Sociopolitical: (+) U.S. military culture facilitates teamwork. Economic: (-) Limited financial resources	Not specified
<p>Note. <i>a.</i> Domains are from the Health Equity Implementation Framework (e.g., innovation, societal influences), although one domain, the clinical encounter, is omitted because no factors in this domain were identified in data collection. <i>b.</i> Societal influences could include: Sociopolitical factors (e.g., laws, policies), Economic factors (e.g., insurance), or Physical Structures (e.g., the built environment, signs, location of health care). (+) = this factor was a facilitator or strength for implementation. (-) = this factor was a barrier or deterrent for implementation. <i>c.</i> Health disparity population is defined as a group that experiences disparities in health outcomes or access to or quality of health care in within a certain health condition (e.g., HIV). <i>d.</i> All locations based in the United States unless noted otherwise. UK = United Kingdom. VHA = Veterans Health Administration in the United States.</p>						

We identified 26 examples of consumer engagement in implementation of healthcare service delivery (either through research or routine clinical practice), in the U.S. or Canada. We identified nine recurring challenges and promising solutions.

Levels of Consumer Engagement in Implementation

Most examples featured implementers engaging consumers in coordination (see Fig. 2). Coordination, a mid-tier consumer engagement level per Goodman and Sanders Thompson (2017), typically involved convening consumers for provision of unidirectional feedback, often in groups.

Coordination entailed more purposeful connection and active solicitation of information from consumers than outreach or education yet was limited in its work *with* consumers in which they might assist with tasks (e.g., cooperation) or be decision makers in an implementation effort (e.g., collaboration, CBPR). See Table 3 for all examples.

Table 3

Examples of Consumer Engagement in Implementation Initiatives by Intensity Level of Consumer Engagement identified in an environmental scan

Data Source	Consumer Engagement Level
	Outreach Example (n = 1)
Implementer 1	Used community organizations and service providers to reach and engage consumers in implementation activities. Also used network connections with other colleagues to reach consumers.
	Education Example (n = 1)
Implementer 1	Hosted engagement events to educate consumers on health communication and information tools to manage chronic diseases.
	Coordination Examples (n = 13)
Asch 2018 (Webinar)	Involved a patient representative on a grant-funded implementation project series, ranging from identifying current variation in implementation practice to implementing an innovation.
Elwy 2018 (Webinar)	Involved patients through steering committees and advisory boards in guiding development of implementation research and/or disseminating findings from implementation research.
LaChapelle 2017 (Webinar)	Coordinated a recurring, monthly patient engagement group that consults with researchers (some of whom study implementation). Researchers presented to patient engagement group and get feedback on their research at the idea generation stage through study completion, all the way to the dissemination stage.
Fehling 2016 (Webinar)	Coordinated a patient engagement group described above in LaChapelle 2017.
Implementer 8	Organized patients who were involved in research studies (some of which were implementation) to attend a national conference and present at talks and station an informational table. The patients' goals at the conference were to disseminate findings, answer other researchers' questions in group discussions, and market the value of patient consumers in implementation research to more researchers.
Absolom 2015 (Literature article)	Patients on a research advisory group were involved in usability testing of a web interface and providing feedback.
Implementer 1	Used input from patient focus groups and a patient advisory group to develop tools for accessing information about certain health conditions and design new care pathways in a healthcare system. Also used input from patient focus groups for implementation planning, e.g., "we work with consumers [patients] to develop outcome measures that are meaningful to patients."
Implementer 2	Interviewed and selected patients to serve as advisors and co-investigators on a patient advisory group for quality improvement and implementation initiatives.
Tapp 2017 (Literature article)	Engaged up to sixteen patients on a patient advisory board who participated in one or more of implementation study phases: study design, approving protocols, intervention implementation, study management, data analysis, or dissemination.
Implementer 3	Consumers engaged as patients in adapting use of evidence-based psychotherapy in routine care and after treatment, providing feedback via qualitative interviews on feasibility, acceptability, and suggested adaptations of the psychotherapy.

Note. Categorized according to Goodman and Sanders Thompson's (2017) stakeholder engagement framework.

Data Source	Consumer Engagement Level
	Outreach Example (n = 1)
Angstman 2009 (Literature article)	Parents of child patients were engaged in a patient advisory group with an interest in improving healthcare for a clinic.
Perez Jolles 2017 (Literature article)	For children's mental health efforts, a parents advisory group met every three months provided input on implementation research protocols, implementation decisions in the context of a study, interpreted findings, and suggested next steps.
Implementer 4	For children's mental health services, an outside agency helped one clinic form a clinic-family advisory council. This council engaged in workshops together to brainstorm projects for improving healthcare delivery at their clinic. Once they selected projects to improve care, clinic staff carried out most steps to implement changes and reviewed these with families from the council periodically. Everyone had input and the clinic director had final approval.
Data Source	Consumer Engagement Level
	Cooperation Examples (n = 5)
Elwy 2018 (Webinar)	Consumers disseminated information about implementation studies and results to key consumer groups and policymakers through social media and conference presentations.
Duong 2015; Eriksson 2013 (Literature article)	Consumers trained as facilitators to organize diverse stakeholder groups and implement innovations that improve neonatal health and survival.
Implementer 8	29 patient consumers involved in dissemination of implementation research findings at a national research conference.
Tapp 2017 (Literature article)	Patient advisory board gave input on dissemination strategies that facilitated implementation of toolkits for patients with asthma.
Implementer 6	Consumers who served on a central consumer-only advisory board acted independently on behalf of the board by participating as a consumer representative on many hospital-wide committees.
Data Source	Consumer Engagement Level
	Collaboration Examples (n = 4)
Absolom 2015 (Literature article)	Patient representative served as co-investigator in a grant application.
Implementer 2	Members of patient advisory groups served as co-investigators on certain projects.
Tapp 2017 (Literature article)	Caregiver advocates (proxies to consumers) attended project meetings, gave input into patient-centered approaches, assisted with data interpretation and analysis, contributed to dissemination strategies, and were involved in advocacy and policy development.
Implementer 7	Consumers co-created an advisory board partnership with implementation researchers. Consumers were considered to be research partners, completed human ethics training, listed as key personnel on studies, wrote letters of support for grants, developed name, mission, and meeting purpose of the board, and helped to design, operationalize, and complete implementation research as needed.

Note. Categorized according to Goodman and Sanders Thompson's (2017) stakeholder engagement framework.

Data Source	Consumer Engagement Level Outreach Example (n = 1)
Data Source	Consumer Engagement Level Patient-Centered Example (n = 1)
Implementer 5	Information gathered in preliminary participatory research with consumers was then used by consumers to implement a new diabetes self-management program at a community clinic. Consumers who worked at the clinic also engaged consumers through an advisory board and community organization to determine delivery of the program.
Data Source	Consumer Engagement Level Community-Based Participatory Research Example (n = 1)
Norman 2013 (Literature article)	The community advisory council consisting of consumers developed a CBPR approach to develop and test messages and dissemination strategies for several healthcare issues. The council considered potential projects presented by researchers from the nearby university and selected topics based on the community priority list, potential for funding, and potential impact on their community. The council has also helped with data analysis, interpretation of results, and dissemination of findings. The council was joined by health professionals, health department representatives, hospital administrators, and patients with the health condition of interest.
Note. Categorized according to Goodman and Sanders Thompson's (2017) stakeholder engagement framework.	

[insert Table 3 here]

Recurring Challenges and Solutions to Engaging Consumers in Implementation

Recurring challenges to engaging consumers in implementation efforts were barriers mentioned in at least two examples. We also extracted all promising solutions to these challenges identified from any data source. These promising solutions are not an exhaustive list. See Table 4 for frequency with which we identified challenges, examples, and promising solutions. Some solutions were meant to address more than one challenge—they are not duplicated in Table 4, however. We describe in depth two recurring challenges and their promising solutions, and readers can reference Table 4 for all challenges and solutions.

Recurring Challenge 1: Recruiting a diversity of consumers representative of actual patients served

Many implementers described difficulties recruiting consumers for implementation efforts, no matter the level of engagement. Specifically, implementers reported issues recruiting patients who had a demographic makeup consistent with actual patients served. Implementers clarified that the consumers they were engaging were more homogenous than the populations they represented or most had the same set of skills. For example, one implementer discussed challenges to engaging U.S. military Veterans who were women or from diverse racial groups to serve on Veteran engagement advisory boards. Many data sources pointed to difficulty specifically engaging “vulnerable populations,” as epitomized in a statement from Tapp (2017) in a literature article concerning implementation of asthma interventions:

[the] limitation for patient involvement in general is the issue of recruiting and facilitating involvement of the patients who represent the vulnerable populations most affected by the disease...A limitation may be that the patients most heavily involved with the study had backgrounds in health care (not related to asthma) or advanced professional degrees. Essentially, across most data sources and levels of consumer engagement, implementers or researchers had difficulty recruiting consumers who had lived experience with racism, classism, sexism, and other societal disadvantage. Thus, the voices of more societally marginalized consumers were often not well-represented in implementation efforts.

Promising Solution to recruiting a diversity of consumers representative

Implementer 1 felt strongly the solution was “accommodation to facilitate participation (providing childcare, transportation, etc.)... I found that it is impossible to work with new immigrant [consumers] without fair honorariums... we required hiring a trusted community member to recruit and conduct engagement activities.” Tapp et al. (2017) also reinforced this suggestion.

Absolom et al. also recommended: “the involvement of [consumer] representatives at two levels, both local [consumer] advisors and those with experience of national research committees [relevant to the health condition]. This combined strategy has worked very well in our experience with the different skills sets and perspectives providing valuable insight.” (p. 1084, 2015)

Recurring Challenge 2: Lack of processes to communicate equitably among all stakeholders

Implementers described a dearth of communication modes and informal and formal processes to ensure consumers could communicate feedback or questions equitably with healthcare staff and professionals. Equitable communication would consist of comfort sharing and receiving feedback bidirectionally, a nonjudgmental atmosphere, and shared opportunities for all to speak and listen. Processes were needed to establish a shared level of understanding about problems or contexts, and to ensure all stakeholders were able and felt comfortable communicating their thoughts. In one webinar, Asch (2018) emphasized the difficulty that healthcare professionals face in learning “to speak with [consumers] effectively about research,” and implementation. Absolom and colleagues (2015) also provided an example of a power hierarchy inhibiting open communication, clarifying that consumers felt “daunted” by the complicated terminology deployed by “experienced academics and clinicians.” Another webinar presented by LaChapelle (2017) discussed encouraging consumers to engage while also safeguarding them from being forced to overshare. Communication processes were also needed to ensure the “right” people for an issue were able to share feedback at the level of their comfort and that others could understand this feedback.

Promising Solutions to lack of processes to communicate equitably

Solutions to ensure equitable communication were behaviors the consumers could engage in, or behaviors the implementers or healthcare professionals could engage in. The goal of both was to help consumers feel comfortable with clear communication processes and ensure all stakeholder voices were represented.

One suggested behavior for consumers was to take some basic research courses. As Implementer 7 mentioned, “[consumers] decided on their own to take the [human subjects ethics] training, so when they were at the table with researchers, they could have conversations.” Another suggestion was for consumers to contribute to formal processes to guide discussions. One speaker in a webinar described multiple aspects of a successful set of communication guidelines in their collaboration:

“The [consumers] have created rules of engagement that guide our board meetings. And one of those rules is confidentiality in the meeting and a right to pass. And this right to pass is not only the right to pass if they don't feel like mentioning or talking about a topic that would make them uncomfortable or disclosing any personal health information, but it's also the right to pass somewhat on the question the [implementers] bring to the meetings and bring up other questions that they think might be more valuable. So we really try ...to empower [consumers] to have the say in what they think would be most valuable.” (LaChapelle, webinar, 2017)

For healthcare professionals, one implementer recommended making their presentations more patient-friendly and that, in fact, even the presence of one consumer can make professionals more aware of this need: “Sometimes our [consumer]

influence is just our presence – they change the way the information is shared, and the way they operate because a patient is there.” (Implementer 6, 2019) Another presenter during a webinar described this shift in thinking:

“What [consumer] groups tend to want is a lot more in the direction of practicality. What program or policy does the [healthcare system] need to do? How is this going to affect the program or policy? ...I would emphasize that more. I would also say that we researchers [and implementers] tend to speak in nuance and numbers. And that nuance and numbers can undercut the message. So you have to go to the far end of your comfort zone in trying to say what you know forcefully and certainly. And then of course, these generalizable bits of advice I just gave you are just that. They won't necessarily work in any specific circumstance. You have to know the individual across the table from you and figure out what it is that they want and they know.” (Asch, webinar, 2018).

Another solution mentioned by authors of a research article was that consumer value was highlighted clearly at meetings, through recording consumer input in the meeting minutes, and having the chairperson at meetings actively include consumers. They also ensured consumers were well-oriented by providing: written documents regularly, an in-person orientation, and a consumer led orientation.(Absolom, literature article, 2015) In these processes, one presenter suggested concretely to “Spell out acronyms and do not use acronyms; also use layperson terms, not medical terms.” (Fehling, webinar, 2016) Further instructions for the person leading consumer engagement processes were described in a literature article (Angstman, 2009):

“As expected, our [consumer advisory group] had several suggestions for best practices for the [leader of the group]. The person or persons would need to be versed in group dynamics, allowing suggestions and comments to be made that are not always “prohealthcare.” ... There would certainly be times not only for general roundtable discussion but also for direct questioning of less-vocal group members to ensure the broadest possible discussion of opinions. On occasion, a guest facilitator has been utilized. Generally, a guest facilitator is a person interested in soliciting the group's opinion of a very specific question or program with which they are responsible for. On these occasions, the group is alerted ahead of time of the guest and provided with the necessary background and purpose of the members joining the group. The guest is encouraged to facilitate with open-ended questions, if they are seeking general ideas, or present 3 to 4 very specific questions. Either format has been effective and provided positive direction. Our [consumer] members strongly agreed that the facilitator should be in a position of responsibility within the clinic and be able to implement recommendations of the [consumers].”

Angstman et al. (2009) also suggested that group “size should be limited to approximately 15 members. A larger group may be intimidating and may limit discussion, whereas a smaller group may be limited by having too few people... Members should be a representative sample of the patients or family members who are served. Generally, the members should have a commitment to healthcare and be personally invested in the clinic.”

Resources to Engage Consumers in Implementation Activities

Implementers need to develop skills in and attend to cultural humility, structural oppression, and power imbalances when engaging consumers, especially those who are experiencing health and health care disparities. Across data sources, we extracted any resources implementers mentioned to assist in these efforts and compiled them in Additional File 3.

Discussion

Prior recommendations from implementation experts in a consensus process suggest five consumer engagement implementation strategies to increase use of an intervention or practice [42]: 1) involve consumers / family members; 2) intervene with consumers to enhance uptake and adherence; 3) prepare consumers to be active participants; 4) increase demand; and 5) use mass media. Majority of examples from this scan fell under “involve consumers and family members,” which was the strategy rated by experts in the consensus process as most important *and* feasible. An interesting finding is

none of the examples in this scan were intentionally to “increase demand” or “use mass media”—the two consumer engagement strategies rated by experts as the least feasible.[42] This underscores the need for either training to use less feasible strategies or development of other consumer engagement implementation strategies.

Most examples involved mid-level intensity of engagement (“coordination”), such that implementers worked with consumers to obtain feedback on implementation but did not collaborate in ways such as paying consumers, empowering them to make decisions, or asking them to assist with or lead tasks. Our findings parallel those from the in-depth analysis of barriers to and facilitators of consumer engagement in primary care practices in Ireland. Researchers found activities similar to or less intense than coordination, such as information events or consultation with healthcare teams, as more feasible than higher intensity engagement. Engaging consumers with higher intensity, such as consumers on interdisciplinary primary care teams, proved more difficult and its usefulness was less clear.[29] The level of engagement might depend on how many implementation efforts are required, demographics of intended recipients of the innovation, and local and organizational contexts in which health care is received. Very few examples in this scan truly used a CBPR approach to implementation, which emphasizes capacity building, equitable distribution of finances, co-ownership, and having consumers collect and analyze data. A CBPR approach to implementation requires a higher intensity of consumer engagement and significantly more resources than, say, coordination. In fact, Ramanadhan and others suggested that higher intensity engagement, even CBPR, may not be ideal, but that implementers and communities should evaluate their goals for an implementation effort to select the optimal consumer engagement level.[20]

The challenges we identified to consumer engagement in implementation activities were consistent with, and expanded upon, barriers identified by Bodison and colleagues from a forum of community, healthcare leadership, and implementer stakeholders, including consulting consumers too late in the process, and lack of financial or logistic resources.[43] See their original article for specific solutions to supplement our results. Another challenge from our scan was implementers were not always able to engage consumers, especially those burdened by societal barriers. This is similar to a barrier mentioned by Bodison and colleagues[43]—engaging health disparity populations means frequently overcoming societal disadvantage and mistrust experienced by these populations, perpetuated by racist and elitist historical events, at least in U.S. health research. Implementers need to be more proactive, creative, and intentional about engagement strategies for consumers experiencing health disparities.

We coded whether consumers and the healthcare problem addressed represented a health or healthcare disparity (“health disparity population”). Most data sources did not specify whether recipients/consumers experienced health or healthcare disparities. The impact of consumer engagement in implementation on healthcare disparities has not been assessed; and we believe this is partially a result of lack of attention specifically to disparities and variation in consumer engagement in implementation and reporting across studies.[44] A future research question is whether more robust use of consumer engagement methods in implementation activities reduces healthcare disparities. Implementers need to be interrogating various privileges and biases they bring to engagement encounters with people impacted by health disparities, in line with cultural humility and competency from healthcare professions.[45] It is important to consider what behaviors are engaged in by implementers that can compromise participatory engagement and reinforce existing disparities and inequities.

Limitations

This work is formative and an essential first step toward consensus, best practices, and future research on engaging consumers in implementation initiatives. We did not review webinars outside of the Veterans Health Administration, although we did scan published literature and interview implementers from outside this healthcare system. We were limited in recruiting more implementers and found it challenging to identify any workgroups discussing in consumer engagement in implementation efforts. These limits on data collection may restrict internal validity of our conclusions—we may be missing major examples or challenges. This is an inherent risk of an environmental scan of this type as it captures breadth, not depth.[36]

Conclusion

Despite consumers being engaged in numerous implementation efforts across healthcare settings, there are no clear guidelines on how to facilitate their participation or what level of engagement is recommended. We found implementers engage consumers most frequently at a medium intensity (coordination). Also, many implementers, regardless of health problem or context, face recurring challenges to this work. Although health disparities populations are engaged in some implementation activities, special consideration should be taken when involving them in these efforts. We believe consumer engagement should be considered as another piece of the implementation puzzle in healthcare, along with implementation strategies engaging clinic staff and leadership, to reduce healthcare disparities.

Declarations

- **Ethics approval and consent to participate:** This study deemed exempt as not human subjects research by the Central Arkansas Veterans Healthcare System Institutional Review Board. The implementers interviewed were not formally consented since this was not research; however, they were given a rationale for the study and explained their information would be de-identified.
- **Consent for publication:** Not applicable.
- **Availability of data and materials:** Although the data are not publicly housed, we are happy to share de-identified data for others to evaluate or build upon our work. Please contact the first, second, or last author.
- **Competing interests:** We have no competing interests with this research or its outcomes.
- **Funding:** Locally Initiated Project, FY2019, Health Services Research and Development, Veterans Health Administration. The funder approved the project as described in this manuscript and had no role in the interpretation or writing of results.
- **Authors' contributions:** ENW conceptualized the study and designed study methods, conducted data collection and analysis, interpreted results and wrote and edited the manuscript; AMC collected and analyzed data, interpreted results, and edited the manuscript; GT refined study methods, especially regarding sampling, and assisted in refining interpretation of results and editing the manuscript; CW refined study methods, interpreted results, wrote sections of the discussion, and edited the entire manuscript; JEK assisted in conceptualizing the study and methods, assisted in interpreting results, and edited the entire manuscript.
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Tables

Due to technical limitations, table 4 is only available as a download in the Supplemental Files section.

Figures

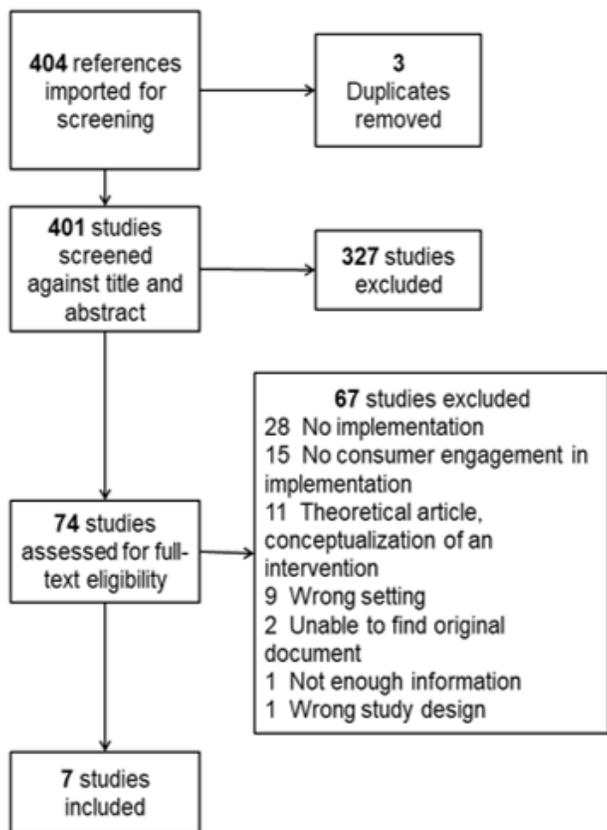
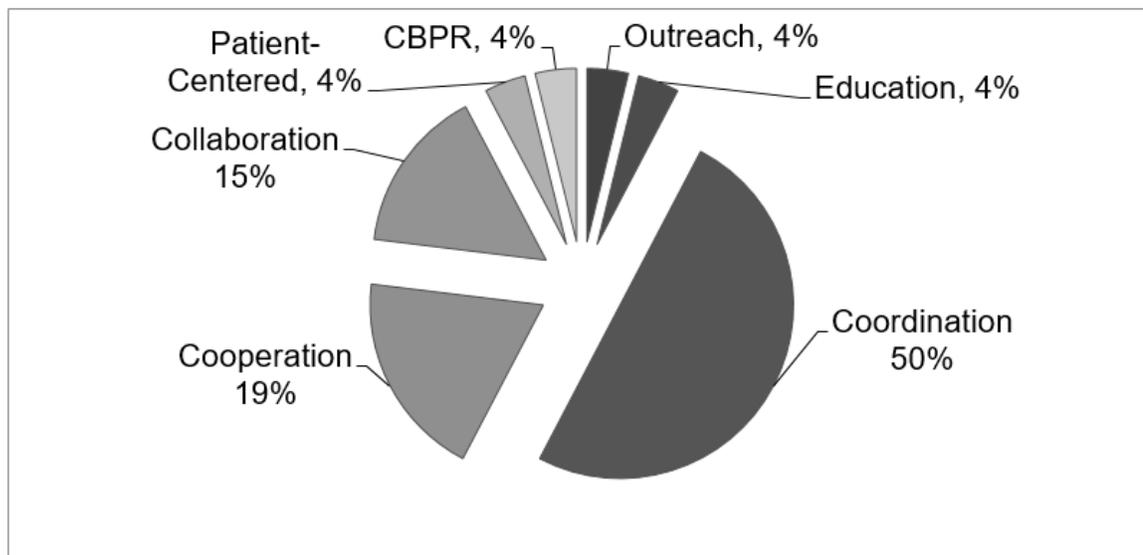


Figure 1

PRISMA flowchart of systematic literature search



Note. CBPR = community-based participatory research. Starting at outreach and going clockwise, the levels range from least intensive to more intensive consumer engagement, ending with CBPR.

Figure 2

Percentage of examples of consumer engagement in implementation by classification, according to Goodman and Sanders Thompson (2017)

Supplementary Files

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