

UCLA

UCLA Previously Published Works

Title

Embedding research study recruitment within the patient portal preCheck-in

Permalink

<https://escholarship.org/uc/item/8zb737dw>

Journal

Journal of the American Medical Informatics Association, 30(12)

ISSN

1067-5027

Authors

Leuchter, Richard K

Ma, Suzette

Bell, Douglas S

et al.

Publication Date

2023-11-17


DOI

10.1093/jamia/ocad164

Peer reviewed

Brief Communications

Embedding research study recruitment within the patient portal preCheck-in

Richard K. Leuchter, MD^{1,*}, Suzette Ma, BS², Douglas S. Bell, MD, PhD^{1,3},
Ron D. Hays , PhD^{1,4}, Fernando Javier Sanz Vidorreta, BS³, Sandra L. Binder, MHS³,
Catherine A. Sarkisian, MD, MSHS^{1,5}

¹Division of General Internal Medicine & Health Services Research, Department of Medicine, David Geffen School of Medicine at UCLA, Los Angeles, CA 90024, United States, ²UCLA Health Information Technology, UCLA Health, Los Angeles, CA 90095, United States, ³Clinical and Translational Science Institute, UCLA, Los Angeles, CA 90095, United States, ⁴Department of Health Policy and Management, Fielding School of Public Health, UCLA, Los Angeles, CA 90095, United States and ⁵VA Greater Los Angeles Healthcare System Geriatric Research Education and Clinical Center, Los Angeles, CA 90073, United States

*Corresponding author: Richard K. Leuchter, MD, Division of General Internal Medicine & Health Services Research, David Geffen School of Medicine, University of California, Los Angeles (UCLA), 1100 Glendon Avenue #726, Los Angeles, CA 90024 (rleuchter@mednet.ucla.edu)

ABSTRACT

Objective: Patient portals are increasingly used to recruit patients in research studies, but communication response rates remain low without tactics such as financial incentives or manual outreach. We evaluated a new method of study enrollment by embedding a study information sheet and HIPAA authorization form (HAF) into the patient portal preCheck-in (where patients report basic information like allergies).

Materials and Methods: Eligible patients who enrolled received an after-visit patient-reported outcomes survey through the patient portal. No additional recruitment/messaging efforts were made.

Results: A total of 386 of 843 patients completed preCheck-in, 308 of whom signed the HAF and enrolled in the study (37% enrollment rate). Of 93 patients who were eligible to receive the after-visit survey, 45 completed it (48% completion rate).

Conclusion: Enrollment and survey completion rates were higher than what is typically seen with recruitment by patient portal messaging, suggesting that preCheck-in recruitment can enhance research study recruitment and warrants further investigation.

Key words: HIPAA authorization form; patient portal; preCheck-in; survey; research study recruitment

Background and significance

Patient portals and electronic research consents are increasingly used to recruit participants in research studies.^{1–3} However, these efforts are limited by patient portal message open rates of 50% or less,^{4–7} and completion rates under 15% for questionnaires used in broad-based patient messaging campaigns.^{8–18} Another barrier to recruitment is completion of the Health Insurance Portability and Accountability Act (HIPAA) authorization form (HAF), which has been criticized for unnecessarily overburdening patients in minimal-risk research such as survey-based studies.^{19–21} For example, enrollment rates for studies that newly added a HAF decreased by 65%–75%,^{22–24} and studies that received approval to drop the HAF observed 36%–167% increases in enrollment.^{21,25}

Investigators have sought to enhance recruitment and questionnaire completion rates by utilizing financial incentives and reminder messages, engaging clinicians and staff to encourage patient participation, and hiring research associates to administer in-person consent and questionnaires.^{26–30} While these efforts have successfully increased enrollment rates, less resource-intensive methods to enhance study

participation are needed.^{31–33} Like many other institutions, UCLA Health has historically obtained electronic signatures on the HAF using approved third-party data capturing software such as REDCap.^{2,3,34,35} For patient portal-based recruitment and survey efforts, the additional complexity of navigating to an external website that patients would not normally visit poses substantial recruitment challenges.³⁶

We added a new functionality to our institution's patient portal that embedded a study information sheet and HAF into the visit preCheck-in process, allowing patients to electronically sign the HAF and enroll in a survey-based study during a workflow they were already completing. We evaluated this minimally disruptive recruitment strategy by assessing study enrollment and after-visit survey completion rates during a 2-week period.

Materials and methods

Study setting and design

The University of California, Los Angeles (UCLA) Health System is a large academic medical system including more than 50 primary care clinics. We designed a survey-based study

specifically for the purpose of evaluating the research enrollment rate achieved by a new preCheck-in recruitment process, which was tested from November 7, 2021 to November 23, 2021 at a single primary care clinic staffed by internal medicine residents and attendings.

Eligible patients were 18 years or older, had a UCLA primary care provider (PCP), an active patient portal account, and a scheduled clinic visit during the trial period. A study information sheet and the University of California HAF³⁷ (with interactive checkboxes and an electronic signature field) were made available to eligible patients as part of the preCheck-in process (Figure 1).

These documents appeared under a newly created “Sign Documents” tab and were voluntary to view (Figure 2). This tab also displays other documents with the option to electronically sign such as advance directives (electronically signing these forms was not an option prior to this study). In addition to the required information regarding voluntary participation, risks, benefits, and confidentiality, the study information sheet stated (full text in Supplementary Material):

“The goal of the study is to gain a better understanding of how patients’ own perceptions of their health (called “patient-reported outcomes”, PROs) relate to other measures of health in the medical record. You are receiving this

form because you have a UCLA primary care provider, use UCLA’s electronic patient portal (MyChart), and have an upcoming doctor visit. If you agree to participate in this study, you may receive a questionnaire(s) measuring PROs after your visit.”

Patients who signed the HAF were enrolled in the study and received no further previsit communication.

After patients enrolled in the study and completed their visit, we employed a second set of eligibility criteria to determine who would receive the after-visit survey. Eligibility was determined after patient encounters were signed so that inclusion logic could include the primary diagnostic code and encounter type (cases such as no-shows or conversions to telephone visits cause encounter types to change day-of). Enrolled patients were eligible if the primary encounter ICD-10 code matched a list of conditions that were preselected to be a mix of symptomatic and asymptomatic illnesses (eTable 1 in Supplementary Material), and if their encounter type was office visit or telemedicine (video visit). We excluded encounters that were no-shows, immunization, clinical support, orders only, patient messages, surgical consult (ie, pre-op), or telephone only (usually for lab or imaging follow-up), to be consistent with our messaging to patients that surveys were to track health after physician visits.

The primary outcome was study enrollment rate (no. of patients signed HAF/no. of patients received HAF) and the

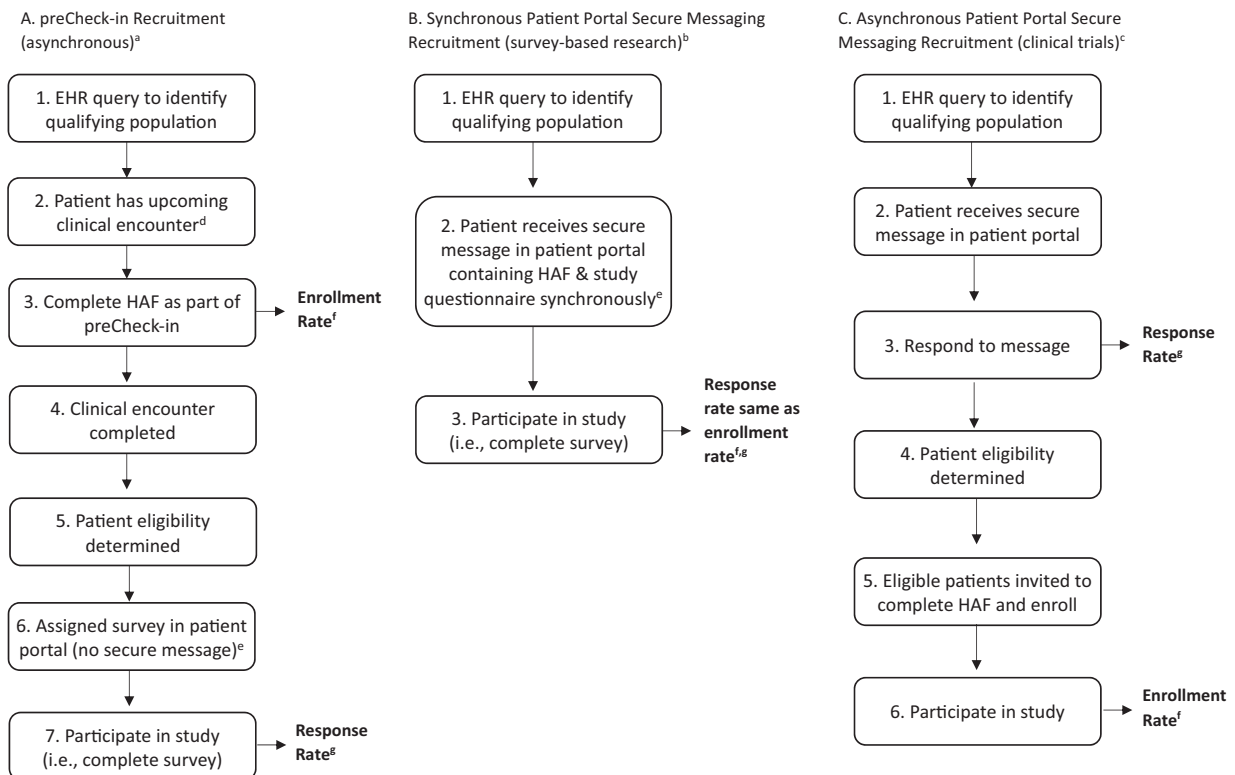


Figure 1. Comparison of preCheck-in recruitment to synchronous and asynchronous patient portal secure messaging recruitment. ^aThis report describes an asynchronous application of preCheck-in recruitment for survey-based research, though this framework could be modified to mimic synchronous enrollment (ie, administering the survey simultaneously with the HAF during pre-Check-in) or for use in clinical trial or voluntary research registry recruitment. ^bA commonly utilized workflow for survey-based research, though some studies do collect surveys asynchronously from the time of HAF completion. ^cA commonly utilized workflow for clinical trial recruitment through the patient portal. preCheck-in recruitment could theoretically be adapted to replace steps 1–3. ^dClinical encounter does not need to be related to the research study (ie, occurring regardless of any research activity). ^eThese steps trigger a generic notification to be sent to a patient’s personal email asking that they log in to the patient portal. Notification emails do not contain links to surveys; these can only be accessed by logging into the patient portal. ^fCalculated as the number of patients who signed the HAF divided by the number of patients who received the HAF. ^gCalculated as the number of patients who responded to the communication (eg, secure message, survey) divided by the number of patients who received the communication. Abbreviations: HAF: HIPAA authorization form.

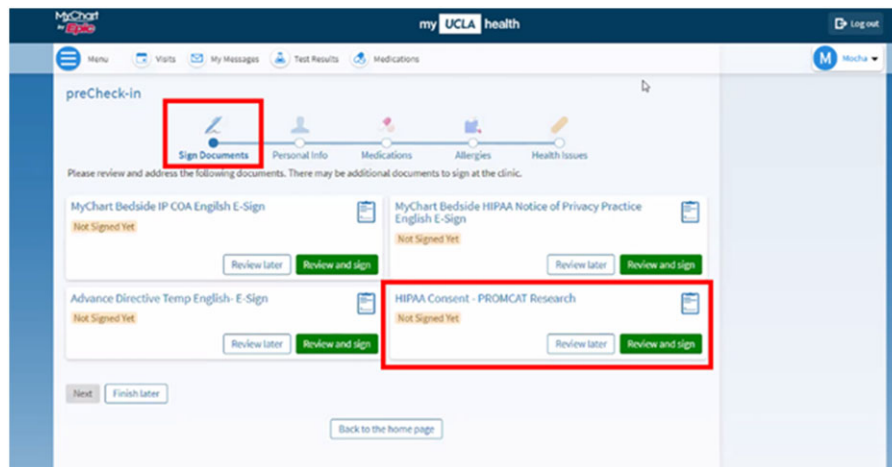


Figure 2. Patient portal screenshot of new preCheck-in process for HIPAA authorization form (HAF) completion and study enrollment. Red boxes outline the newly created “Sign Documents” tab and HAF. Prior to the modification the “Sign Documents” tab was absent, and the remainder of the preCheck-in process was unchanged. The myUCLAhealth App is powered by MyChart[®] licensed from Epic Systems Corporation, © 1999–2023.

secondary outcome was the survey completion rate (no. of patients completed survey/no. of patients received survey).

UCLA Health uses Epic System Corporation (Verona, WI) for its electronic health record (EHR) and patient portal. The research study protocol was approved by the UCLA Health Institutional Review Board (IRB No. 21-000739), and the electronic HAF was approved by the UCLA Office of Compliance Services. The EHR modification was approved by the UCLA Health IT governance.

Patient-reported outcomes measure

The NIH Patient-reported Outcomes Measurement and Information System (PROMIS)-29 + 2,^{38,39} a global health-related quality of life instrument, was the after-visit survey that eligible patients received immediately after their encounter was signed (triggered by primary ICD-10 code and encounter type). The PROMIS-29 + 2 appeared within the “Questionnaires” section of the patient portal, which automatically triggered an email notification directly to patients’ personal emails (Figure 1). This is distinct from a patient portal secure message, which appears in the Message Center of the portal; no portal messages were sent at any point during the study. The survey was preceded by a brief version of the study information sheet reminding patients that the survey was voluntary, purely for research, and would not be viewed by their treatment team (full text in [Supplementary Material](#)). Surveys disappeared after 30 days of inactivity.

Results

Of 932 adult patients with UCLA PCPs and scheduled appointments between November 7, 2021 and November 23, 2021, 843 (90%) had active patient portal accounts and were eligible for MyChart preCheck-in, and thus received a HAF (cohort flow diagram shown in [Figure 3](#)). Of these patients, 386 (46%) completed preCheck-in and 308 (37%) completed the HAF and enrolled in the study. After patient encounters were signed, we excluded patients with ineligible encounter types ($n = 59$) and ICD-10 codes ($n = 156$). The remaining 93 patients received an after-visit survey, of whom 45 (48%) completed the survey (average days after the encounter = 2.0 [SD 2.6]).

Sociodemographic distributions of enrolled patients were generally representative of the UCLA Health patient population, with the exceptions that the enrolled cohort was: (1) slightly older, (2) contained fewer patients with no documented race/ethnicity, and (3) contained more Black/African American and “Other” race patients (and fewer non-Hispanic White patients) ([Table 1](#)).

Discussion

In this study, we found that embedding an electronic study information sheet and HAF in the patient portal preCheck-in process led to a 37% study enrollment rate and 48% survey completion rate among eligible patients. This low-cost, minimally disruptive recruitment method yielded these high participation rates without any patient portal secure messages, financial incentives, or in-person/telephone communications.

The primary outcome of enrollment rate seen here with preCheck-in recruitment was substantially higher than what has been observed in studies using the prevailing method of recruiting patients through secure portal messages. As employed here, preCheck-in recruitment differed from traditional portal messaging recruitment by consenting patients to participate in the study protocol (ie, enrolling patients) during the first point of contact, and asynchronously collecting surveys at a later date from enrolled patients who met inclusion criteria ([Figure 1A](#)). This workflow naturally produces definitions for enrollment and response rate that differ from the traditional processes of either enrolling and collecting surveys from patients synchronously in a single patient portal message ([Figure 1B](#)), or messaging patients and only enrolling a subset who respond and meet inclusion criteria ([Figure 1C](#)).¹¹ Thus, the most appropriate contextualization of preCheck-in recruitment is to compare our enrollment rate to the first-message response rates of other recruitment workflows (ie, [Figure 1A](#) step 3 vs [Figure 1B](#) step 3 vs [Figure 1C](#) step 3). Similar studies that have widely recruited generally healthy patient portal users with minimal exclusion criteria have reported first-message response rates of 0.9%–7.5%,^{8–10} in contrast to preCheck-in recruitment which yielded a 37% response rate to the first effort of contact.

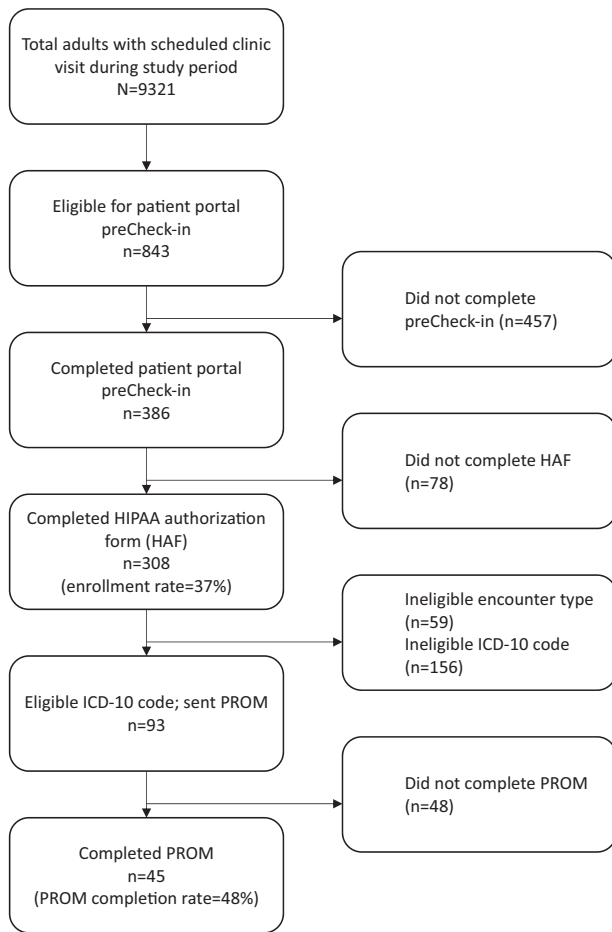


Figure 3. Cohort flow diagram. The PROM used as the after-visit survey was the PROMIS-29 + 2. See the *Materials and methods* regarding eligible encounter types and ICD-10 codes. Abbreviation: PROM, patient-reported outcome measure.

While we cannot generalize recruitment into this survey-based study to other types of recruitment efforts, preCheck-in recruitment may hold promise for enrollment into voluntary research registries or clinical trials. For context, patient portal-based efforts to recruit patients into research registries have reported enrollment rates of 4.8%–9.7%,^{9,16,41} and similar recruitment efforts for clinical trials have reported first-message response rates of 1.7%–14.7%.^{11–14,18} Given that lack of patient engagement is a major barrier to research recruitment,^{2,42,43} preCheck-in recruitment may help overcome this hurdle and improve rates of consent to be contacted about both future research and clinical trials.

Another potential advantage to preCheck-in recruitment is that it may help overcome problems with underrepresentation of less well-resourced and minoritized populations in study enrollment.^{10,16,44–47} Specifically, preCheck-in recruitment enrolled a cohort ($n = 308$) composed of more Black or African American patients and with an equal or greater social vulnerability index compared to the UCLA Health patient population. Of note, the sample that completed the questionnaire ($n = 45$) was less demographically diverse than both the enrolled sample and the health system population. While this study is unable to determine the reason(s) for this observed difference, possibilities include an artifact of small sample size (a single patient represented 2% of respondents), or true differential rates of attrition owing to historically marginalized

groups being less likely to use patient portals.^{48,49} Future research should investigate different methods to retain the enrolled cohort's diversity.

To contextualize the secondary outcome of survey completion rate, the most analogous comparisons are to efforts that have sent questionnaires to patient portal users who had already completed a HAF for involvement in future research. Such studies have reported that 18%–24% of patients who received a survey completed it,^{50,51} while preCheck-in recruitment produced a 48% survey completion rate. This rate is particularly notable given that response rates for clinics that are newly administering patient-reported outcomes measures (PROMs; as was the case here) are regularly under 10%,^{27,52} and more successful efforts collect a majority of PROMs during clinical encounters using a combination of tablets, patient financial incentives, multiple patient portal messages, research associates, leadership mandates, designated administrative support, and clinician engagement (the current study used none of these).^{27–30}

This investigation did not collect data on patient perception or usability. We hypothesize that the unexpectedly high enrollment rate may be explained by decreased barriers or “frictions” to completing the HAF as a result of embedding it within a pre-existing workflow.^{53,54} One plausible hypothesis for the high survey completion rate may be that the study information sheet and HAF signed during preCheck-in served as a precommitment to completing the after-visit survey. In contrast with one-off communication attempts, precommitments can increase the likelihood that someone engages in a target behavior through individuals' innate desire to be internally consistent with prior actions.^{55,56}

Limitations

This study has several limitations. First, we restricted enrollment to patients with an active patient portal and UCLA PCP. Second, preCheck-in recruitment requires patients to have an upcoming appointment. While these 2 factors may introduce selection bias,^{48,49} we demonstrated that both the patient portal activation rate in our overall sample (90%) and our enrolled population's sociodemographic diversity were similar to those of the UCLA Health patient population. Third, this was a 2-week single-center preliminary evaluation. Fourth, this study did not contain a control group to directly compare enrollment and response rates between preCheck-in recruitment and traditional portal messaging recruitment, and relied on retrospective comparisons to previously published studies. Finally, even though the voluntary study information sheet and HAF had to be selected and completely scrolled through before they could be signed (they were not automatically displayed during preCheck-in), we cannot exclude the possibility that bundling enrollment with preCheck-in decreased understanding of the informed consent by inadvertently signaling to patients that these forms should be completed as part of their upcoming health care.⁵⁷ Future research should investigate participant understanding of preCheck-in informed consent and whether this is associated with study response rates.

Conclusions

Embedding a study information sheet and HAF into the patient portal preCheck-in process yielded a 37% enrollment rate and 48% after-visit survey completion rate, all without any financial incentives, patient portal messages,

Table 1. Patient characteristics and rates of completing HIPAA authorization form (HAF) and the after-visit PROMIS-29 + 2 survey.

| | UCLA health (<i>n</i> = 1 014 135) ^a | Total study patients (<i>n</i> = 932) | preCheck-in eligible (<i>n</i> = 843) | Completed preCheck-in (<i>n</i> = 386) | Completed HAF (<i>n</i> = 308) | Survey eligible (<i>n</i> = 93) | Completed survey (<i>n</i> = 45) |
|--|---|--|--|---|------------------------------------|--|--------------------------------------|
| Female, no. (%) | 558 207 (55%) | 516 (55%) | 466 (55%) | 224 (58%) | 140 (56%) | 51 (54%) | 22 (49%) |
| Social vulnerability index (SD) ^b | 0.38 (0.26) | 0.42 (0.28) | 0.42 (0.27) | 0.42 (0.26) | 0.42 (0.27) | 0.46 (0.28) | 0.38 (0.25) |
| Age bands | | | | | | | |
| <18 years | 141 581 (n/a %) | 0 | 0 | 0 | 0 | 0 | 0 |
| 18–30 years | 219 559 (25%) | 76 (8%) | 137 (16%) | 36 (9%) | 34 (11%) | 5 (5%) | 1 (2%) |
| 31–45 years | 219 393 (25%) | 146 (16%) | 190 (23%) | 75 (19%) | 62 (20%) | 7 (8%) | 2 (4%) |
| 46–60 years | 214 846 (25%) | 212 (23%) | 274 (33%) | 88 (23%) | 78 (25%) | 27 (29%) | 11 (24%) |
| 61–75 years | 110 824 (13%) | 297 (32%) | 168 (20%) | 121 (31%) | 89 (29%) | 38 (41%) | 19 (42%) |
| >75 years | 107 932 (12%) | 201 (22%) | 74 (9%) | 66 (17%) | 45 (15%) | 16 (17%) | 12 (27%) |
| Race | | | | | | | |
| American Indian or Alaska Native | 3824 (0.4%) | 2 (0.2%) | 1 (0.1%) | 0 | 0 | 0 | 0 |
| Asian, Native Hawaiian/Pacific Islander | 88 242 (9%) | 129 (14%) | 113 (13%) | 51 (13%) | 30 (12%) | 12 (13%) | 6 (13%) |
| Black or African American | 42 535 (4%) | 105 (11%) | 96 (11%) | 46 (12%) | 28 (11%) | 12 (13%) | 1 (2%) |
| Middle Eastern or North African | 9445 (1%) | 17 (2%) | 17 (2%) | 8 (2%) | 6 (2%) | 5 (5%) | 1 (2%) |
| White or Caucasian | 404 343 (40%) | 314 (34%) | 275 (33%) | 117 (30%) | 70 (28%) | 30 (32%) | 17 (38%) |
| Multiple races | 29 049 (3%) | 29 (3%) | 27 (3%) | 15 (4%) | 12 (4%) | 2 (2%) | 1 (2%) |
| Other ^c | 166 298 (16%) | 203 (22%) | 189 (22%) | 93 (24%) | 76 (25%) | 24 (26%) | 16 (36%) |
| Unknown/declined | 270 398 (27%) | 133 (14%) | 125 (15%) | 56 (15%) | 51 (17%) | 8 (9%) | 3 (7%) |
| Ethnicity | | | | | | | |
| Hispanic, Latino/a ^d | 140 159 (14%) | 134 (14%) | 123 (15%) | 53 (14%) | 39 (16%) | 15 (16%) | 5 (11%) |
| Not Hispanic or Latino/a | 612 321 (60%) | 704 (76%) | 630 (75%) | 297 (77%) | 190 (76%) | 73 (78%) | 37 (82%) |
| Unknown/declined | 261 655 (26%) | 94 (10%) | 90 (11%) | 36 (9%) | 20 (8%) | 5 (5%) | 3 (7%) |

^a Patients seen at UCLA for any visit type or provider specialty at least once within the year prior to this study. Approximately 84% of this population have an active patient portal account.
^b Social vulnerability index (SVI) is a composite of 16 social factors (poverty, lack of vehicle access, crowded housing, etc.) for each US Census tract. The patient’s neighborhood SVI is used by the CDC as a surrogate for their own social determinants of health based on geocoding the patient’s address.⁴⁰ SVI exhibited 42% missingness for the UCLA Health population as a result of addresses being geocoded improperly or a problem with addresses themselves (format, typo, data entry error); there was no missingness for other populations.
^c Patients self-reported “other” as their race. This category is not an aggregation.
^d Includes Cuban, Puerto Rican, Mexican, Mexican American, Chicano/a, and any Spanish origin.
 Percentages calculated from within-column totals, and may not sum to 100% due to rounding.

administrative staff/research assistant support, or in-person/telephone communication. Both the enrollment and the survey response rates using preCheck-in recruitment were higher than what is typically seen for studies recruiting by patient portal messages, and the enrolled cohort was more sociodemographically diverse than our institution's general patient population. Hence, preCheck-in recruitment may enhance research study recruitment, contribute to more equitable sociodemographic representation in biomedical research, and warrants further investigation.

Acknowledgments

The authors would like to thank Sharon Evans for her assistance supervising and coordinating the build of the Sign Documents tab within the patient portal, and Arjun Kumar who was instrumental in programming the new patient portal functionality.

Author contributions

R.K.L., C.A.S., R.D.H., D.S.B., and S.M. provided substantial contributions to the conception or design of this work. R.K.L., C.A.S., F.J.S.V., and S.L.B. provided contributions to the analysis of data. All authors provided contributions to the interpretation of data for this work. R.K.L. drafted the manuscript and all authors made contributions to revise it for content. All authors gave final approval of the current version of the manuscript.

Supplementary material

[Supplementary material](#) is available at *Journal of the American Medical Informatics Association* online.

Funding

R.K.L. was supported by the NIH-NHLBI (grant number 1K38 HL164955-01). R.D.H. and C.A.S. were supported in part by the UCLA Resource Centers for Minority Aging Research Center for Health Improvement of Minority Elders (RCMAR/CHIME), NIH/NIA (grant number P30-AG021684). D.S.B., F.J.S.V. S.L.B., and C.A.S. were supported by the UCLA Clinical and Translational Science Institute (CTSI), NIH/NCATS (grant number UL1TR001881). C.A.S. was also supported in part by the NIH-NIA (grant number 5K24AG047899-06).

Conflicts of interest

None declared.

Data availability

The data underlying this article will be shared in a deidentified format on reasonable request to the corresponding author.

References

1. Harle CA, Golembiewski EH, Rahmanian KP, *et al.* Patient preferences toward an interactive e-consent application for research using electronic health records. *J Am Med Inform Assoc.* 2018;25(3):360-368. <https://doi.org/10.1093/Jamia/Ocx145>
2. Skelton E, Drey N, Rutherford M, Ayers S, Malamateniou C. Electronic consenting for conducting research remotely: a review of current practice and key recommendations for using e-consenting. *Int J Med Inform.* 2020;143:104271. <https://doi.org/10.1016/j.ijmedinf.2020.104271>
3. Chen C, Turner SP, Sholle ET, *et al.* Evaluation of a REDCap-based workflow for supporting federal guidance for electronic informed consent. *AMIA Jt Summits Transl Sci Proc.* 2019;2019:163-172.
4. Lerner C, Albertin C, Casillas A, *et al.* Patient portal reminders for pediatric influenza vaccinations: a randomized clinical trial. *Pediatrics* 2021;148(2):2020048413. <https://doi.org/10.1542/peds.2020-048413/179780>
5. Szilagyi PG, Albertin C, Casillas A, *et al.* Effect of patient portal reminders sent by a health care system on influenza vaccination rates: a randomized clinical trial. *JAMA Intern Med.* 2020;180(7):962-970. <https://doi.org/10.1001/jamainternmed.2020.1602>
6. Wijesundara JG, Fukunaga MI, Ogarek J, *et al.* Electronic health record portal messages and interactive voice response calls to improve rates of early season influenza vaccination: randomized controlled trial. *J Med Internet Res.* 2020;22(9):e16373. <https://doi.org/10.2196/16373>
7. Cutrona SL, Golden JG, Goff SL, *et al.* Improving rates of outpatient influenza vaccination through EHR portal messages and interactive automated calls: a randomized controlled trial. *J Gen Intern Med.* 2018;33(5):659-667. <https://doi.org/10.1007/s11606-017-4266-9>
8. Bruno B, Steele S, Carbone J, Schneider K, Posk L, Rose SL. Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals. *Health Technol (Berl).* 2022;12(1):59-67. <https://doi.org/10.1007/s12553-021-00628-5>
9. Samuels MH, Schuff R, Beninato P, *et al.* Effectiveness and cost of recruiting healthy volunteers for clinical research studies using an electronic patient portal: a randomized study. *J Clin Transl Sci.* 2017;1(6):366-372. <https://doi.org/10.1017/cts.2018.5>
10. Son H, Nahm ES, Zhu S, *et al.* Testing a model of patient portal use in adult patients. *J Nurs Scholarsb.* 2021;53(2):143-153. <https://doi.org/10.1111/jnu.12633>
11. Miller HN, Gleason KT, Juraschek SP, *et al.* Electronic medical record-based cohort selection and direct-to-patient, targeted recruitment: early efficacy and lessons learned. *J Am Med Inform Assoc.* 2019;26(11):1209-1217. <https://doi.org/10.1093/jamia/ocz168>
12. Miller HN, Charleston J, Wu B, *et al.* Use of electronic recruitment methods in a clinical trial of adults with gout. *Clin Trials.* 2021;18(1):92-103. <https://doi.org/10.1177/1740774520956969>
13. Plante TB, Gleason KT, Miller HN, *et al.*; STURDY Collaborative Research Group. Recruitment of trial participants through electronic medical record patient portal messaging: a pilot study. *Clin Trials.* 2020;17(1):30-38. <https://doi.org/10.1177/1740774519873657>
14. Yuh T, Srivastava T, Fiore D, *et al.* Using a patient portal as a recruitment tool to diversify the pool of participants in COVID-19 vaccine clinical trials. *JAMIA Open.* 2022;5(4):ooac091. <https://doi.org/10.1093/jamiaopen/ooac091>
15. Baucom RB, Ousley J, Poulouse BK, Rosenbloom S T, Jackson GP. Case report: patient portal versus telephone recruitment for a surgical research study. *Appl Clin Inform.* 2014;5(4):1005-1014. <https://doi.org/10.4338/ACI-2014-07-CR-0059>
16. Gleason KT, Ford DE, Gumas D, *et al.* Development and preliminary evaluation of a patient portal messaging for research recruitment service. *J Clin Transl Sci.* 2018;2(1):53-56. <https://doi.org/10.1017/cts.2018.10>
17. Forster M, Dennison K, Callen J, Georgiou A, Westbrook JI. Maternity patients' access to their electronic medical records: use

- and perspectives of a patient portal. *Health Inf Manag.* 2015;44(1):4-11. <https://doi.org/10.1177/183335831504400101>
18. Pfaff E, Lee A, Bradford R, *et al.* Recruiting for a pragmatic trial using the electronic health record and patient portal: successes and lessons learned. *J Am Med Inform Assoc.* 2019;26(1):44-49. <https://doi.org/10.1093/jamia/ocy138>
 19. Ness RB; Joint Policy Committee, Societies of Epidemiology. Influence of the HIPAA privacy rule on health research. *JAMA* 2007;298(18):2164-2170. <https://doi.org/10.1001/jama.298.18.2164>
 20. Wipke-Tevis DD, Pickett MA. Impact of the Health Insurance Portability and Accountability Act on participant recruitment and retention. *West J Nurs Res.* 2008;30(1):39-53. <https://doi.org/10.1177/0193945907302666>
 21. Krousel-Wood M, Muntner P, Jannu A, Hyre A, Breault J. Does waiver of written informed consent from the institutional review board affect response rate in a low-risk research study? *J Investig Med.* 2006;54(4):174-179. <https://doi.org/10.2310/6650.2006.05031>
 22. Ness RB. A year is a terrible thing to waste: early experience with HIPAA. *Ann Epidemiol.* 2005;15(2):85-86. <https://doi.org/10.1016/j.annepidem.2004.12.001>
 23. Armstrong D, Kline-Rogers E, Jani SM, *et al.* Potential impact of the HIPAA privacy rule on data collection in a registry of patients with acute coronary syndrome. *Arch Intern Med.* 2005;165(10):1125-1129. <https://doi.org/10.1001/archinte.165.10.1125>
 24. Wolf MS, Bennett CL. Local perspective of the impact of the HIPAA privacy rule on research. *Cancer* 2006;106(2):474-479. <https://doi.org/10.1002/cncr.21599>
 25. Beebe TJ, Ziegenfuss JY, Jenkins SM, Haas LR, Davern ME. Who doesn't authorize the linking of survey and administrative health data? A general population-based investigation. *Ann Epidemiol.* 2011;21(9):706-709. <https://doi.org/10.1016/j.annepidem.2011.03.007>
 26. Harle CA, Golembiewski EH, Rahmanian KP, *et al.* Does an interactive trust-enhanced electronic consent improve patient experiences when asked to share their health records for research? A randomized trial. *J Am Med Inform Assoc.* 2019;26(7):620-629. <https://doi.org/10.1093/jamia/ocz015>
 27. Sisodia RC, Dankers C, Orav J, *et al.* Factors associated with increased collection of patient-reported outcomes within a large health care system. *JAMA Netw Open.* 2020;3(4):e202764. <https://doi.org/10.1001/jamanetworkopen.2020.2764>
 28. Horn ME, Reinke EK, Mather RC, O'Donnell JD, George SZ. Electronic health record-integrated approach for collection of patient-reported outcome measures: a retrospective evaluation. *BMC Health Serv Res.* 2021;21(1):626. <https://doi.org/10.1186/s12913-021-06626-7>
 29. Borowsky PA, Kadri OM, Meldau JE, Blanchett J, Makhni EC. The remote completion rate of electronic patient-reported outcome forms before scheduled clinic visits—a proof-of-concept study using patient-reported outcome measurement information system computer adaptive test questionnaires. *JAAOS Glob Res Rev.* 2019;3(10):e19.00038. <https://doi.org/10.5435/JAAOSGlobal-D-19-00038>
 30. Ayers B, Lee E, Wood K, *et al.* Patient-reported outcomes measurement information system (PROMIS) in left ventricular assist devices. *Ann Thorac Surg.* 2022;113(3):859-865. <https://doi.org/10.1016/j.athoracsur.2020.11.011>
 31. Sherman JD, McGain F, Lem M, Mortimer F, Jonas WB, MacNeill AJ. Net zero healthcare: a call for clinician action. *BMJ* 2021;374:n1323. <https://doi.org/10.1136/bmj.n1323>
 32. Wasfi R, Stephens ZP, Sones M, *et al.* Recruiting participants for population health intervention research: effectiveness and costs of recruitment methods for a cohort study. *J Med Internet Res.* 2021;23(11):e21142. <https://doi.org/10.2196/21142>
 33. Kakumanu S, Manns BJ, Tran S, *et al.* Cost analysis and efficacy of recruitment strategies used in a large pragmatic community-based clinical trial targeting low-income seniors: a comparative descriptive analysis. *Trials* 2019;20(1):577. <https://doi.org/10.1186/s13063-019-3652-5>
 34. Harris PA, Taylor R, Minor BL, *et al.*; REDCap Consortium. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform.* 2019;95:103208. <https://doi.org/10.1016/j.jbi.2019.103208>
 35. 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):377-381. <https://doi.org/10.1016/j.jbi.2008.08.010>
 36. McCambridge J, Kalaitzaki E, White IR, *et al.* Impact of length or relevance of questionnaires on attrition in online trials: randomized controlled trial. *J Med Internet Res.* 2011;13(4):e96. <https://doi.org/10.2196/jmir.1733>
 37. University of California Office of the President. HIPAA Authorization Forms. Published 2023. Accessed February 7, 2023. <https://www.ucop.edu/ethics-compliance-audit-services/compliance/hipaa/hipaa-authorization-forms.html>
 38. Cella D, Choi SW, Condon DM, *et al.* PROMIS[®] adult health profiles: efficient short-form measures of seven health domains. *Value Health.* 2019;22(5):537-544. <https://doi.org/10.1016/j.jval.2019.02.004>
 39. Hays RD, Spritzer KL, Schalet BD, Cella D. PROMIS[®]-29 v2.0 profile physical and mental health summary scores. *Qual Life Res.* 2018;27(7):1885-1891. <https://doi.org/10.1007/s11136-018-1842-3>
 40. Centers for Disease Control (CDC)/Agency for Toxic Substances and Disease Registry (ATSDR). Social Vulnerability Index. Accessed March 30, 2023. https://www.atsdr.cdc.gov/placeand-health/svi/fact_sheet/fact_sheet.html
 41. Kannan V, Wilkinson KE, Varghese M, *et al.* Count me in: using a patient portal to minimize implicit bias in clinical research recruitment. *J Am Med Inform Assoc.* 2019;26(8-9):703-713. <https://doi.org/10.1093/jamia/ocz038>
 42. Caldwell PHY, Hamilton S, Tan A, Craig JC. Strategies for increasing recruitment to randomised controlled trials: systematic review. *PLoS Med.* 2010;7(11):e1000368. <https://doi.org/10.1371/journal.pmed.1000368>
 43. Tabriz AA, Fleming PJ, Shin Y, *et al.* Challenges and opportunities using online portals to recruit diverse patients to behavioral trials. *J Am Med Inform Assoc.* 2019;26(12):1637-1644. <https://doi.org/10.1093/jamia/ocz157>
 44. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in enrollment and use of an electronic patient portal. *J Gen Intern Med.* 2011;26(10):1112-1116. <https://doi.org/10.1007/s11606-011-1728-3>
 45. Pecina J, North F, Williams MD, Angstman KB. Use of an on-line patient portal in a depression collaborative care management program. *J Affect Disord.* 2017;208:1-5. <https://doi.org/10.1016/j.jad.2016.08.034>
 46. Halbert CH, Jefferson M, Allen CG, *et al.* Racial differences in patient portal activation and research enrollment among patients with prostate cancer. *JCO Clin Cancer Inform.* 2021;5(5):768-774. <https://doi.org/10.1200/CCL.20.00131>
 47. Obeid JS, Shoaibi A, Oates JC, Habrat ML, Hughes-Halbert C, Lenert LA. Research participation preferences as expressed through a patient portal: implications of demographic characteristics. *JAMIA Open.* 2018;1(2):202-209. <https://doi.org/10.1093/jamiaopen/ooy034>
 48. Wallace LS, Angier H, Huguet N, *et al.* Patterns of electronic portal use among vulnerable patients in a nationwide practice-based research network: from the OCHIN practice-based research

- network (PBRN). *J Am Board Fam Med*. 2016;29(5):592-603. <https://doi.org/10.3122/jabfm.2016.05.160046>
49. Ancker JS, Barrón Y, Rockoff ML, *et al*. Use of an electronic patient portal among disadvantaged populations. *J Gen Intern Med*. 2011;26(10):1117-1123. <https://doi.org/10.1007/s11606-011-1749-y>
50. Ganesh R, Ghosh AK, Nyman MA, *et al*. PROMIS scales for assessment of persistent post-COVID symptoms: a cross sectional study. *J Prim Care Community Health*. 2021;12:21501327211030413. <https://doi.org/10.1177/21501327211030413>
51. Kelly-Pumarol IJ, Henderson PQ, Rushing JT, Andrews JE, Kost RG, Wagenknecht LE. Delivery of the research participant perception survey through the patient portal. *J Clin Transl Sci*. 2018;2(3):163-168. <https://doi.org/10.1017/cts.2018.32>
52. Li J, Yazdany J, Trupin L, *et al*. Capturing a patient-reported measure of physical function through an online electronic health record patient portal in an ambulatory clinic: implementation study. *JMIR Med Inform*. 2018;6(2):e31. <https://doi.org/10.2196/medinform.8687>
53. Thaler RH, Sunstein CR. *Nudge: Improving Decisions about Health, Wealth, and Happiness*. Yale University Press; 2008.
54. Bhargava S, Manoli D. Psychological frictions and the incomplete take-up of social benefits: evidence from an IRS field experiment. *Am Econ Rev*. 2015;105(11):3489-3529. <https://doi.org/10.1257/aer.20121493>
55. Ariely D, Wertenbroch K. Procrastination, deadlines, and performance: self-control by precommitment. *Psychol Sci*. 2002;13(3):219-224. <https://doi.org/10.1111/1467-928000441>
56. Mertens S, Herberz M, Hahnel UJJ, Brosch T. The effectiveness of nudging: a meta-analysis of choice architecture interventions across behavioral domains. *Proc Natl Acad Sci USA*. 2022;119(1):e2107346118. <https://doi.org/10.1073/pnas.2107346118>
57. Falagas ME, Korbila IP, Giannopoulou KP, Kondilis BK, Peppas G. Informed consent: how much and what do patients understand? *Am J Surg*. 2009;198(3):420-435. <https://doi.org/10.1016/j.amjsurg.2009.02.010>