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Research and Applications

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The association between method of solicitation and patient permissions for use of surplus tissues and contact for future research

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ABSTRACT

Objective: Obtaining patient permissions for research contact and for surplus tissue use as part of routine clinical practice can improve research participation. This study aims to investigate the difference in patient permissions for use of surplus tissues, and for direct contact for research, using 2 different methods of solicitation.

Methods: An opt-in, population-based approach for gathering research permissions was implemented in 2 methods. The first method, applied a 2-item patient questionnaire delivered through the electronic health record patient portal. The questionnaire composed of 2 questions (1) whether de-identified surplus specimens may be used for research and (2) whether patients could be contacted about research. In the second method, the same questionnaire was physically presented in clinic within the clinical workflow. We used 1 to 1 propensity score matching and multivariate logistic regression to estimate the odds of obtaining permission and the difference between the 2 methods of solicitation.

Results: The propensity score model matched 8044 observations (4114 submissions in each group). Among the in-clinic submission group, 70.13% provided permission for surplus tissue compared with 66.65% in the patient portal submission group (odds ratio [OR] = 1.20; 95% confidence interval [CI] 1.09–1.32; $P < 0.001$). Permission for future research contact was similar among in-clinic (65.07%) and patient portal submission (66.65%) groups (OR = 0.94; 95% CI 0.85–1.03; $P = 0.175$). These trends were consistent among European Americans and African American patients. However, among patients of other race, higher permission for both future contact (OR = 0.58; 95% CI 0.39–0.86; $P < 0.007$) and surplus tissue use (OR = 0.65; 95% CI 0.43–0.97; $P = 0.036$) was observed among patient portal submission.

Discussion: Our findings suggest that in-clinic solicitation of patient permissions may provide the same opportunity to patients who do not use patient portals and may be associated with higher permission rate for surplus tissue. However, this was primary true for European American and African Americans patients. Patients of other race minorities might respond better to online approaches.

Conclusion: Adopting a patient-centric approach that combines in-clinic and portal-based administration may be feasible and promising. Further research is required in this area.

Key words: permission to contact, permission to surplus tissue use, permission to contact platform, patients portals, biobank studies, research voluntarism

INTRODUCTION

Obtaining patient permissions for future research contact and for surplus tissue use as part of routine clinical practice can efficiently improve research participation while maintaining their autonomy.[1,2] Comprehensive biobanking protocols require a full informed consent process that includes, description of risks, benefits, and other mandatory elements. The permission approach can act as the first step of the consent process by routinely documenting research participation preferences, from all patients within a health system in 1 separate step. Documenting patients' preferences for surplus tissue use and/or contact for future research may be done using short questionnaires with appropriate informational links and contact information. This process provides patients an explicit and direct path to choose whether their specimens could be used for research and/or whether they could be contacted for research opportunities. Previous studies have shown that establishing a "permission to contact" (PTC) platform improves patients' engagement in research, minimizes potential workload and sets the stage for enhanced consent and enrollment into multiple research programs, especially biobanks.[2,3]

Patient permissions can be collected online (remotely) using existing patient portal platforms, or physically during a clinic visit. In late of 2014, the Medical University of South Carolina (MUSC) implemented an opt-in, electronic, and population-based approach for gathering research permissions. This policy aims to afford patients the opportunity to express their preferences by responding to a 2-item questionnaire (Figure 1) with 2 questions: (1) whether de-identified surplus specimens may be used for research or not and (2) whether they could be contacted about future research opportunities. Since then, research permissions from the MUSC clinical population have been solicited within existing electronic health record (EHR) clinical workflows as described previously.[4] Patient permissions were solicited and submitted using 2 different methods. Initially, research permissions were collected exclusively using a patient portal, where patients respond to the questionnaire in a self-directed manner. In a later stage, the same questionnaire was presented within a physical clinic workflow. This takes place between rooming of the patient and the provider visit, using the exam room computer and facilitated by a protocol and software tools in the EHR. Data from both methods are tabulated in a registry.

Patient portals can cost-effectively improve patient engagement in both care and research.[5] However, the use of online portals to engage patients can introduce selection biases related to the unique socioeconomic and racial profiles of patients who tend to use online portals.[6,7] This may exacerbate existing disparities in research participation by minority groups, particularly African Americans.[8–10] Capturing patient perception toward research while they are physically in-clinic may provide an opportunity to improve permission prospects by eliminating the patient portal enrollment bias. Furthermore, the physical contact with care provider at the clinic may enhance trust which encourages research voluntarism among patients. This study aims to investigate the relationship between method of solicitation and permission rate for use of surplus tissues and contact for future research. We hypothesize that in-clinic submission is associated with higher permission rate for surplus tissue use and contact for future research. In a stratified analysis, we also explore the association between solicitation method and permission rate among European Americans, African Americans, and non-European/non-African Americans separately.

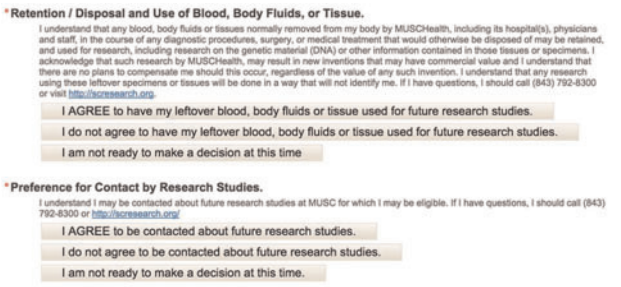

Figure 1. Research permission 2-item questionnaire.

METHODS

MUSC's EHR population-based research preference program

The details of MUSC population-based approach for implementing opt-in research permissions is described elsewhere.[4] In brief, the program consisted of 2 approaches to surveying patients. Initially, we attempted to contact all patients who had accounts in our EHR patient portal. Patients who are portal users received a series of 3 emails around 1 month after portal enrollment requesting their response to the research permission questionnaire (Figure 1). The invitation email contains the link to the patient portal log-in page. Once there, patients can log into their portal account and complete the online questionnaire at their convenience. Non-respondents to the initial message receive up to 2 follow-up reminders at 1-month intervals. Once the questionnaire invitation was sent to patients, they could read, review, and edit their responses via a questionnaire tab within the portal.

In a second phase (in-clinic), the same questionnaire was implemented within a clinic workflow during outpatient visits. In this phase, a protocol and software tools in epic were used that are designed to support direct patient responses to the questionnaire in the period between rooming the patient and the provider visit. On the computers of the exam room, a drop-down menu item locks the patient chart and opens a new session in the patient portal with the patient's questionnaire queue displayed. From this screen, the patient may select and complete the research preferences questionnaire while waiting for the provider. After the patient completes the questionnaire, the terminal returns to the secure workstation state for rapid access to the patient's chart by the provider. Providers may also interrupt and take over the computer before completion of questionnaires to preserve workflows. Permissions responses from both approaches were tabulated in a registry for use by investigators for feasibility assessment of research studies and recruitment. The implementation of Phase 1 started in December 2014, and the implementation of the second phase was carried out gradually on a clinic by clinic basis starting March 2016.

Study population

For this study, we included patients who newly registered for the patient portal and responded to the research permission questionnaire between April 1st 2016 and April 30th 2017. We selected this time period to allow enough time for the in-clinic phase of the program to be fully implemented and stabilized across several MUSC outpatient adult clinics. During this window of time, both methods of preference solicitation were available for MUSC patients. Patients were given the opportunity to self-select to either method. We excluded those who were younger than 18 years old, or had an invalid

birth date or were indicated as diseased at the time of response submission. Since patients were able to edit their submission and/or make more than one submission throughout the study period, we only included the last submission as of April 30th 2017.

Variables and data sources

The main outcomes of this study are a positive expression of permission for research contact and permission for surplus tissue use. The 2 types of permissions were captured via the same questionnaire shown in Figure 1. Patients indicated their preferences by choosing 1 out of 3 responses for research contact and surplus tissue use separately: "opt-in", "opt-out," or "not ready to make a decision." For this analysis, we defined permission (a positive response) as selecting the opt-in option when responding to the questionnaire. "Opt-out" and "not ready to make a decision" were considered as "did not provide permission." We modeled the odds of obtaining permission (positive response) for research contact and surplus tissue as 2 separate binary outcomes.

Data on submissions were obtained from the registry for the study period. In addition to the patients' responses, the registry contains the date, the exact time, and the site at which the submissions were made from (patient portal vs in-clinic). Patient demographics including age, gender, race, and ethnicity was obtained from MUSC Clinical Data Warehouse. Race was categorized into 3 groups; European Americans, African Americans, and others which includes American Indians, Asians, and others. Information on medical conditions coded in ICD-10 CM vocabulary was obtained from the problem list documented in the medical record. The ICD-10 CM list at the date of submission was used to compute the Charlson commodity index (CCI).[11,12] We used CCI as a universal and validated scale of comorbidity. The continuous CCI scale was computed following the algorithm described by Quan *et al.*[13] and classified into 4 ordinal groups (0–3) following the original approach of Charlson *et al.*[14] Patients in Group 0 were the least sick with a CCI score of 0, Group 1 are those with CII score (1–2), Group 2 are those with CC1 score of (3–4), and those in Group 3 were the most sick with a CCI score of 5 and above.

Statistical analysis

We calculated percentages for categorical variables. We used propensity score matching to address selection bias and control for unmeasured confounding. Every patient in the "in-clinic submission" group was matched to 1 patient in the "patient portal submission" based on greedy matching method. The propensity score model was fitted using a set of demographic and clinical characteristics (see Table 1). We then used multivariate logistic regressions to estimate the odds of obtaining permission (positive response) as a binary outcome among the study population and estimate the difference between the 2 methods of solicitation (patient portal vs in-clinic). Two outcomes models were fitted separately for the use of biobank and permission for future contact. To insure the robustness of our analysis we further adjusted for covariates that were of a priori interest including demographic (race, age, gender, and ethnicity) and CCI.

To explore the effect of solicitation method among African Americans specifically, we also ran a stratified analysis and reported the results among European Americans, African Americans, and patients of other race separately using the original data set. Further, to test if there is statistical evidence of effect modification by race, we included an interaction term between method of solicitation and race in the models running on the overall sample. We present results in terms of odds ratio (OR), 95% confidence interval (CI), and 2-sided *P* values. We conducted all analyses using SAS 9.4 (SAS Institute, Cary, NC, USA) at a significance level of <0.05.

This research was approved as an expedited protocol with a waiver of consent and HIPAA authorization by the Medical University of South Carolina Institutional Review Board (IRB) under the regulations of the Office for Human Research Protections; Research Permissions Response under approval #Pro00040823.

RESULTS

During the study period of April 1, 2016 and April 30, 2017, 15 809 unique patients' response were identified. Of those, 11 555 (73.09%) were submitted through the patient portal and 4254 (26.91%) were submitted through the in-clinic workflow method. Table 1 illustrated the patients' characteristics by solicitation method before and after propensity score matching. The study population was dominantly European Americans (79.52%, 13 114), 15.76% (2600) of the study population was AA, and 4.73% (780) was of other race. The majority of the submissions were from female patients (67.43%, 11122) and 83.6% (13 789) of the study population were in Group 0 of the CCI scale (had a CCI score of zero). We obtained relatively high overall permission rate from patients who used the in-clinic method and from those who used the patient portal; 3008 (69.94%) patients responded positively on the biobank question, and 2802 (65.15%) on the future contact question through the in-clinic methods, compared with 8544 (70.1%) for biobank, and 8180 (67.1%) for contact through the patient portal. In our sample, in-clinic submissions were more frequent among younger ages, female, AA, and patients with higher number of comorbidities as compared with patient portal submissions.

The propensity score model resulted in 8228 matched observations (140 observations in the in-clinic submissions group did not have available matched patient portal submissions). Table 1 illustrates the comparable distribution of the demographic and baseline measures in the matched data set after fitting the propensity score model. Figure 2 displays a cloud plot that compares the values of the logit of the propensity score for observations in the treated (in-clinic submission group) and control groups (patent portal submission group), based on all observations and on matched observations.

After matching, higher permission rate was observed among in-clinic submission for surplus tissue when compared with patient portal submission (70.13% in-clinic compared with 66.65% in patient portal submission, $P < 0.001$). Similar trends of permission for future research contact was observed in the 2 groups (65.07% in-clinic compared with 66.65% in patient portal submission, $P = 0.15$).

Table 2 illustrates the findings of the logistic regression models on the overall sample (before matching). After adjusting for confounders, permission for future research contact was similar among in-clinic and patient portal submission (OR = 1.00; 95% CI 0.92–1.08; $P = 0.966$). However, higher permission for surplus tissue use was obtained among in-clinic submission as compared with patient portal submission (OR = 1.21; 95% CI 1.11–1.31; $P < 0.001$). Similar results were observed after propensity score matching. In the matched population, permission for future research contact was similar among in-clinic and patient portal submission (OR = 0.94; 95% CI 0.85–1.03; $P = 0.175$) and higher permission for surplus tissue use was obtained among in-clinic submission as compared with patient portal submission (OR = 1.20; 95% CI 1.09–1.32; $P < 0.001$).

Table 1. Demographic and baseline measures by solicitation method before ($n = 15\,809$) and after ($n = 8228$) propensity score matching

Characteristics	Before matching (original data set)		After matching	
	Patient portal submission, % (*n*)	In-clinic submission, % (*n*)	Patient portal submission, % (*n*)	In-clinic submission, % (*n*)
Total	73.9 (11 555)	26.91 (4254)	50 (4114)	50 (4114)
Age (y)				
18–35	19.48 (2240)	30.31 (1266)	27.88 (1147)	29.97 (1233)
36–50	20.29 (2333)	22.91(957)	24.84 (1022)	22.53 (927)
51–56	31.68 (3642)	26.26 (1097)	27.22 (1120)	26.67 (1097)
>65	28.55 (3283)	20.52 (857)	20.05 (825)	20.83 (857)
Sex				
Male	36.96 (4271)	21.39 (910)	78.73 (3239)	78.73 (3239)
Female	63.04 (7284)	78.61 (3344)	21.27 (875)	21.27 (875)
Race				
European Americans	84.79 (9797)	69.37 (2951)	71.46 (2940)	70.39 (2896)
African American	11.85 (1369)	27.90 (1190)	26.01 (1070)	26.79 (1102)
Others	3.37 (389)	2.73 (116)	2.53 (104)	2.82 (116)
Ethnicity				
Hispanic	1.19 (138)	1.36 (58)	1.05 (43)	1.34 (55)
Non-hispanic	98.81 (11 417)	98.64 (4196)	98.95 (4071)	98.66 (4059)
Charlson comorbidity index				
Scale 0 (CCI = 0)	85.82 (9916)	75.81 (3225)	79.19 (3258)	77.03 (3169)
Scale 1 (CCI = 1–2)	11.63 (1344)	20.92 (890)	17.70 (728)	19.71 (811)
Scale 2 (CCI = 3–4)	1.05 (121)	2.12 (90)	1.90 (78)	2.07 (85)
Scale 3 (CCI ≥5)	1.51 (174)	1.15 (49)	1.22 (50)	1.19 (49)
Permission for surplus tissue use				
Provided permission	70.55 (8152)	70.03 (2979)	66.65 (2742)	70.13 (2885)
Did not provide permission	29.45 (3403)	29.97 (1275)	33.35 (1372)	29.87 (1229)
Permission for future research contact				
Provided permission	67.56 (7807)	65.23 (2775)	66.65 (2745)	65.07 (2677)
Did not provide permission	32.44 (3748)	34.77 (1479)	33.35 (1372)	34.93 (1437)

Note: Include "Opt-out" and "not ready to make a decision."
Abbreviation: CCI: Charlson commodity index.

Based on this analysis, the odds of obtaining permission for surplus tissue use among in-clinic submission were 1.2 times the odds of obtaining permission among patient portal method. These same findings were observed in the stratified analysis among European Americans and AA patients (Table 3). Patients of other race seem to behave in an opposite fashion; among this group, higher permission for both future contact (OR = 0.58; 95% CI 0.39–0.86; $P < 0.007$) and surplus tissue use (OR = 0.65; 95% CI 0.43–0.97; $P = 0.036$) was observed among patient portal submission. When running the models on the entire sample using an interaction term between race and solicitation method, the interaction term was statistically significant for both the permission for future research contact ($P = 0.001$) and the permission for surplus tissue ($P < 0.002$). These findings indicate that the effect of the solicitation method on permission significantly varies across the 3 race groups.

DISCUSSION

Among this matched sample of patients, we found that permission rate for future research contact was similar among in-clinic and patient portal submissions. However, in-clinic submission was associated with higher permission rate after adjusting for confounders.

To our knowledge, this is the first study to investigate how the method/site of solicitation of research permissions may influence patients' willingness to participate in research. In-person contact with providers at the clinic setting is known to improve trust which may promote research volunteerism among patients.[15,16] This is because health providers often perceived as gatekeepers to potential research study subjects. The difference can also be attributed to social disability effect that is more likely to play a role in-clinic setting. Respondents have been shown to give more positive and socially desirable responses when surveyed in person than postal or electronic surveys.[17,18] Studies have also shown that the timing of obtaining consent for surplus tissue use impacts patients' tendency to provide a positive response.[19] In clinic, patients submitted their responses after being checked in and before they are examined by the physician. In the case of portal submissions, timing is uncontrolled. This might also explain the higher permission rate observed at the clinic setting. In addition to the method of administration, our findings suggest that age, gender, race, and health status have to be considered in understanding opt-in rates for research participation. In specific, our results replicate previous findings that older age, European American race, and preexisting illness predisposed to obtaining permission and willingness to participate in research.[4]

Previous studies have shown that PTC is an effective strategy to improve patient engagement without overloading the clinical workload.[2] Similar to previous findings, we obtained relatively high overall permission rate from patients using both methods. In a comparable setting, a permission rate of 80% or greater was reported for 4 PTC platforms established in 3 types of outpatient health clinics (cancer, cardiac, and maternal health) in different British Columbia health centers.[1,2] The full implementation of the same

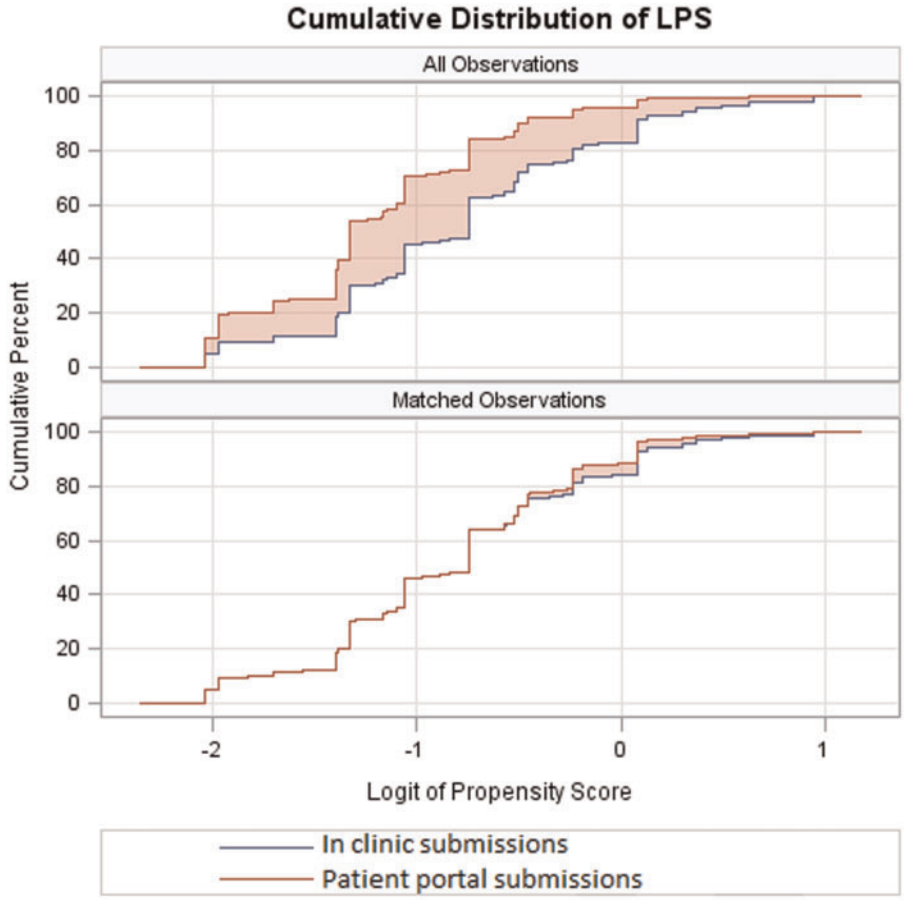

Figure 2. Cumulative distribution of the propensity score for observations in the clinic submission and the patient portal submission, based on all observations and matched observations. LPS: logit of the propensity score.

PTC platform at British Columbia health centers was shown to significantly increase overall biobank referrals (1.78-fold) and consented patients (1.25-fold).[1,2] Institutions have historically separated permission for research contact and for surplus tissue use. To improve efficiency, MUSC platform captures both types of permissions in a single, integrated, and process. By doing so, the platform not only enables patients to declare their preferences but also provides an explicit method for patients to easily opt-out from further consent attempts for different research program including biobanks, if they wish to. Our findings suggest that in-clinic submission may slightly improve permission rate for surplus tissue use but not permission for future contact. While the 2 types of permission are not completely independent (in our data the agreement kappa coefficient was 0.51; 95% CI 0.49–0.52), these findings may indicate that the factors that drive willingness to participate are possibly not identical for both types.

Our findings also suggest that patients who submitted their research preference in-clinic were more likely to be AA when compared with those submitting via the patient portal. In fact, the demographic characteristics of patients who submitted their research preference in-clinic were similar and representative of MUSC general patient population. In contrary, the patient profile of the online portal submissions was biased particularly against minority patients. Large racial/ethnic disparities are typically seen in patient portal enrollment and utilization.[7,20] For example, in a utilization report of a popular patient portal for diabetes care; AAs were 2.6 times less likely to log on when compared with Caucasians. Similarly, minority patients were reported to be significantly less likely to enroll than whites.[7,21] Racial disparities in this context are critical because it is important that all patients get the same opportunity to be involved for a permission population-based approach to work. While online solicitation method can be very cost-effective, easy to use and efficient, it has the potential to exclude patients who do not use patient portals. Excluding AA and minority patient groups at this early stage of research participation may have negative impact in widening the existing gap of racial disparities in clinical research and limit generalizability of research findings. Our findings suggest that in-clinic method may provide an opportunity to patients who do not use online patient portal and maybe beneficial in improving permission rate overall and among AAs for use of surplus tissue. Interestingly, the stratified analysis suggests that this might not be the case for non-European/non-AA minorities. In this subpopulation, a higher permission rate was observed in the online submission as compared with the in-clinic submission. However, this group of patients contained fewer individuals and is not necessarily homogenous. More data are needed to carefully investigate the effect of different solicitation methods among patients of different racial backgrounds.

Documenting research participation preferences in the EHR offers the advantage of (1) linking these preferences to health record information for recruitment, (2) the ability to integrate preferences into population-based patient registries, and (3) offering automate

Table 2. Permission rate, logistical regression estimates, and 95% CIs in analyses examining solicitation method and patient permissions for future research contact and surplus tissue use using the entire study population (before matching, $n = 15\,809$)

	Permission for future research contact			Permission for surplus tissue use		
Factors	Provided permission, % (*n*)	OR (95% CI)	*P*-value	Provided permission, % (*n*)	OR (95% CI)	*P*-value
Age (y)						
18–35	59.38 (2082)	0.76 (0.68–0.83)	<0.001	63.72 (2234)	0.74 (0.67–0.82)	<0.001
35–50	66.87 (2200)	1.00 (0.91–1.10)	0.97	67.69 (2227)	0.84 (0.76–0.93)	0.00
50–65	69.99 (3317)	1.07 (0.97–1.17)	0.162	72.72 (3446)	0.95 (0.86–1.04)	0.273
>65	70.05 (2900)	Reference		75.85 (3140)	Reference	
Gender						
Female	65.48 (6959)	0.93 (0.87–1.00)	0.062	68.22 (7250)	0.85 (0.79–0.92)	<0.001
Male	69.93 (3623)	Reference		74.91 (3881)	Reference	
Race						
African American	55.79 (1426)	0.57 (0.52–0.63)	<0.001	50.12 (1281)	0.35 (0.32–0.38)	<0.001
Others	55.84 (282)	0.70 (0.60–0.83)	<0.001	63.96 (323)	0.68 (0.58–0.81)	<0.001
European Americans	69.61 (8874)	Reference		74.73 (9527)	Reference	
Chronic illness						
Charlson scale 0	65.82 (8649)	0.70 (0.51–0.95)	0.02	69.10 (9081)	0.50 (0.35–0.71)	0.001
Charlson scale 1	72.52 (1620)	0.95 (0.69–1.31)	0.73	76.72 (1714)	0.73 (0.50–1.05)	0.085
Charlson scale 2	69.67 (147)	0.82 (0.54–1.26)	0.36	72.04 (152)	0.58 (0.36–0.92)	0.021
Charlson scale 3	74.44 (166)	Reference		82.51 (184)	Reference	
Ethnicity						
Non-hispanic	66.98 (10 458)	1.01 (0.74–1.38)	0.947	70.42 (10 994)	0.91 (0.65–1.26)	0.55
Hispanic	63.27 (124)	Reference		69.90 (137)	Reference	
Solicitation method						
In-clinic	65.23 (2775)	1.00 (0.92–1.08)	0.966	70.03 (2979)	1.21 (1.11–1.31)	<0.001
Patient portal	67.56 (7807)	Reference		70.55 (8152)	Reference	

Abbreviations: CI: confidence intervals; OR: odds ratio.

Table 3. Permission rates, adjusted logistical regression estimates and 95% CIs in analyses examining solicitation method and patient permissions for future research contact and surplus tissue use in different study population

		Permission for future research contact			Permission for surplus tissue use		
Population	Solicitation method	Provided permission, % (*n*)	OR (95% CI)[a]	*P*-value	Provided permission, % (*n*)	OR (95% CI)[a]	*P*-value
Propensity score-matched population	In-clinic	65.12 (2678)	0.94 (0.85–1.03)	0.175	70.27 (2891)	1.20 (1.09–1.32)	<0.001
	Patient portal	66.65 (2742)	Reference		66.65 (2742)	Reference	
European Americans	In-clinic	69.81 (2060)	1.02 (0.93–1.12)	0.617	77.50 (2287)	1.24 (1.12–1.37)	<0.001
	Patient portal	69.5 (6814)	Reference		73.90 (7240)	Reference	
African American	In-clinic	55.69 (661)	1.011 (0.86–1.19)	0.893	52.91 (628)	1.26 (1.07–1.49)	0.006
	Patient portal	55.88 (765)	Reference		47.70 (653)	Reference	
Others	In-clinic	46.55 (54)	0.577 (0.39–0.86)	0.007	55.17 (64)	0.65 (0.43–0.97)	0.036
	Patient portal	58.61 (228)	Reference		66.58 (259)	Reference	

Abbreviations: CI: confidence intervals; OR: odds ratio.

[a]Adjusted for age, gender, ethnicity, and Charlson comorbidity index.

notifications of surplus specimen availability in particular patient phenotypes. In this study, we were able to use a large number of patient preferences submission to explore differences between the 2 different methods of solicitation, while controlling for important factors such as race, sex, age, and comorbidity. However, this study has some main limitations and the results should be interpreted with caution. First, the data used in this study is collected from a single health system. This helps making the patient portal and in-clinic submission groups comparable but the generalizability of the results to other health systems need further investigation. Second, since patients self-selected to submit their responses using either method, selection bias, and confounding can still be an issue. This is clear when comparing the 2-unmatched groups (Table 1). We used propensity score matching to address this issue. Third, response rate (the proportion of patients who completed the survey over those who were invited to complete it) is not considered in this analysis. This is because none-response at the clinic setting is not routinely captured. Fourth, the same patient might have seen the online portal and responded to it, then later encountered and responded again to the in-clinic portal or vice versa. In that case, the earlier submission would be overwritten, and we only considered the last submission.

CONCLUSION

A population-based approach for obtaining patient permissions by systematically introducing preference questionnaires to patients

during routine clinical care is promising. It generates a large registry of potential prospective research participants. At the same time, it may empower a large number of patients to explicitly make decisions regarding future contact for research and allow control over utilization of discarded specimens. This study demonstrates the feasibility of establishing a research permissions registry using a patient portal with a patient-centric, opt-in approach that combines in-clinic and portal-based questionnaires. The in-clinic approach may provide the same opportunity to patients who do not use the patient portal, and may be associated with higher permission rate for surplus tissue among European American and African American patients. Patients of other race minorities might respond better to online approaches. Low-permission rates among African Americans are of particular importance given its effect on the generalizability of research results and health disparities. Given the limitations of this study, further research is required to assess the effect of solicitation methods on permission rates, specifically among racial minority groups.

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Conflict of interest statement. None declared.

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