


# Amplifying consumers as partners in dissemination and implementation science and practice

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## Abstract

**Background:** This Viewpoint argues for consumers (people with lived experience and their families) to be amplified as key partners in dissemination and implementation science and practice.

**Method:** We contend that consumer opinion and consumer demand can be harnessed to influence practitioners and policymakers.

**Results:** Amplifying consumers' voices can improve the fit of evidence-based interventions to the intended end user. We offer recommendations of frameworks to engage consumers in the dissemination and implementation of health interventions. We discuss the primary types of evidence consumers may rely upon, including testimonials and lived experience.

**Conclusions:** Our intention is for this Viewpoint to continue the momentum in dissemination and implementation science and practice of engaging consumers in our work.

**Plain Language Summary:** Dissemination and implementation science has insufficiently acknowledged the importance of consumers (people with lived experience and their families) as partners in implementation initiatives. In this viewpoint, we highlight the role consumer opinion can play in influencing practitioners' and policymakers' decisions to sustainably implement evidence-based practices. We encourage implementation researchers and practitioners to solicit and respond to consumer perspectives during their implementation efforts.

## Keywords

consumers, lived experience, partners, dissemination, implementation, participatory research

## Introduction

Dissemination and implementation (D&I) science and practice aims to increase the use of evidence-based interventions (EBIs) within health and public health settings (Wensing et al., 2021). For EBIs to reach their intended audience, there must be both a supply of providers who offer the EBI and consumer demand for the EBI. Historically, D&I efforts have placed much more emphasis on the supply side of health services through activities such as building provider capacity and modifying organizational factors to support EBIs. We contend that D&I science and practice could be strengthened by greater integration of consumers as key partners. We use the term consumer to include both the end user of a service or prevention effort (e.g., the patient, recipient of EBI, or service user) and the person who drives decision-making about whether to engage in the service (e.g., a caregiver selecting a treatment

for their child; Becker, 2015). Broadly defined, health consumers are individuals with lived experience (self or loved ones) with health difficulties (Becker, 2015). Consumers can include past, present, or future recipients of EBIs.

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Dissemination and implementation science theories, models, frameworks, and measures have inconsistently and insufficiently included consumers as a relevant audience to consider. Consumer perspectives about EBIs are included in many implementation determinant frameworks—such as the Consolidated Framework for Implementation Research and the Practical and Robust Implementation and Sustainability Model (Damschroder et al., 2022; Feldstein & Glasgow, 2008). In addition, activities designed to “engage consumers” are recognized as one of the nine primary clusters in the ERIC taxonomy of implementation strategies (Waltz et al., 2015).

However, foundational papers have left out consumers when defining key partners in D&I science (Brownson et al., 2022) or have explicitly stated that interventions aiming to influence consumer attitudes, knowledge, or behaviors are out of scope for D&I frameworks (Baumann et al., 2022; Leeman et al., 2017; Wensing et al., 2021). *Implementation Science*, a flagship journal in the field, explicitly excludes manuscripts that target consumers as the recipient of the intervention or implementation strategy, stating that their scope “excludes most interventions to inform patients or populations about healthcare improvements or interventions to involve patients more actively in their healthcare [...] Such interventions are covered by other fields” (pp. 2, Wensing et al., 2021). The field of D&I science has historically justified excluding consumers as targets of implementation efforts based on arguments such as: (a) D&I efforts are separate activities that should be reported independently; (b) understanding patient perspectives is a topic of study in other fields, including health services research, social marketing, and public health (Baumann et al., 2022; Wensing et al., 2021), and/or (c) communication strategies aiming to shift consumer perspectives are an EBI, rather than a D&I strategy (Leeman et al., 2017). In this viewpoint, we argue that explicitly including consumers as partners in D&I science and practice is essential to increase access to EBIs. This viewpoint consists of three sections. We first provide a rationale for partnering consumers in the process of disseminating and implementing health interventions, we then consider the sources of evidence that consumers rely upon, and we conclude by sharing frameworks to enhance consumer engagement throughout implementation.

## Rationale for Engaging Consumers in the D&I Processes

Consumers can be involved in both D&I efforts. Dissemination refers to strategic communication about EBIs to a target audience (National Institutes of Health, 2022). Within the dissemination process, consumers can be the target of, and/or the actor in dissemination campaigns (Purtle et al., 2022). Dissemination efforts aim to change

consumers’ attitudes, behaviors, and intentions to seek EBIs (Crane et al., 2021), based on the assumption that consumers can make more informed health choices when they have a greater understanding of treatment options (Langer & Jensen-Doss, 2018). Consumers also can be actors in the dissemination process as the messenger of information, such as by providing testimonials. Implementation refers to the adoption and integration of EBIs within health settings (National Institutes of Health, 2022). Within the implementation process, consumers can provide feedback on the implementation process to ensure that implementation efforts are patient-centered (Sanchez et al., 2023), and consumers can exert influence on individuals involved in the implementation process (Purtle et al., 2022).

Consumers are commonly agents of change in the D&I process via their opinions on and demand for EBIs, as well as their subsequent influence on other partners. It has been argued that pull demand—when consumers seek out a service—could lead providers to become trained in EBIs, and that patient knowledge of and demand for interventions could affect whether providers choose to sustain EBIs (Becker, 2015; Crane et al., 2021; Frank et al., 2022). Consumer perspectives influence the decision-making of policymakers who set EBI funding priorities, as such policymakers often rely on constituent stories as a source of evidence (Brownson et al., 2022; Purtle et al., 2022). Patient advocates, many of whom have lived experience, inform policy decisions (Funk et al., 2006). Moreover, public sentiment and sociopolitical climate can be influenced by media and social media campaigns targeted at consumers (Yanovitzky, 2002).

Extant research has reified a false dichotomy between individuals serving in a professional capacity and consumers. Many of the typical partners (e.g., researchers, practitioners, policymakers) in D&I initiatives are likely consumers with lived experiences of seeking or receiving health treatment (Jones et al., 2021). Regarding behavioral health, over 80% of faculty, graduate students, and other professionals affiliated with doctoral and internship programs in clinical, counseling, and school psychology reported having lifetime mental health difficulties (Victor et al., 2022). Similarly, nearly 20% of state legislators disclose seeking treatment for a mental health issue (Pilar et al., 2023). It can be helpful to acknowledge an individual’s positionality related to D&I initiatives (Sanchez et al., 2023), recognizing that individuals can simultaneously serve as consumers with lived experience and as professionals in the field. Implementation teams can foster a discussion of lived experiences when designing D&I initiatives to understand the experiences researchers, implementers, and other partners bring to their work. However, it is important to respect individual autonomy in disclosing such information. There are many legitimate reasons why a person may not wish to disclose having lived experience on a specific health topic. If the implementation team does not wish to discuss lived experiences,

they can still consider how individuals' intersecting identities, including being a consumer of healthcare, may impact all team members' perspectives, attitudes, and priorities. Acknowledging that many researchers, practitioners, and policy makers are also consumers can help our field more intentionally elevate tacit (lived experience) knowledge (Brownson et al., 2022).

Consideration of the consumer voice is also critical from an equity perspective (Woodward et al., 2022). Partners who are involved with EBI implementation in a professional capacity often serve in positions of power (e.g., hospital administrators, policymakers, providers) relative to consumers. Consumers themselves are often underrepresented and/or marginalized, especially those with stigmatized health conditions (e.g., mental illness, substance use disorders, HIV). It is possible that EBI voltage drops in community practice are due to a lack of acceptability, desirability, and effectiveness of EBIs to consumers outside of efficacy research trials, which in turn contributes to health disparities and inequities.

Finally, it is essential to explicitly consider the nonresearch sources of evidence used by consumers (including consumers acting in a professional capacity) to fully understand contextual factors influencing adoption, implementation, and sustainment of EBIs. Studies suggest that consumers are often unfamiliar with EBIs, or they misunderstand or are skeptical of the concept (Becker, 2015; Ringle et al., 2020). Most concerning, distrust of EBIs is greatest among consumers from disadvantaged backgrounds (Becker, 2015; Ringle et al., 2020). Consumers may rely upon sources of evidence beyond research, including lived experiences (self or loved ones), testimonials from trusted influencers, the media, and social media. Additionally, it is possible that consumers do not prioritize EBIs when they seek treatments, and instead prioritize minimizing structural barriers (e.g., cost, distance), or interpersonal aspects of treatment (e.g., provider from same racial/ethnic background; interpersonal connection; Kirk et al., 2016). Provider- and implementation-focused strategies that fail to consider determinants prioritized by consumers may unintentionally exacerbate existing disparities, by increasing the supply of EBIs without addressing consumer-level barriers that prevent consumers from underserved or minoritized backgrounds from seeking such services. Careful consideration of consumer perspectives and preferences for information is important during the D&I process given that consumers ultimately are the individuals whose health D&I science and practice aims to improve.

### **Frameworks to Incorporate Consumer Engagement into D&I Research and Practice**

There are many strategies and frameworks from D&I science and health services research that can assist with promoting consumer engagement in D&I initiatives,

including shared decision-making (Elwyn et al., 2012), patient-centered care (Epstein & Street, 2011), patient advisory committees (Sharma et al., 2017), user-centered design (Lyon & Koerner, 2016), direct-to-consumer marketing (Becker, 2015), health communication (Cusack et al., 2018; Nsangi et al., 2017; Turon et al., 2023), and knowledge translation (Chapman et al., 2020). Instead of being separate from dissemination, we posit that health communication and advertising can be conceptualized as dissemination strategies when information about EBIs is being communicated (Purtle et al., 2022). Dissemination frameworks that have been researched in the context of informing policymakers about EBIs can be applied to dissemination to consumers. For example, audience segmentation can be used to identify target consumer groups and tailor dissemination efforts to meet their unique characteristics and preferences (Purtle et al., 2018). Health equity and community-driven frameworks can be applied to amplify the consumer voice across all phases of research (e.g., Health Equity Implementation Framework; Patient/Participant-Driven Community model). Similarly, implementation codesign strategies to elicit feedback from providers, such as innovation tournaments and boot camp translation (Norman et al., 2013; Stewart et al., 2019), can be used to elicit feedback from consumers (Woodward et al., 2023). Additional frameworks targeting consumers can be found on dissemination-implementation.org and the Patient-Centered Outcomes Research Institute Engagement Tool and Resource Repository by filtering for patient/target audience. These frameworks can be employed by D&I scientists and practitioners to engage consumers, enhance their participation, and ensure that EBIs are accessible, relevant, and responsive to their needs and preferences.

The Consumer Voice toolkit provides implementers with guidance on what, where, when, how, and why they can engage consumers in the implementation process (Woodward et al., 2023). Consumers can be involved by serving as members of the implementation planning team, serving on advisory council, working with other consumers in the system, and providing consultation on outreach methods and marketing and other materials (Woodward et al., 2023). Becker et al. (2020) provide an informative example of how to engage consumers in tailoring dissemination materials. They conducted a survey using the marketing mix framework to understand consumer preferences. Based on survey results, they compared a standard educational description about EBIs with a user-informed infographic. The user-informed infographic emphasized terms that parents preferred such as "effective therapy" and "customized treatment" instead of "evidence-based." Results indicated that the user-informed infographic, which was shorter and easier to read, was a more effective direct-to-consumer marketing strategy to encourage parents to seek EBIs. This study demonstrates the benefit of incorporating consumer feedback and specific dissemination frameworks into D&I efforts.

Consumer feedback throughout the D&I process can ensure that the initiative meets consumer needs.

## Conclusion

This Viewpoint proposes the explicit inclusion of consumers as a key audience influencing the adoption, implementation, and sustainment of EBIs for health. Thus far, the majority of D&I research has focused on providers and organizations, with far less attention on the end consumer. As a result, we often have elevated the voices of those who decide whether to adopt or deliver EBIs, instead of the voices of those who ultimately receive EBIs. We must continue the recent momentum of engaging consumers in D&I research and practice. For D&I science and practice to benefit consumers, we need to amplify their voices in our work so D&I efforts are conducted *with* consumers, rather than just for them.

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