

## Research and Applications

# If you build it, they may not come: modifiable barriers to patient portal use among pre- and post-kidney transplant patients

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## ABSTRACT

**Background:** Patient access to health information using electronic patient portals is increasingly common. Portal use has the potential to improve patients' engagement with their health and is particularly important for patients with chronic illness; however, patients' abilities, attitudes, and use of portals are poorly understood.

**Methods:** A single-center, cross-sectional survey was conducted of 240 consecutive pre- and post-kidney transplant patients of all levels of technological proficiency who presented to an urban transplant center in the United States. The investigator-developed Patient Information and Technology Assessment-Patient Portal was used to assess patients' attitudes towards the use of patient portals.

**Results:** Most patients surveyed did not use the patient portal ( $n = 176$ , 73%). Patients were more likely to use the patient portal if they were White, highly educated, in the post-transplant period, more comfortable with technology, and reported being a frequent internet user ( $P < .05$ ). The most common reasons for not using the patient portal included: (1) preference for traditional communication, (2) not being aware of the portal, (3) low technological proficiency, and (4) poor interoperability between the portal at the transplant center and the patient's primary care center.

**Conclusions:** We identified several modifiable barriers to patient portal use. Some barriers can be addressed by patient education and training on portal use, and federal initiatives are underway to improve interoperability; however, a preference for traditional communications represents the most prominent barrier. Additional strategies are needed to improve portal adoption by encouraging acceptance of technologies as a way of clinical communication.

**Key words:** patient portal, web portals, patient, transplantation, renal, internet, health disparities

## INTRODUCTION

Over the last several decades, advancements in information technology, particularly personal computing, have provided new opportunities for medical communication. One emerging technology is an electronic

health record (EHR) with secure areas where patients can access their health information, also known as an electronic patient portal.<sup>1–3</sup>

The Health Information Technology for Economic and Clinical Health Act (HITECH), part of The American Recovery and

Reinvestment Act of 2009, drove widespread adoption of EHRs in the United States.<sup>4,5</sup> This Act included and financially incentivized the concept of EHR “meaningful use” (MU).<sup>6–8</sup> The Centers for Medicare & Medicaid Services (CMS), the administrator of the MU program, defines meaningful use as the use of the EHR to promote quality and safety and reduce health disparities; engage patient and families in care; improve care co-ordination; and maintain security of electronic health information.<sup>9</sup> The ultimate goal of MU is to improve population health by increased adoption of EHRs to provide access to health information that is useful to both patients and health care providers.<sup>5,10,11</sup> Within EHRs, patient portals are the major mechanism by which patients can access their health information and communicate with their health care provider. Patient access to useful, understandable, and actionable personal health information will become increasingly important under the 21st Century Cures Act, which prioritizes patient access to health information that is not overly burdensome. Identifying patient-reported barriers to patient portal use will shed light on patient challenges with patient portals.

One area where the use of an electronic patient portal system may be of value is in solid organ transplantation. Receiving an organ involves several steps: referral to the transplant center, completing a pretransplant medical evaluation, maintenance on the transplant waiting list, and management after transplantation. Each step requires complex and timely communication between patients and providers. In a recent study of patients that presented to an urban transplant center to be evaluated for suitability to receive a kidney transplant, we found that poor communication (between patients and providers and among providers) was the greatest barrier to completing the prekidney transplant evaluation.<sup>12,13</sup> Also, low health literacy and numeracy are common among transplant patients,<sup>14–18</sup> both being important mediators of patient portal use.<sup>19–23</sup>

Electronic patient portal use allows kidney transplant patients to monitor their renal status, immunosuppression levels, and other important allograft functioning indicators through continuous access to their laboratory results. Patients can access their most up-to-date medication lists, which can be shared with providers outside the transplant center, important in the early post-transplantation phase when immunosuppressant medication doses change frequently. Also, the patient portal provides a direct communication channel to the patient’s transplant center health care providers. Thus, electronic patient portals could prove a valuable resource for engaging kidney transplant patients and their families in complex self-care.<sup>1,24–27</sup> Unfortunately, adoption among patients remains low.<sup>11,28,29</sup>

Less than half of patients at centers with MU-certified EHRs are signed up for a patient portal account, and even fewer report using patient portals regularly.<sup>1–3,28–30</sup> Building on previous findings related to technology in the kidney transplant population, we set out to gain a better understanding of characteristics of electronic patient portal use in an urban pre- and post-kidney transplant population. The purpose of the study was to characterize patient’s abilities, attitudes, and use of the electronic patient portal and identify facilitators and potentially modifiable barriers. Some barriers to health care may be modifiable or amenable to intervention, while others are more resistant to change, as demonstrated in other areas of transplantation, including medication adherence, physical activity, and accessing the prekidney transplant evaluation.<sup>31,32</sup> Thus, we aimed to identify (1) overall portal usage rates, (2) predictors of portal use, and (3) reasons for portal nonuse.

## METHODS

Between January and August 2016, we conducted a cross-sectional survey of 240 pre- and post-kidney transplant patients at an urban

transplant center in the United States. A consecutive sample of all adult English-speaking patients who presented to the transplant center for the prekidney transplant evaluation or postkidney transplant clinic were offered the opportunity to participate in the study. Nearly all accepted: 240 of 249 (96% response rate). We did not collect characteristics of patients who declined to participate. No participants were excluded for language barriers. All participants provided informed consent prior to participation in the study. The study was approved by the University Institutional Review Board and conducted in adherence with the Declaration of Helsinki.

### Patient portal

The patient portal used at this setting, “MyChart,” is a secure software developed by Epic Systems Corporation.<sup>33</sup> The software gives patients online access to their laboratory results, parts of their medical record, medication refill requests, appointment requests, and general medical information.<sup>34</sup> In addition, patients have access to demographic, insurance data, and visit summaries; however, they are not able to access physicians notes. While features of a patient portal vary by manufacturer and the package selected by the organization, these features are consistent with other patient portals.

### Instrument development

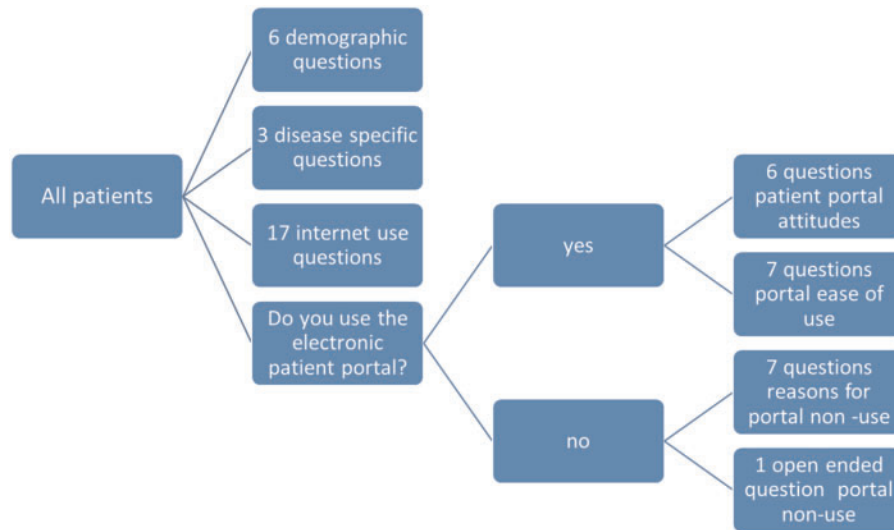
We developed the Patient Information Technology Assessment-Patient Portal (PITA-PP) based on an extensive literature review. We assessed content validity using a focus group that included several transplant clinicians, including physicians (1 transplant surgeon, 1 transplant nephrologist, and 1 living donor advocate), nurses (2 post-transplant co-ordinators, 1 research nurse, and 1 transplant social worker), and intake personnel. In addition, individual interviews were conducted by the principal investigator (M.B.L.) in a sample of pre- and post-kidney transplant patients, representing both genders and a variety of ages, races, and socioeconomic status (SES), as part of the survey validation ( $n=8$ ). Purposive sampling was used to ensure the patients reviewing the instrument reflected the characteristics of the study population (~60% Black, gender evenly divided, varying education levels). Patients were offered the opportunity to review the survey during their regularly scheduled clinic visit. Both clinicians and patients reviewed the dimensions being measured, such as their comfort level using the electronic patient portal, and determined the extent to which the questions accurately reflected these dimensions and were clear. We revised all items as needed based on clinician and patient feedback. Then we conducted a test of the readability of the survey using the Flesch-Kincaid readability test. The Flesch Reading ease score was 64.3, indicating that the survey was written at the eighth grade level, and would be easily understandable by 13- to 15-year-old students.

### Instrument

PITA-PP is a yes/no or 5-point Likert scale item survey consisting of 6 demographic questions, 3 disease-specific questions, and 17 internet use questions. The item structure can be found in [Figure 1](#).

### Data collection procedures

Survey data were collected using an electronic survey on a tablet computer. The principal investigator (M.B.L.) administered the survey to each participant to allow those who may not be proficient with technology, a group often excluded from technology studies, the opportunity to participate in the survey. To reduce social desirability bias, the PI informed all participants that he was not part of



**Figure 1.** Item structure: patient information technology assessment-patient portal (PITA-PP).

their clinical transplant team, and that the individual results would not be shared with the transplant team. Technologies included in the survey were briefly described to participants prior to administration of the survey, to ensure clarity of technological devices. In addition, participants were given an opportunity to have questions about the survey answered during administration of the survey. Study data were collected and managed using REDCap (Research Electronic Data Capture) tools hosted at the University.<sup>35</sup>

### Statistical analysis

We conducted bivariate analysis to assess variables associated with electronic patient portal use: demographic, disease-specific, and technology-specific. Demographic variables include age, race/ethnicity, education, income, and gender. Disease-specific variables included years of kidney disease, pretransplant dialysis status, dialysis type, and transplant status. Technology-specific variables included frequency of internet use, ownership of a smartphone, comfort using the internet, and level of trust in health information from the internet. Candidate predictor variables were identified by using  $\chi^2$ , Student's  $t$ , or Fischer's exact tests where appropriate and included in multivariate logistic regression models if the  $P$ -value in bivariate models was  $\leq .2$ . Income and dialysis status were included as variables of interest in the final regression model despite not reaching the 0.2 level of significance because these were shown to be significant predictors of technology use in previous studies.<sup>12,13,36</sup> We also explored bivariate associations between the covariates listed above and each of the 7 individual reasons for nonuse, to assess whether certain groups were more likely to report specific barriers.

Three multivariate logistic regression models were constructed in a stepwise fashion to identify determinants of patient portal use. Model 1 included demographic variables: gender (male/female), race/ethnicity (White, Black, Hispanic/Latino, other), age (18–39, 40–54, 56–64, and 65+), education level (high school [Hs] or less, some college, college and beyond), and income. Income was treated as continuous and imputed for each person using patient race and median household income based on zip code, which came from the American Community Survey 2011–2015 5-year estimates for ZIP Code Tabulation Areas (ZCTAs). The census does not provide population estimates (only economic estimates) at the ZIP Code level;

thus, ZCTA data were used. ZCTAs closely represent ZIP Code Boundaries but are not always the same.<sup>37</sup> To confirm accuracy, we verified that ZIP Codes matched ZCTAs in our population using the UDS Mapper tool recommended by the Census Bureau.<sup>37</sup> True matches were present for all 119 Illinois and Indiana ZIP Codes represented in our population.

In addition to the demographic variables in Model 1, Model 2 contained disease-specific variables: transplant status (pre- or post-transplant) and pretransplant dialysis status (on dialysis yes/no). Model 3 included demographic variables; disease-specific variables; 2 objective technology variables: frequency of internet use (frequent internet user  $\geq 5$  hours per week, infrequent internet user  $\leq 5$  hours per week) and smartphone ownership (yes/no); and 2 subjective technology variables (both Likert items ranging from *strongly disagree* to *strongly agree*): trust information from the internet and feel comfortable using the internet. Additionally, likelihood ratio tests were performed to test the value of adding the disease- and technology-specific sets of variables to the demographic model. All statistical analyses were conducted using Stata 11.0 (Stata Corporation, College Station, TX, USA).  $P$ -values  $< .05$  were deemed significant in multivariate models.

### Analysis of nonportal user quantitative and qualitative responses

Participants who reported that they did not use the patient portal ( $n = 176$ , 73%) were directed to a set of 7 questions about barriers to patient portal use. In addition, an open-ended question was included, “Are there any other reasons you do not use the patient portal?”

We used directed content analysis procedures to analyze the open-ended question in 3 steps: developing the code dictionary, establishing inter-rater agreement, and final coding of the responses.<sup>38</sup> This included: (1) grouping responses with similar meanings; (2) assigning each group a code name; (3) developing a code dictionary by 1 author (H.P.); and (3) discussing and reaching consensus on code names and code definitions. Next, we determined inter-rater agreement on coding decisions, by: (a) generating a random sample representing 10% of the total number of responses; (b) distributing the sample to 2 authors (L.B., M.B.L.) who

independently coded the random sample; (c) comparing the coding assignments of the 2 authors; and (d) repeating the coding with a new sample until >90% agreement was achieved. Final coding consisted of: (1) assigning responses that aligned with 1 survey item to the survey item tabulation and (2) assigning and tabulating unique codes that were not represented in the survey separately.

## RESULTS

Most of the sample was Black, male, with a mean age of 51.2 years (Standard deviation [SD] = 13.5). Median household income was \$50 556 (SD = \$24 520); however, this varied by race (\$72 338 for Whites, \$38 929 for Blacks, \$46 929 for Hispanics). Most participants reported having kidney disease for greater than 5 years (75%), and most were on/had received dialysis (86%). Education was evenly divided among high school or less, some college, and college and beyond. A comprehensive list of sample characteristics by the electronic patient portal use (yes/no) is presented in [Table 1](#).

### Overall patient portal usage

Only 64 (27%) of the participants reported that they used the electronic patient portal. Among portal users, participants in the post-kidney transplant phase were more likely to use the electronic patient portal compared to those in the pretransplant phase, as were those with a college education or higher or some college compared to those with a high school education or less. Whites were significantly more likely to use the electronic patient portal compared to Blacks. There was no significant difference in electronic patient portal use by gender, income, years of kidney disease, pretransplant dialysis status, or type of dialysis. Gender differences did exist (females were more likely to be users), but these differences were not statistically significant. One-third of portal users reported some level of anxiety (12.9% rarely, 17.7% sometimes, and 3.2% often) when reviewing results in the patient portal.

### Predictors of patient portal use

Results of multivariate logistic regression models can be found in [Table 2](#). The analysis sample was fixed at  $n = 229$  for Models 1, 2, and 3, so that the results represented covered the same population (11 people were removed through listwise deletion based on missing data on 1 or more key variable). In an iterative process, we constructed 3 multivariate logistic regression models to determine predictors of patient portal use (yes as the referent). In Model 3, frequency of internet use, transplant status, comfort using the internet, and trust in information found on the internet remained significant predictors of patient portal use after controlling for demographic, disease-specific, and technology-specific variables. The likelihood ratio tests indicated that the disease-specific questions added value to the demographic model ( $P = .0075$ ). Objective (internet use, smartphone;  $P = .001$ ) and subjective technology questions (feel comfortable using internet, trust information on internet;  $P = .0106$ ) also contributed, and the variable sets as a whole were significant ( $P = .0106$ ). More frequent internet users were more likely to report using the patient portal than were infrequent internet users. The most important predictor, however, was post-transplant status; in the fully adjusted model, this group had 3.6 times the odds of being a portal user compared to the pretransplant group ( $P < .01$ ).

### Associations between covariates and nonuse responses

Bivariate associations were calculated between covariates and the 7 reasons for not using the portal system. Those who reported less frequent internet use were more likely to be Blacks or Hispanic/Latinos with low education. Older adults were more likely to report technical issues related to user proficiency as a reason for not using the portal. Those who reported owning a smartphone and those who reported being a frequent internet user were more likely to report not knowing about the patient portal system. Females were more likely to report preferring traditional communication with clinicians and that the portal was a low priority or they lacked interest. Those who reported being frequent internet users and being comfortable using the internet were most likely to report technical difficulties with the portal system.

### Patient-reported reasons for not using patient portal

Patient-reported reasons for not using the electronic patient portal with subcategories of responses can be found in [Figures 2–4](#) and [Table 3](#). The most commonly reported reason for not using the electronic patient portal was patients' preference for traditional forms of communication (eg during clinic visits, getting information directly from providers), which included 43% of portal nonusers overall. Hispanics/Latinos (56%) and females (54%) were most likely to report this reason for portal nonuse. The second most frequent answer among participants was "I did not know about the electronic patient portal," which was the most frequent response among Blacks (41%). Challenges related to user proficiency with technology and reports of challenges with usability of the portal were also prominent.

## DISCUSSION

As access to health information systems evolves, patients will require certain technological proficiency to take full advantage of these systems. In our study of patient portal use at an urban transplant center in the United States, we found that overall use was low (27%). Many of the barriers associated with nonuse are likely modifiable. Some of these findings may be specific to solid organ transplant centers; others may be generalizable to similar urban low-income populations. These results should inform strategies to improve patient portal use, as well as future efforts to develop patient-specific health-related technologies.

Our findings confirm results of previous studies demonstrating that Blacks, Hispanic/Latinos, and those who are less technologically savvy are less likely to use a patient portal.<sup>10,20,28,39–43</sup> However, we found that, after adjusting for technology-related covariates, race/ethnicity and education were no longer significant predictors of patient portal use. This may indicate that training patients to use electronic health technologies may aid in increasing patient portal use and serve as a tool in addressing longstanding disparities related to race/ethnicity and low education that have been previously reported.<sup>10,28,41–43</sup> Randomized controlled trials using interventions that support patient comfort with technology/internet use would be needed to confirm this.

Of interest to the transplant community is the finding that post-kidney transplant patients were more likely to use the patient portal than prekidney transplant patients. After controlling for covariates, patients in the post-transplant phase were more than 3 times as likely to use the patient portal. This may be due to close follow-up

**Table 1.** Demographic, disease, and technology use characteristics of electronic patient portal users versus nonusers ( $n = 240$ )

Variable	Nonuser ( $n = 176$ )	User ( $n = 64$ )	Total ( $n = 240$ )	P-value
	Mean (SD)	Mean (SD)	Mean (SD)	
Imputed household income	\$49 963 (\$25 066)	\$52 164 (\$23 094)	\$50 556 (\$24 520)	.547
	%	%	%	
<b>Demographic</b>				
<b>Gender</b>				
Male	70	58	67	
Female	30	42	33	.079
<b>Race-ethnicity</b>				
White	26	44	31	
Black	60	45	56	
Latino/Hispanic	10	5	9	
Other	3	6	4	.028
<b>Education</b>				
HS or less	35	19	31	
Some college	35	38	36	
College and beyond	30	44	33	.030
<b>Age</b>				
18–39	19	30	22	
40–54	35	39	36	
55–64	26	20	24	
65+	20	11	18	.128
<b>Disease</b>				
<b>Years of kidney disease</b>				
Less than 3 years	19	17	18	
3–5 years	7	8	7	
Greater than 5 years	74	75	75	.937
<b>Pretransplant dialysis status</b>				
No	13	16	14	
Yes	87	84	86	.611
<b>Dialysis type</b>				
Not on dialysis	14	16	14	
Peritoneal	17	25	19	
Hemo	69	59	67	.305
<b>Transplant status</b>				
Pre	46	22	40	
Post	54	78	60	.001
<b>Technology use</b>				
<b>Frequency of Internet use</b>				
<5 h per week	53	19	44	
>5 h per week	47	81	56	.000
<b>Uses Smartphone to access Internet</b>				
No	31	17	28	
Yes	69	83	73	.031
<b>Feels comfortable using the internet</b>				
Strongly disagree	15	0	11	
Disagree	3	5	4	
No opinion/not sure	6	3	5	
Agree	38	20	33	
Strongly Agree	39	72	48	.000
<b>Trusts the health information found on the internet</b>				
Strongly disagree	15	2	11	
Disagree	14	13	13	
No opinion/not sure	27	42	31	
Agree	37	41	38	
Strongly agree	8	3	7	.012

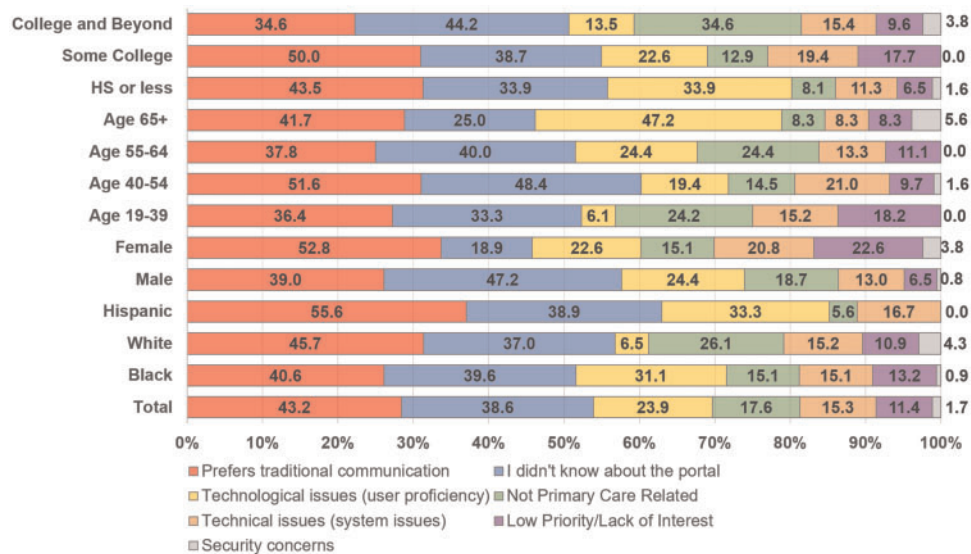
at the transplant center and presumably more exposure to information about the patient portal. This finding is supported by other studies that showed patients with chronic medical conditions were more likely to use the patient portal than were healthy individuals.<sup>44,45</sup> This may suggest that opportunities for repeated exposure to information about the patient portal and to practice use during

post-transplant follow-up may increase portal adoption. It may also suggest that patients who have successfully navigated the complicated pretransplant process demonstrate better self-efficacy or are more technologically savvy than patients who have not.

Another potential explanation for greater patient portal use among postkidney transplant patients is that they have a greater

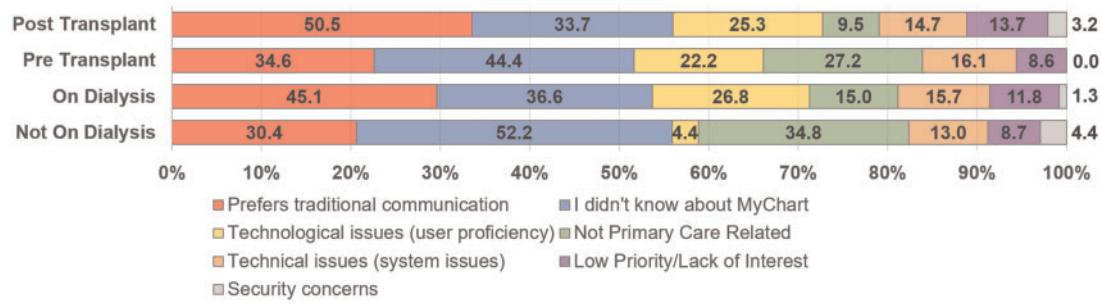
**Table 2.** Predictors of electronic patient portal use ( $n = 229$ )

Measure		Adjusted odds ratios and 95% Confidence Interval [CI]			Crude odds ratios and 95% CI
		Model 1	Model 2	Model 3	
Gender, compared to females	Male	0.638 (0.332, 1.225)	0.766 (0.387, 1.516)	0.89 (0.44, 1.8)	0.626 (0.343, 1.142)
Race compared to Whites	Black	0.317 (0.128, 0.782)**	0.374 (0.147, 0.949)**	0.444 (0.168, 1.175)	0.461 (0.247, 0.864)**
	Hispanic	0.229 (0.057, 0.93)**	0.224 (0.054, 0.925)**	0.316 (0.071, 1.405)	0.268 (0.072, 0.993)**
	Other	0.901 (0.125, 6.517)	2.009 (0.245, 16.467)	3.421 (0.432, 27.069)	1.071 (0.168, 6.816)
Income	CONTINUOUS	0.988 (0.970, 1.006)	0.985 (0.967, 1.004)	0.986 (0.966, 1.006)	1.004 (0.992, 1.015)
Education compared to college grads	≤HS Grad	0.443 (0.189, 1.039)*	0.523 (0.219, 1.251)	0.847 (0.333, 2.156)	0.385 (0.176, 0.839)**
	Some College	0.894 (0.43, 1.86)	0.932 (0.441, 1.971)	1.101 (0.509, 2.382)	0.81 (0.413, 1.586)
Age compared to youngest group 19–39	40–54	0.772 (0.352, 1.695)	0.703 (0.312, 1.584)	0.932 (0.402, 2.158)	0.691 (0.33, 1.446)
	55–64	0.642 (0.261, 1.579)	0.53 (0.209, 1.344)	0.787 (0.291, 2.125)	0.517 (0.222, 1.205)
	65+	0.255 (0.081, 0.8)*	0.239 (0.075, 0.766)**	0.634 (0.17, 2.356)	0.227 (0.076, 0.678)**
Pretransplant dialysis, compared to No	Yes		0.639 (0.247, 1.649)	0.705 (0.27, 1.841)	0.707 (0.311, 1.61)
Transplant status, compared to pre	Post		3.213 (1.484, 6.957)***	3.604 (1.631, 7.966)***	3.005 (1.54, 5.863)***
Internet use, compared to ≥5 h/week	(<5 h/week)			0.422 (0.177, 1.006)*	0.221 (0.11, 0.444)***
Smartphone, compared to users	Nonuser			0.98 (0.374, 2.571)	0.397 (0.182, 0.867)**
Trust information seen on Internet	ORDINAL			1.086 (0.765, 1.544)	1.216 (0.922, 1.603)
Feel comfortable using Internet	ORDINAL			1.558 (0.992, 2.448)*	2.093 (1.41, 3.106)

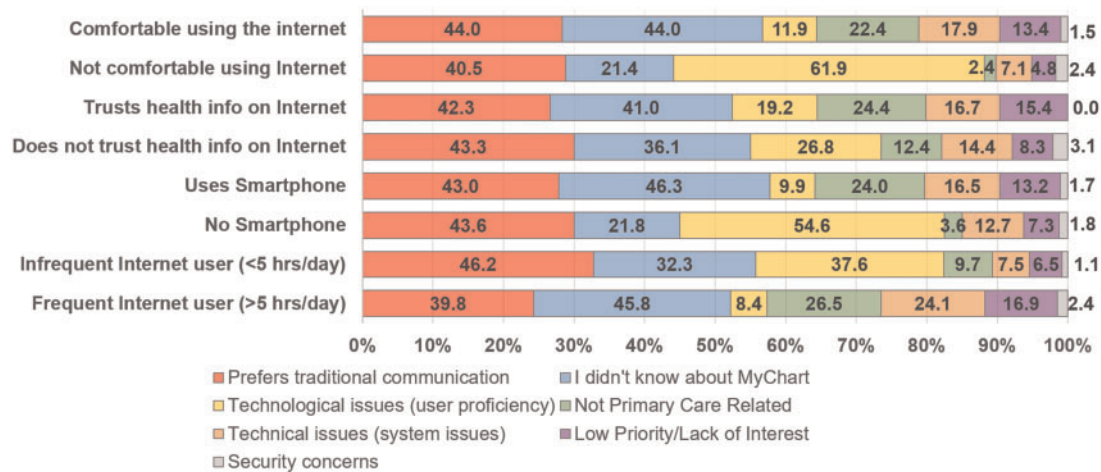
\* $P < .10$ ; \*\* $P < .05$ ; \*\*\* $P < .01$ .**Figure 2.** Barriers to electronic patient portal use among demographic population subgroups. Reasons for not using the patient portal are not mutually exclusive by subgroup. Proportions shown should be interpreted as, for example 43.2% of the total population reported preferring traditional communication, while an additional 38.6% reported not knowing about MyChart. In many cases, people reported more than one reason, which is why the proportions sum to > 100%.

perceived need. Patients in the pretransplant setting also receive intensive follow-up at dialysis centers; for many, this follow-up rarely occurs at the transplant center. Medical information contained in the patient portal, including laboratory results, medication lists, and patient education resources, may be viewed as more important to patients in the post-transplant period. This would be consistent with the Technology Acceptance Model,<sup>46</sup> a widely

used model to study technology adoption that posits that perceived usefulness and perceived ease of use are the major variables that influence technology use.<sup>47</sup> Providing features that would be perceived by pretransplant patients as being more useful may improve adoption in the pretransplant period. For example, including hyperlinks that direct the patients to educational videos related to their immunosuppression, guidance on diet and exer-



**Figure 3.** Barriers to electronic patient portal use among disease population subgroups. Reasons for not using the patient portal are not mutually exclusive by subgroup. Proportions shown should be interpreted as, for example 43.2% of the total population reported preferring traditional communication, while an additional 38.6% reported not knowing about MyChart. In many cases, people reported more than one reason, which is why the proportions sum to > 100%.



**Figure 4.** Barriers to electronic patient portal use among technology population subgroups. Reasons for not using the patient portal are not mutually exclusive by subgroup. Proportions shown should be interpreted as, for example 43.2% of the total population reported preferring traditional communication, while an additional 38.6% reported not knowing about MyChart. In many cases, people reported more than one reason, which is why the proportions sum to > 100%.

cise, or ways to manage their comorbid medical conditions may be useful in engaging patients is self-care. More research is needed to better understand greater portal adoption rates among postkidney transplant patients.

We identified several modifiable barriers to patient portal use. The most frequently identified barrier to patient portal use was the desire for traditional, face-to-face communications with clinicians. A preference for in-person communications has been cited elsewhere as a barrier to patient portal use.<sup>20,48–51</sup> Current strategies to improve patient provider communication via the electronic patient portal include design of more meaningful, patient-friendly, portal messaging platforms.<sup>32</sup> In addition, technologies are currently in development that use more realistic computer agents to simulate portal communication in ways that mimic in-person interactions between patients and clinicians rather than patients reading results directly from a computer screen.<sup>52</sup> Development is needed of multimedia information campaigns that educate patients and providers on how the electronic patient portal can serve as a tool to enhance in-person communications with clinicians.

The second most frequently reported barrier to patient portal use was that patients did not know about the portal. This is consistent with other studies.<sup>25,28,53–55</sup> Interestingly, not knowing about the patient portal was the most prevalent answer among frequent inter-

net users and those who reported being comfortable using the internet. These people, at least theoretically, should be most adept at using the portal. Of concern is the fact that lack of awareness of the electronic patient portal was most prominent among Blacks, a group with a well-documented history of inequities related to accessing health care. Lack of awareness can be addressed through a comprehensive communication campaign that educates both patients and clinicians on the potential benefits of portal use.

Next, technological issues were reported related to (1) “user proficiency,” which included responses related to the patient’s ability to use technology, and (2) “system issues,” which included responses related to the ease of use of the portal system. Together, those who experienced technology issues related to user proficiency and those who experienced technological issues related to functionality of the patient portal system comprised 40% of self-reported reasons for not using the electronic patient portal. As health information continues to become digitized, patients must be able to access information electronically to improve patient engagement in self-care and reduce the potential of worsening existing inequities in health care.

Lastly, among patients who reported *not* using the patient portal, nearly 20% cited that they did not use the patient portal at the transplant center because it was not their primary care home. In addition, several patients who did not use the portal at the transplant

**Table 3.** Examples of self-reported responses to open-ended question related to reasons for not using the electronic patient portal ( $n = 176$ )

Reasons for not using the patient portal	<i>n</i> (%)	Sample responses
Prefers traditional communication	76 (43)	“Prefer doctor tells me the results,” “I don’t see the need for it. Doctors and nurses tell me everything I need to know,” “Someone already calls with the results,” “I don’t like to look at my medical information online,” “Results already discussed by physician so no need to look up the information in MyChart.”
I didn’t know about MyChart	69 (39)	“No one has ever presented MyChart to me,” “Just started getting care here”
Technological issues (user proficiency)	46 (26)	“I don’t use the Internet. I don’t have anyone to teach me,” “No one ever showed me how to use it,” “I think it could be too complicated to use,” “Don’t really use the computer that much. I am old school”
Not primary care related/ interoperability issues	31 (18)	“I don’t get my primary care here,” “I’m only here for a transplant,” “I use a portal elsewhere”
Technical issues (system issues)	24 (14)	“Can’t remember password,” “Every time I try to sign up it asks for a code. I forget what the password is,” “Lost paperwork about how to log in,” “I’m visually impaired”
Low priority/lack of interest	20 (11)	“Not interested,” “I haven’t taken the time to use it,” “I don’t have time”
Security concerns	3 (2)	“Worried about security. I don’t want to get hacked,” “Security reasons”

center reported using portals at their primary care center only or portals at multiple health care sites, a challenge that has been previously reported.<sup>56</sup> A recent systematic review by Adler-Milstein and Jha<sup>56</sup> reported that most hospitals in the United States are still not engaged in health information exchange (HIE), including organizations that actively resist participation due to lack of perceived benefit. Lack of integration between the patient’s primary care home, dialysis centers, and transplant center results in lack of interest for the patient and a missed opportunity for improved communication between patients and providers and among providers. Fortunately, federal efforts are underway to improve interoperability of health information nationwide under the 21st Century Cures Act.<sup>9</sup>

In previous work, we demonstrated that patients who had other internet users in their home were more likely to be frequent internet users themselves.<sup>13,36</sup> Transplant centers may consider developing programs that identify patient information champions, technologically savvy friends or family members who may be able to assist with the technology needs of the patient. Because the need for technological proficiency of patients will increase over time, it may be prudent to have dedicated staff at the transplant center to facilitate technological proficiency. Patient information champions on staff at the transplant center could serve as liaisons to families by aiding in identification of a champion within the family and assisting with information technology training. In addition, information champions could serve as liaisons within the transplant center by assisting staff who may be slow to adopt use of the patient portal due to their own technological challenges. Several studies have demonstrated that a major barrier to patient adoption of electronic portals is lack of adoption among providers.<sup>20,57–60</sup> Thus, further research, including randomized controlled trials, is needed to evaluate if the use of patient information champions in the transplant setting would increase efficiency and result in increased portal use among patients and providers.

### Limitations

The study was conducted at an urban transplant center that serves a large percentage of patients known to face socioeconomic challenges (low health literacy and low SES). Findings are likely to be transferable to similar urban tertiary care centers in low SES neighborhoods. While our sample may not be representative of the U.S. population

as a whole, end-stage renal disease (ESRD) disproportionately affects individuals who are racial and ethnic minorities and individuals with low SES, both groups well represented in our sample.<sup>61–63</sup> Second, while we made every effort to reduce the potential of social desirability bias, it is possible that these estimates may be overinflated/underinflated, particularly as they relate to patients’ feelings about the patient portal. Continued use of qualitative methods may be most informative in developing more user-friendly systems in the future. This study was not intended to evaluate the organization’s patient portal engagement strategy, making it difficult to interpret why lack of knowledge was a prominent issue. Future research on the effectiveness of patient engagement strategies is warranted. In addition, more research is needed to understand of how provider’s attitudes towards patient portal use influence the patient’s willingness to use of the portal. Thoughtful development of EHRs and patient portals will be critical because communication strategies will continue to become digitized, increasing the possibility of worsening existing disparities.

### CONCLUSION

Patient portals can play an important role in improving both individual and population health outcomes. Transplant centers face unique challenges related to patient portal use among patients. Underuse is thwarting the promise of electronic patient portals. As these portals become integral in delivering clinical care, novel patient-centered strategies are needed that overcome existing barriers to use and engage patients in their health.

### CONTRIBUTORS

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## REFERENCES

- Amante DJ, Hogan TP, Pagoto SL, English TM. A systematic review of electronic portal usage among patients with diabetes. *Diabetes Technol Ther* 2014; 16 (11): 784–93.
- Coughlin SS, Prochaska JJ, Williams LB, et al. Patient web portals, disease management, and primary prevention. *Risk Manag Healthc Policy* 2017; 10: 33–40.
- Griffin A, Skinner A, Thornhill J, Weinberger M. Patient portals: who uses them? What features do they use? And do they reduce hospital readmissions? *Appl Clin Inform* 2016; 07 (02): 489–501.
- US Department of Health and Human Services. Hitech act enforcement interim final rule. 2017; <https://www.hhs.gov/hipaa/for-professionals/special-topics/HITECH-act-enforcement-interim-final-rule/index.html>. Accessed January 22, 2018.
- Adler-Milstein J, Jha AK. Hitech act drove large gains in hospital electronic health record adoption. *Health Aff (Millwood)* 2017; 36 (8): 1416–22.
- Holmgren AJ, Adler-Milstein J, McCullough J. Are all certified EHRs created equal? Assessing the relationship between EHR vendor and hospital meaningful use performance. *J Am Med Inform Assoc* 2017; 25:654–660.
- Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *J Med Internet Res* 2015; 17 (2): e44.
- Neuner J, Fedders M, Caravella M, Bradford L, Schapira M. Meaningful use and the patient portal: patient enrollment, use, and satisfaction with patient portals at a later-adopting center. *Am J Med Qual* 2015; 30 (2): 105–13.
- HealthIT.gov. Meaningful use definition and objectives. 2015; <https://www.healthit.gov/providers-professionals/meaningful-use-definition-objectives>. Accessed January 22, 2018.
- Ancker JS, Hafeez B, Kaushal R. Socioeconomic disparities in adoption of personal health records over time. *Am J Manag Care* 2016; 22 (8): 539–40.
- Wildenbos GA, Peute L, Jaspers M. Facilitators and barriers of electronic health record patient portal adoption by older adults: a literature study. *Stud Health Technol Inform* 2017; 235: 308–12.
- Lockwood MB, Saunders MR, Lee CS, Becker YT, Josephson MA, Chon WJ. Kidney transplant and the digital divide: is information and communication technology a barrier or a bridge to transplant for African Americans? *Prog Transplant* 2013; 23 (4): 302–9.
- Lockwood M, Saunders M, Josephson MA, Becker YT, Lee C. Determinants of frequent internet use in an urban kidney transplant population in the United States: characterizing the digital divide. *Prog Transpl* 2015; 25 (1): 9–17.
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011; 155 (2): 97–107.
- Escobedo W, Weismuller P. Assessing health literacy in renal failure and kidney transplant patients. *Prog Transplant* 2013; 23 (1): 47–54.
- Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. *Clin J Am Soc Nephrol* 2009; 4 (1): 195–200.
- Kazley AS, Hund JJ, Simpson KN, Chavin K, Baliga P. Health literacy and kidney transplant outcomes. *Prog Transplant* 2015; 25 (1): 85–90.
- Taha J, Sharif J, Czaja SJ. The impact of numeracy ability and technology skills on older adults' performance of health management tasks using a patient portal. *J Appl Gerontol* 2014; 33 (4): 416–36.
- Davis SE, Osborn CY, Kripalani S, Goggins KM, Jackson GP. Health literacy, education levels, and patient portal usage during hospitalizations. *AMIA Annu Symp Proc* 2015; 2015: 1871–80.
- Irizarry T, DeVito Dabbs A, Curran CR. Patient portals and patient engagement: a state of the science review. *J Med Internet Res* 2015; 17 (6): e148.
- Smith SG, O'Connor R, Aitken W, Curtis LM, Wolf MS, Goel MS. Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort. *J Am Med Inform Assoc* 2015; 22 (4): 888–95.
- Zide M, Caswell K, Peterson E, Aberle DR, Bui AAT, Arnold CW. Consumers' patient portal preferences and health literacy: a survey using crowdsourcing. *JMIR Res Protoc* 2016; 5 (2): e104.
- Zikmund-Fisher BJ, Exe NL, Witteman HO. Numeracy and literacy independently predict patients' ability to identify out-of-range test results. *J Med Internet Res* 2014; 16 (8): e187.
- Irizarry T, Shoemaker J, Nilsen ML, Czaja S, Beach S, DeVito Dabbs A. Patient portals as a tool for health care engagement: a mixed-method study of older adults with varying levels of health literacy and prior patient portal use. *J Med Internet Res* 2017; 19 (3): e99.
- Gee PM, Paterniti DA, Ward D, Soederberg Miller LM. E-patients perceptions of using personal health records for self-management support of chronic illness. *Comput Inform Nurs* 2015; 33 (6): 229–37.
- Neyhart CD. Education of patients pre and post-transplant: improving outcomes by overcoming the barriers. *Nephrol Nurs J* 2008; 35 (4): 409–10.
- Sieverdes JC, Raynor PA, Armstrong T, Jenkins CH, Sox LR, Treiber FA. Attitudes and perceptions of patients on the kidney transplant waiting list toward mobile health-delivered physical activity programs. *Prog Transpl* 2015; 25 (1): 26–34.
- Powell KR. Patient-perceived facilitators of and barriers to electronic portal use: a systematic review. *Comput Inform Nurs* 2017; 35 (11): 565–73.
- Tieu L, Sarkar U, Schilling D, et al. Barriers and facilitators to online portal use among patients and caregivers in a safety net health care system: a qualitative study. *J Med Internet Res* 2015; 17 (12): e275.
- Coughlin SS, Williams LB, Hatzigeorgiou C. A systematic review of studies of web portals for patients with diabetes mellitus. *mHealth* 2017; 3: 23.
- Reber S, Morawa E, Stössel L, et al. Prevalence and modifiable determinants of non-adherence in adult kidney transplant recipients in a German sample. *Zeitschrift Fur Psychosomatische Medizin Und Psychotherapie* 2016; 62 (3): 270–83.
- Waterman AD, Peipert JD, Hyland SS, McCabe MS, Schenk EA, Liu J. Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant. *Clin J Am Soc Nephrol* 2013; 8 (6): 995.
- Epic. Patient engagement. n.d.; <https://www.epic.com/software/#PatientEngagement>. Accessed February 27, 2018.
- UChicago. Mychart. n.d.; <https://mychart.uchospitals.edu/mychart/>. Accessed February 27, 2018.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and

- workflow process for providing translational research informatics support. *J Biomed Inform* 2009; 42 (2): 377–81.
36. Lockwood MB, Dunn-Lopez K, Burke L, Becker YT, Saunders M. Frequency of in-home internet use among prekidney and postkidney transplant patients—facilitators and barriers to use and trends over time. *Transplant Direct* 2017; 3 (11): e216.
  37. United States Census Bureau. Zip code tabulation areas (ZCTAs). 2015; <https://www.census.gov/geo/reference/zctas.html>. Accessed January 22, 2018.
  38. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15 (9): 1277–88.
  39. Ketterer T, West DW, Sanders VP, Hossain J, Kondo MC, Sharif I. Correlates of patient portal enrollment and activation in primary care pediatrics. *Acad Pediatr* 2013; 13 (3): 264–71.
  40. Lober WB, Zierler B, Herbaugh A *et al*. Barriers to the use of a personal health record by an elderly population. *AMIA Annu Symp Proc* 2006: 514–8.
  41. Ancker JS, Barron Y, Rockoff ML, *et al*. Use of an electronic patient portal among disadvantaged populations. *J Gen Intern Med* 2011; 26 (10): 1117–23.
  42. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *J Am Med Inform Assoc* 2011; 18 (Supplement 1): i8–12.
  43. Mikles SP, Mielenz TJ. Characteristics of electronic patient-provider messaging system utilisation in an urban health care organization. *J Innov Health Inform* 2014; 22 (1): 214–21.
  44. Silvestre AL, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. *Health Aff (Millwood)* 2009; 28 (2): 334–44.
  45. Weingart SN, Rind D, Tofias Z, Sands DZ. Who uses the patient internet portal? The PatientSite experience. *J Am Med Inform Assoc* 2006; 13 (1): 91–5.
  46. Davis FD. User acceptance of information technology: system characteristics, user perceptions and behavioral impacts. *Int J Man Mach Stud* 1993; 38 (3): 475–87.
  47. King WR, He J. A meta-analysis of the technology acceptance model. *Inform Manag* 2006; 43 (6): 740–55.
  48. Eden KB, Totten AM, Kassakian SZ, *et al*. Barriers and facilitators to exchanging health information: a systematic review. *Int J Med Inform* 2016; 88: 44–51.
  49. North F, Crane SJ, Chaudhry R, *et al*. Impact of patient portal secure messages and electronic visits on adult primary care office visits. *Telemed J E-Health* 2014; 20 (3): 192–8.
  50. Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. *JAMA* 2012; 308 (19): 2012–9.
  51. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)* 2010; 29 (7): 1370–5.
  52. Morrow D. Technology-based support for older adult communication in safety-critical domains. In: Ross B, ed. *Psychology of Learning and Motivation*. Vol. 64. Cambridge, MA: Academic Press; 2016: 285–317.
  53. Shah SD, Liebovitz D. It takes two to tango: engaging patients and providers with portals. *PM R* 2017; 9 (5s): S85–97.
  54. Pai HH, Lau F, Barnett J, Jones S. Meeting the health information needs of prostate cancer patients using personal health records. *Curr Oncol* 2013; 20 (6): e561–e569.
  55. Demian MN, Shapiro RJ, Thornton WL. An observational study of health literacy and medication adherence in adult kidney transplant recipients. *Clin Kidney J* 2016; 9 (6): 858–65.
  56. Adler-Milstein J, Jha AK. Health information exchange among U.S. hospitals: who's in, who's out, and why? *Healthcare (Amsterdam, Netherlands)* 2014; 2 (1): 26–32.
  57. Nazi KM. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. *J Med Internet Res* 2013; 15 (4): e70.
  58. Morrow D, Clark D, Tu W *et al*. Correlates of health literacy in patients with chronic heart failure. *Gerontologist* 2006; 46 (5): 669–76.
  59. Black H, Gonzalez R, Priolo C, *et al*. True “meaningful use”: technology meets both patient and provider needs. *Am J Manag Care* 2015; 21 (5): e329–337.
  60. Mishuris RG, Stewart M, Fix GM, *et al*. Barriers to patient portal access among veterans receiving home-based primary care: a qualitative study. *Health Expect* 2015; 18 (6): 2296–305.
  61. Bratton C, Chavin K, Baliga P. Racial disparities in organ donation and why. *Curr Opin Organ Transplant* 2011; 16 (2): 243–9.
  62. Sarkar U, Karter AJ, Liu JY, *et al*. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *J Am Med Inform Assoc* 2011; 18 (3): 318–21.
  63. Saunders MR, Lee H, Alexander GC, Tak HJ, Thistlethwaite JR, Jr, Ross LF. Racial disparities in reaching the renal transplant waitlist: is geography as important as race? *Clin Transplant* 2015.