JAMIA Open, 6(1), 2023, ooad004
https://doi.org/10.1093/jamiaopen/ooad004
Research and Applications

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Research recruitment through the patient portal: perspectives of community focus groups in Seattle and Atlanta

Kathryn M. Porter [1], Stephanie A. Kraft [1,2], Candace D. Speight [3,4], Devan M. Duenas [1], Nyiramugisha K. Niyibizi [4], Andrea Mitchell [3,4], M. Rebecca O'Connor [5], Charles Gregor [6], Kendra Liljenquist [2], Seema K. Shah [7,8], Benjamin S. Wilfond [1,2], and Neal W. Dickert [3,4]

[1]Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute, Seattle, Washington, USA, [2]Department of Pediatrics, University of Washington School of Medicine, Seattle, Washington, USA, [3]Division of Cardiology, Department of Medicine, Emory University School of Medicine, Atlanta, Georgia, USA, [4]Georgia Clinical and Translational Science Alliance, Emory University, Atlanta, Georgia, USA, [5]Child, Family & Population Health Nursing, School of Nursing, University of Washington, Seattle, Washington, USA, [6]Institute of Translational Health Sciences, University of Washington, Seattle, Washington, USA, [7]Bioethics Program, Lurie Children's Hospital, Chicago, Illinois, USA and [8]Department of Pediatrics, Northwestern Feinberg School of Medicine, Chicago, Illinois, USA

Corresponding Author: Kathryn M. Porter, JD, MPH, Treuman Katz Center for Pediatric Bioethics, Seattle Children's Research Institute, 1900 9th Ave., M/S JMB-6, Seattle, WA 98101, USA; kathryn.porter@seattlechildrens.org

Received 20 January 2022; Revised 16 June 2022; Editorial Decision 10 January 2023; Accepted 13 January 2023

ABSTRACT

Objective: Research recruitment through patient portals (ie, patient-facing, web-based clinical interfaces) has the potential to be effective, efficient, and inclusive, but best practices remain undefined. We sought to better understand how patients view this recruitment approach.

Materials and Methods: We conducted 6 focus groups in Atlanta, GA and Seattle, WA with members of patient advisory committees and the general public. Discussions addressed acceptability of patient portal recruitment and communication preferences. Focus groups were audio-recorded, transcribed, and analyzed using deductive and inductive codes. Iterative team discussions identified major themes.

Results: Of 49 total participants, 20 were patient advisory committee members. Participants' mean age was 49 (range 18–74); 59% identified as non-Hispanic White and 31% as Black/African American. Participants were supportive of patient portal recruitment and confident that messages were private and legitimate. Participants identified transparency and patient control over whether and how to participate as essential features. Concerns included the frequency of research messages and the ability to distinguish between research and clinical messages. Participants also discussed how patient portal recruitment might affect diversity and inclusion.

Discussion: Focus group participants generally found patient portal recruitment acceptable and perceived it as secure and trustworthy. Transparency, control, and attention to inclusiveness were identified as key considerations for developing best practices.

Conclusion: For institutions implementing patient portal recruitment programs, continued engagement with patient populations can help facilitate translation of these findings into best practices and ensure that implemented strategies accomplish intended goals.

Key words: patient portals, electronic health records, recruitment, biomedical research, focus groups

Lay Summary

Healthcare systems are increasingly implementing, or considering implementation of, research recruitment functionality through the patient portal (ie, patient-facing, web-based clinical interfaces). To better understand the views of patients/potential research participants, we conducted 6 focus groups in Seattle, WA and Atlanta, GA, recruiting from the general public as well as members of a medical institution's patient advisory committee. Research recruitment through the patient portal was viewed favorably by our focus group participants. They reported feeling confident that patient portal messages were private and legitimate compared to other messaging approaches such as email. Transparency and patient control over whether and how to participate were viewed as important features of patient portal recruitment. Potential concerns included the frequency of research messages, the ability to distinguish between research and clinical messages, and how patient portal recruitment might impact diversity and inclusion. These findings support current efforts by healthcare systems to implement this recruitment method. Continued engagement with patient populations can help to facilitate translation of these findings into best practices and to ensure that implemented strategies accomplish their intended goals.

BACKGROUND AND SIGNIFICANCE

Patient portals are designed to give patients within a healthcare system better access to their personal health information and streamline communication with clinical teams. Patient portal users can typically access certain health information (eg, laboratory results, immunization history), communicate with clinicians via secure messaging, and conduct administrative tasks (eg, schedule appointments, refill prescriptions).[1] Patient portals are increasingly being considered as a method for research recruitment.[2] Potential advantages of portal-based recruitment include efficient links to electronic health records (EHRs), allowing researchers to target individuals who meet study inclusion criteria, and increased security compared to other modes of communication. Despite this potential, certain groups of patients are underrepresented among patient portal users[3] and some patients may have negative feelings about the use of patient portals for research purposes, leading to feelings of disrespect or mistrust.

Data about the implementation and evaluation of patient portal research recruitment are limited and are often narrowly focused on recruitment rates compared to other methods.[4,5] Few studies have examined patient perspectives. Related work has included qualitative studies of patient preferences for investigator versus physician contact,[6] opt-in versus opt-out consent,[6] and notification and permission approaches.[7] It is unknown how patients might perceive researchers having access to EHRs and directly contacting patients through the portal, the potential burden of receiving research messages, and the impact on their existing clinical relationships.

Recognizing the potential value of patient portals for research recruitment while also acknowledging potential concerns, we sought to better understand the views of individuals who may be engaged should a patient portal recruitment program be implemented within their healthcare system. We conducted focus groups to elicit patient perspectives about research recruitment through the patient portal and identify key areas of concern to guide implementation efforts.

MATERIALS AND METHODS

Overview

We explored patient perspectives on the use of patient portals for research recruitment in a series of focus groups. Focus group methodology is well suited to allow for the exchange of ideas through facilitated in-depth conversation among participants.[8] This exploratory, qualitative study sought to identify a range of views about patient portal recruitment and possibly determine where further engagement would be beneficial.

Focus group guide development

We developed a semistructured focus group guide that included questions about privacy, trust and trustworthiness, informed consent, comfort with technology, the role of healthcare providers, potential harms, and preferences on recruitment methods (see Supplementary Appendix). Questions were developed based on a literature review of relevant patient portal considerations as well as other recruitment contexts. The focus group guide included hypothetical recruitment scenarios in which patients were contacted directly via the patient portal by a researcher or targeted through the patient portal based on disease profile. We pilot tested the focus group guide in 2 mock focus groups, one with colleagues and one with patient advisory board members. We revised the guide for clarity after each pilot test.

Focus groups

We conducted 6 focus groups in Atlanta, GA and Seattle, WA between December 2018 and October 2019. To ensure we included individuals with a working knowledge of the healthcare systems, we recruited participants for 3 of the focus groups through patient advisory committees affiliated with Emory University or the University of Washington. Participants in the remaining focus groups were members of the general public. In Seattle, general public participants were recruited using Participate in Research, an online resource supported by the University of Washington that connects individuals interested in research participation with existing studies. In Atlanta, recruitment involved approaching patients in the Emory cardiology clinic and calling patients who had authorized being contacted about research opportunities.

Focus groups were conducted in English, lasted 60–90 min each, and were moderated by an experienced study team member with at least one other team member present for note-taking and general support. Participants were offered a $50 gift card incentive.

Data analysis

Each focus group was audio-recorded and transcribed verbatim by a professional transcription service. Deidentified transcripts were uploaded into Dedoose (www.dedoose.com), a qualitative coding software program, for data analysis. We developed a coding framework from core content domains within the guide and inductive

codes from the review of all transcripts. Two out of 3 authors (KMP, CDS, and DMD) independently coded each transcript. Discrepancies were resolved by consensus by all 3 coders. We reviewed and summarized key codes and identified major themes through iterative discussions with the larger study team.

Regulatory oversight

This study was approved by the Seattle Children's and Emory University IRBs.

RESULTS

We conducted 6 focus groups, 3 at each site, with a total of 49 participants. Participants were from institutional patient advisory committees ($n = 20$) or members of the general public ($n = 29$). More than half of participants were female, and the sample was diverse in age, race, and educational attainment (see Table 1).

Almost all participants indicated during the discussions that they were users of the patient portal and were familiar with the features relevant for their clinical care. Participants identified 4 overarching domains of considerations for implementing patient portal recruitment: (1) transparency and control, (2) security, legitimacy, and trust, (3) communication and engagement, and (4) diversity and inclusion.

Transparency and control

Lack of awareness about use of medical records for research recruitment

Many participants made statements suggesting a lack of awareness that EHRs are currently utilized for research recruitment. Several indicated concern about the idea that someone outside their direct medical team would have access to medical records that could lead to a targeted invitation to participate in research. However, some participants distinguished between a person looking at individual records and a computer-generated search, with most participants more comfortable with the latter. On further discussion, this concern primarily surrounded the review of EHR data rather than the recruitment message itself. Referencing a hypothetical recruitment message shared in the focus groups, one participant explained:

> "I'm assuming. . .they didn't look at anybody's chart, but it kind of makes it sound like someone was looking through charts and they saw that you had this thing and they sent you this message personally." (Site A, Group 2)

Other participants questioned how the privacy protections they had been promised, such as those offered through HIPAA, could be reconciled with a message from an unknown person that revealed knowledge of one's medical history. Transparency and assurances about privacy protections in patient/participant communications during research recruitment were identified as potential solutions to these concerns. These issues were viewed as especially important for patients being recruited because of a potentially sensitive or stigmatizing diagnosis, for highly specific indications, or if the study was focused on children or adolescents.

Control over inclusion in recruitment pool

There was near consensus that permission should be obtained from patients before including them in a patient portal recruitment program.

> "I'll be okay as long as. . .they ask me for permission first ahead of time." (Site B, Group 2)

Participants discussed the possibility of having all patients included in a patient portal recruitment pool by default and having to proactively opt-out (commonly referred to as an opt-out approach), or conversely requiring all interested patients to opt-in (commonly referred to as an opt-in approach). Participants generally expressed a preference for an opt-in system but would be willing to accept an opt-out system. Some articulated that an opt-out system may increase the number and diversity of patients in the recruitment pool.

Ability to change decision to be included in recruitment pool

Separate from the initial choice of whether to be included in the recruitment pool, participants also expressed a desire for clear opportunities to opt out of the patient portal recruitment pool on an ongoing basis, for example, by having the option to opt out of future contact in study recruitment messages.

Many participants raised the issue of the length of time a decision to be included in, or excluded from, the patient portal recruitment pool would remain in effect. Many suggested people may change their mind and want to be able to change their designation accordingly.

> "I would also like if you opted out and got a confirmation. . .to say 'If you ever want to opt back in, here, contact this number or go to this website, and here's how you can get information to opt back in,' and that way. . .it's not burdensome to have to seek that out." (Site A, Group 1)

Some suggestions to facilitate patient choice included having a place in the patient portal where one could subscribe or unsubscribe to receiving recruitment messages, having an option for pausing notifications for a time period, providing an option to defer being asked about future contact for some amount of time, being able to indicate preferences with respect to the volume of recruitment messages or the types of studies they would be willing to participate in, and having an option to actively search for research studies rather than waiting for researchers to contact them. In general, there was a preference for options that gave patients greater control over when they would be approached.

Security, legitimacy, and trust

Acknowledging the frequency of spam communications in everyday life, participants spoke favorably about communications through the patient portal, viewing them as more trustworthy and secure than emails or phone calls, especially when communicating about potentially sensitive information. They described patient portal communication positively using terms such as "legitimate," "private," and "confidential." Some of this was based on a feeling of institutional trust and the sense that the patient portal was a more private or closed universe than a regular email account.

> "I think that certainly gives it legitimacy. You know you're not getting a random email from someone. You're already in the network, in the portal network." (Site A, Group 1)

While some expressed concerns about security breaches or hacking, most acknowledged that these are risks for any online database and were comforted by the password protected log-in and institutional security protections within the platform. Participants also expressed a willingness to receive messages from researchers they

Table 1. Self-identified patient portal focus group demographics ($n = 49$)

	Total ($n = 49$)	Atlanta ($n = 22$)	Seattle ($n = 27$)
Participant groups			
Patient Advisory Committee Members	20 (41%)	12	8
General population	29 (59%)	10	19
Age (years)			
Range	18–74[a]	22–74	18–73[a]
Mean	49[a]	56	42[a]
Gender			
Female	30 (61%)	14	16
Male	14 (29%)	7	7
Other	1 (2%)	1	0
Did not answer/return form	4 (8%)	0	4
Race			
Asian	1 (2%)	1	0
Black or African American	14 (29%)	13	1
White or European American	27 (55%)	7	20
Middle Eastern or North African/Mediterranean	1 (2%)	1	0
Selected more than one race	2 (4%)	0	2
Did not answer/return form	4 (8%)	0	4
Ethnicity			
Hispanic/Latino(a)	1 (2%)	0	1
Education			
High school graduate (diploma, GED, or equivalent) or less	10 (20%)	7	3
Associate (2-year) college degree, or occupational, technical, or vocational program	9 (18%)	5	4
Bachelor's degree (eg, BA, AB, BS)	13 (27%)	6	7
Graduate or professional degree (eg, MA, MBA, JD, MD, PhD)	12 (25%)	3	9
Did not answer/return form	5 (10%)	1	4
Annual household income			
Less than $40 000	12 (25%)	7	5
$40 000 to $79 999	12 (25%)	8	4
$80 000 to $139 999	11 (22%)	3	8
$140 000 or more	5 (10%)	2	3
Did not answer/return form	9 (18%)	2	7
Health insurance			
Public insurance (eg, Medicaid or Medicare)	17 (35%)	12	5
Private insurance	24 (49%)	8	16
Public and private insurance	3 (6%)	2	1
Did not answer/return form	5 (10%)	0	5

[a]Four participants from Seattle did not return the demographics form; age calculations are based on Seattle $N = 23$; Atlanta $N = 22$; Total $N = 45$.

didn't know simply because they were affiliated with an institution the participant trusted.

While many participants reported having a high degree of trust in their doctors and healthcare institution, they conveyed a strong desire to be able to verify a message, researcher, or research study. Several participants indicated that they would likely verify a research recruitment message from an unfamiliar researcher by checking the researcher's credentials or a study website or talking to someone at the institution with whom they had an existing relationship.

> "I would call and find out information to see who they are, because you don't know if it's a scam or I'd want to know how they got my information." (Site B, Group 3)

Participants also indicated that their clinical team's involvement in the research could help provide legitimacy and expressed a preference that their clinicians be involved in, or at least aware of, research studies to which they were being recruited. This was especially true if recruitment was based on a specific medical condition or status.

> "I would feel more comfortable. . .having either my nurse or the doctor at a regular appointment say, 'Hey. We're a research institution. We may send you opportunities to participate in studies occasionally. Keep an eye out in your portal and your email'. . .[S]o it's just a regular reminder of 'This is good, and this is safe, and this is fine. We're doing this,' and it gets that trust factor." (Site A, Group 1)

Participants also discussed how clinician involvement could support research decision-making after a recruitment message had been sent because patients valued the input from those with whom they had already established trust. However, a few participants in one focus group raised concerns that clinician involvement could blur the lines between research and clinical care or make potential participants believe that their doctor specifically endorsed their participation in a particular study.

Communication and engagement

Content and frequency of patient portal alert messages

Focus group participants offered feedback on specific details about research messaging, including the email notification that alerts a patient that they have a message in the patient portal. Viewing research as important, some focused on how to convey that

importance through notifications. Participants also emphasized the value of communicating specific details about the study.

> "If. . .I'm not expecting a message, I'll probably ignore it, because I've had kind of spam mail. . .So if it was something important like this, it will be nice to get a little bit of a teaser as to what it was about to get me to click on it." (Site A, Group 1)

In addition, participants raised concerns that research message alerts could interfere with clinical communication if they were too frequent or insufficiently demarcated from clinical messages.

> "If I start all of a sudden getting a bunch of emails saying you have a message, you have a message, and they're all researchers. . .that's going to really mess up how I look at the portal. Because when I get an e-mail saying you have a message, I immediately go check the portal, because I know it's from a doctor, I know it's from a nurse, you know? I know it's about something important." (Site B, Group 1)

Participants discussed how too-frequent research notifications could make patients fatigued or frustrated with the portal messaging system, leading them to ignore potentially important clinical messages. They suggested approaches such as limits on the number of notifications a patient would receive about research, subject lines to indicate a secure message was related to a research opportunity and not a clinical matter, a research tab with research opportunities easily available in one place, and grouping multiple research requests into a single notification or newsletter.

Content of recruitment messages

With respect to the content of study recruitment messages, participants wanted certain key information to be stated, including the purpose of the study and the level of involvement that participation would require (eg, a single survey vs multiple in-person visits). Many appreciated the value of a brief introductory message but wanted a link to access more detailed information about the study. Participants were looking for credibility in the message and spoke of the importance of specificity with respect to who the message was coming from (eg, the investigator's name and not just the institution) so the researcher or study could be verified. For studies involving potentially stigmatizing health conditions, inclusion of information about privacy protections was identified as particularly valuable.

Diversity and inclusion

Some participants viewed patient portal-based recruitment as a way to increase the diversity of study participants by reaching out to a larger and potentially broader group of people.

> "It's an equal opportunity for everybody, so yeah. I mean, if you try to get a diversified group, that's a good way to do it." (Site B, Group 1)

However, others noted that patient portal users might be demographically limited, particularly regarding age and technological comfort or accessibility.

> "People you're trying to reach, do they have access to a computer regularly? Because I can imagine there are a lot of people who might not have regular internet access or something that would opt out of the patient portal in general because they don't have the resources to access that. . ." (Site A, Group 3)

Though all of our participants spoke English, a few questioned whether the patient portal was available in languages other than English. Some also suggested that patients with different medical conditions and degrees of interaction with the healthcare system might be more or less likely to use the patient portal.

DISCUSSION

Our focus group participants generally viewed research recruitment through the patient portal favorably, largely based on the belief that it is a more secure and trustworthy method of communication than email or phone recruitment. Participants also appreciated the efficiency benefits to study teams of recruiting through an institution's patient portal system. These findings support further development and use of patient portal research recruitment. However, our participants identified areas where careful consideration is required in implementation, highlighting the value of patient involvement in creating these programs. These findings are consistent with the growing recognition that communications between research teams and potential participants serve multiple functions and that institutions need to think beyond legalistic or formal notions of consent or authorization. In healthcare settings that include both clinical services and research, interactions in one realm will inevitably impact perceptions of the other. This underscores the importance of listening to, and respecting, stakeholder views and individual preferences to identify concerns and refine implementation strategies. Based on our findings of key domains, we propose 6 recommendations for health systems to incorporate patient perspectives in the development of patient portal recruitment systems and improve research integration within their system (see Table 2).

Allow patients to control whether their information is used for recruitment

Participants resoundingly wanted to choose whether to participate in recruitment through the patient portal. We did not explicitly ask participants whether they prefer an opt-in or opt-out system, but some groups addressed these issues. Consistent with prior work,[6,9] there was a preference for opt-in systems but recognition of the practical advantages of an opt-out system and general acceptance of either. Participants also emphasized that circumstances and priorities change and patients should have the ability to alter preferences regarding research-related contacts. It is important for institutions to consider how long a decision might remain in effect and to explore ways to give portal users control over that as well. Options include time-limited decisions to receive notifications or not, periodic prompts to revisit one's preferences, and design of the patient portal to provide patients the ability to change their decisions at their convenience. Overall, our findings suggest that patients are sensitive to details of implementation and value attempts to enhance their sense of control.

Pursue opportunities for patients to determine the quantity and frequency of research messages

It is also important to explore opportunities for limiting numbers of research notifications. While logistically complex, these options may be highly valued by patients and could help increase the yield of portal-based recruitment over time. "Alert fatigue" has been described among physicians receiving clinical trial alerts,[10,11] and it is reasonable to suspect that the same may occur with patients. One possible solution is to set a threshold for the maximum number of research messages to be sent in a given amount of time, which can be done by setting institutional limits and also allowing patient

Table 2. Six recommendations for patient portal recruitment implementation

Context	Domain(s)	Recommendation
Patient portal	Transparency and control	Allow patients to control whether their information is used for recruitment
	Transparency and control Communication and engagement	Pursue opportunities for patients to determine the quantity and frequency of research messages
	Communication and engagement	Distinguish between clinical and research patient portal alerts
	Security, legitimacy, and trust	Provide linked information or other verification methods for patients to learn more about a study and/or researcher
Health system	Diversity and inclusion	Carefully consider the demographic characteristics of patient portal users compared to the health system population
	Transparency and control Communication and engagement	Clearly communicate that patient information is used for research

portal users to select their own personal limit. Additionally, designing the patient portal to include a research section or tab could also be beneficial in allowing for more creative approaches to presenting research opportunities and allowing portal users to take an active role in seeking out research opportunities.

Distinguish between clinical and research patient portal alerts

One of the most practical sets of concerns identified by these participants related to patients' ability to effectively distinguish research-related messaging from clinical messaging. Patient portals typically alert patients to new messages via email. These participants noted that this could cause confusion if such messages do not clearly identify whether notifications are about research participation or new clinical information. Designing systems that make such distinctions may be one way to minimize interference with clinical care.

Provide linked information or other verification methods for patients to learn more about a study and/or researcher

One very clear finding was participants' generally favorable view of portal-based recruitment messaging as more secure than other traditional modes of communication such as letters, phone calls, or emails. Privacy concerns are not eliminated by this method of communication, but there was a strong preference for portal-based messaging compared to other methods in terms of security and privacy. Nevertheless, many participants also wanted to be able to further validate a study or researcher, either through an institutional website or with a trusted clinician at the same institution. Organizations can support participants in learning about studies by providing organizational support for links to study websites, investigator bios, clinicaltrials.gov registration, and sponsor websites that would allow potential participants to verify the legitimacy of the portal message and learn more about the study.

Carefully consider the demographic characteristics of patient portal users compared to the health system population

Our participants highlighted both advantages and disadvantages of portal-based recruitment for promoting equity, diversity, and inclusion in research. Participants discussed patient populations that may not be represented among portal users, an observation that is borne out in the literature: patients who do not identify as White,[3,12–15] are older,[3,12,13] uninsured,[3,15] with lower educational attainment,[16,17] and with less complex medical needs[3,12] are less likely to use patient portals. Moreover, the use of portals for recruitment further reinforces the importance of developing non-English interfaces since prior research has established that patients who prefer languages other than English are significantly less likely to use portals.[18] This may exclude a sizable portion of a healthcare system's members, depending on location and catchment area, given that 22% of US households speak a language other than English at home.[19] Even if a patient portal is available in Spanish (the second most common language in the United States), speakers of other languages, often sizeable populations within a community, remain excluded. It is essential that investigators know the characteristics of patient portal users as they develop their recruitment plans. It is advisable that investigators use other recruitment methods in conjunction with the patient portal until equitable access to, and use of, portals exist for all patient populations.[20] Furthermore, institutions should consider other ways to improve accessibility of the patient portal in general, such as smartphone apps that could reduce the need for computers and increase privacy for those that share computers, to provide more equitable access to clinical and research benefits associated with portal use.

Clearly communicate that patient information is used for research

Many participants were not aware that medical records are commonly used for research or for facilitating recruitment and found the concept concerning. Other research similarly found a lack of awareness of the use of medical records in research and anticipated negative responses upon learning of such activity.[6] Research recruitment through the patient portal should therefore be coupled with transparent communication about research being done at an institution and how one's medical information might be used in recruitment. To respect participants and help alleviate concerns, research recruitment using electronic health records should be clearly described, with an emphasis on privacy protections. Transparency about how a potential participant is identified and who holds that information is critical. Done carefully, portal-based recruitment has the potential to make people more aware of the important ways that research is integrated into clinical operations and how their data may be used to improve care.

LIMITATIONS

Our focus group participants were drawn from only 2 academic medical centers, thereby limiting demographic diversity (eg, significant

underrepresentation of individuals self-identifying as Hispanic/Latino(a)) and the generalizability of results across all healthcare systems. Furthermore, individuals who are willing to participate in a focus group study may be more trusting of research and healthcare systems overall. Additionally, focus group participants recruited from patient advisory committees may be particularly engaged with the healthcare system, although our findings did not suggest a difference in views between our 2 recruitment groups. While we asked participants to consider the views of their friends and family, we may be missing the perspectives of those who are more reluctant to engage with research. This underscores the importance of including patient portal users in the implementation process at any healthcare institution, including those from communities underrepresented in research, so that the diverse healthcare population is represented and able to provide input and feedback. Nevertheless, many of our findings are aligned with focus group findings in other locations.[6]

CONCLUSION

Research recruitment through the patient portal was viewed favorably by our focus group participants, which supports current efforts by healthcare systems to implement this method. Potential concerns and challenges were identified that can help to guide implementation strategies. Continued engagement with patient populations can help to facilitate translation of these findings into best practices and to ensure that implemented strategies accomplish their intended goals.

FUNDING

This work was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health under grant numbers UL1 TR002378 and UL1 TR002319. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

AUTHOR CONTRIBUTIONS

KMP, SAK, CDS, DMD, NKN, AM, CG, SKS, BSW, and NWD contributed to the conception or design of the work. KMP, SAK, CDS, DMD, NKN, AM, BSW, and NWD contributed to data collection. KMP, SAK, CDS, MRO, SKS, BSW, NWD contributed to drafting the article. KMP, SAK, CDS, DMD, NKN, AM, MRO, CG, KL, SKS, BSW, and NWD contributed to data analysis and interpretation, critical revision of the article, and final approval of the version to be published. All authors agree to be accountable for ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ETHICS APPROVAL

This study was approved by the Seattle Children's IRB and the Emory University IRB.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *JAMIA Open* online.

ACKNOWLEDGMENTS

The authors would like to thank Melissa Habrat for her contributions to this manuscript and Hannah Lewis for her administrative assistance.

CONFLICT OF INTEREST STATEMENT

The authors have no competing interests to declare.

DATA AVAILABILITY

Deidentified data underlying this article would be shared for purposes of verification of results upon reasonable request to the corresponding author.

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