Patient Perceptions of Receiving COVID-19 Test Results via an Online Patient Portal: An Open Results Survey

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Abstract

Background In the United States, attention has been focused on "open notes" and "open results" since the Office of the National Coordinator for Health Information Technology implemented the 21st Century Cures Act Final Rule on information blocking. Open notes is an established best practice, but open results remains controversial, especially for diseases associated with stigma, morbidity, and mortality. Coronavirus disease 2019 (COVID-19) is associated with all three of these effects and represents an ideal disease for the study of open results for sensitive test results.

Objectives This study evaluates patient perspectives related to receiving COVID-19 test results via an online patient portal prior to discussion with a clinician.

Methods We surveyed adults who underwent COVID-19 testing between March 1, 2020 and October 21, 2020 who agreed to be directly contacted about COVID-19-related research about their perspectives on receiving test results via a patient portal. We evaluated user roles (i.e., patient vs. care partner), demographic information, ease of use, impact of immediate release, notification of results, impact of viewing results on health management, and importance of sharing results with others.

Results Users were mostly patients themselves. Users found the portal easy to use but expressed mixed preferences about the means of notification of result availability (e.g., email, text, or phone call). Users found immediate access to results useful for managing their health, employment, and family/childcare. Many users shared their results and encouraged others to get tested. Our cohort consisted mostly of non-Hispanic white, highly educated, English-speaking patients.

Conclusion Overall, patients found open results useful for COVID-19 testing and few expressed increased worries from receiving their results via the patient portal. The demographics of our cohort highlight the need for further research in patient portal equity in the age of open results.

Keywords

- patient portals
- patient access to EHI
- electronic health record
- open results

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Background and Significance

In the United States, significant attention has been paid to the sharing of electronic health information (EHI) due to the Office of the National Coordinator for Health Information Technology's (ONC) recent implementation of the information blocking requirements of the 21st Century Cures Act (Cures Act).[1] Section 4004 of the Cures Act defines *information blocking* as a practice that "…is likely to interfere with, prevent, or materially discourage access, exchange or use of electronic information…" The act explicitly identifies health information technology developers, exchanges, networks, and health care providers as actors who can be held accountable for information blocking. The ONC implemented the Cures Act through the Cures Act Final Rule (Final Rule).[2] The information blocking component of the Final Rule mandates that patients have reasonable access to their EHI contained within the United States Core Data for Interoperability (USCDI) standard. The USCDI includes allergies, clinical notes, immunizations, laboratory results, and many other clinically relevant EHI components. After delays related to the coronavirus disease 2019 (COVID-19) pandemic, the rule went into effect on April 5, 2021.

Prior to the effective date of the Final Rule, My Health at Vanderbilt (MHAV)—Vanderbilt University Medical Center's (VUMC) patient portal—experienced a trend toward increased patient use of laboratory and imaging results review features.[3] Historically, VUMC released most results to MHAV within days, only delaying longer for tests with perceived potential for patient emotional distress if disclosed without context provided by an interpreting clinician. Examples include human immunodeficiency virus testing, tumor markers, and genetic testing for Huntington disease. The increased use of these features locally by patients and care partners raised questions of patient perceptions surrounding the practice of open access to test results ("open results"), especially given increased national interest in the practice.

Patients with COVID-19 face stigma globally,[4] and the disease causes substantial morbidity and mortality,[5] which would have traditionally triggered delayed release of COVID-19 test results through MHAV. However, the overwhelming volume of COVID-19 testing and customer service calls during March and April of 2020 necessitated VUMC's decision to release COVID-19 testing results to patients immediately upon completion. This decision was made in part to alleviate an unmanageable volume of communication and to avoid overwhelming support staff.

Mounting evidence shows that patient access to EHI empowers patients and care partners better manage their health without burdening clinicians.[6–9] However, evidence surrounding the immediate release of sensitive test results remains controversial.[10] A study at our institution evaluating employee access to their own records in the electronic health record (EHR) suggests potential interest in patient access to test results.[11] Given COVID-19 disease's association with social stigma, morbidity, and mortality, understanding patient's reactions to receiving this diagnosis via patient portals would provide valuable insights that might apply to immediate release of other sensitive tests. We sought to contribute to the understanding of open results by evaluating the perspectives of patients who immediately received COVID-19 testing results via patient portals.

Objectives

To evaluate the perspectives of patients and care partners who viewed COVID-19 test results made immediately available via an online patient portal using an online survey.

Methods

Setting

VUMC is a large, private, nonprofit academic medical center in Nashville, Tennessee, United States. MHAV has more than 800,000 active users (defined as having accessed MHAV in the past 2 years) representing 62.4% of the 670,706 unique patients seen since April 1, 2020. Of these patients, 23,852 (3.5%) reported Hispanic ethnicity, with 9,637 (40.4%) having active MHAV accounts. A total of 362,647 (54.1%) patients reported white race, with 238,075 (65.6%) having active MHAV accounts. A total of 58,035 (8.7%) patients reported black or African American race, with 31,357 (54.0%) having active MHAV accounts. Many patients do not have race or ethnicity reported and level of education was not tracked.

Patient Population

The Vanderbilt Institute for Clinical and Translational Research maintained a registry of patients tested for COVID-19 who agreed to direct contact about COVID-19-related research opportunities—the Consent to Contact (C2C) database.[12] When a COVID-19 test is recorded in the EHR, the registry automatically extracts medical record numbers, demographics, type of encounter (i.e., inpatient vs. outpatient), and language preference. Using REDCap,[13] an automated message from Vanderbilt's Executive Vice President for Research is sent in English, Spanish, or Arabic (per preferred language) by email, when available, or by text message. The message introduces the database and invites patients to be included in the C2C database.

Adult patients from this registry who completed COVID-19 polymerase chain reaction (PCR) testing between March 1, 2020 and October 21, 2020 with valid email addresses who indicated English as their preferred language were invited to participate in the survey. (There were not financial resources available to support translation services for this preliminary study.) Patients were excluded if they had not accessed their MHAV account since the test had been ordered or if they had died since the test result was ordered. Data were extracted at the test level and later consolidated to the patient level when joined to the C2C registry, so patients with multiple COVID-19 tests conducted during the study period would be included if at least one of their test results had been viewed in MHAV. The cohort was extracted using the Clarity reporting database (Epic Systems Corporation, Verona, Wisconsin). Baseline age, sex, race, and ethnicity characteristics (from EHR data) for the surveyed cohort are provided in ►Table 1.

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Table 1 Baseline demographics for cohort invited to complete survey

	Invited to complete survey ($N = 1,390$)
Age	
Median [Q1, Q3][a]	41.5 [29.0, 56.0]
Race	
White	862 (62.0%)
Black	70 (5.0%)
Asian	13 (0.9%)
American Indian	3 (0.2%)
Multiple reported	6 (0.4%)
Unknown or declined to answer	436 (31.4%)
Ethnicity	
Hispanic, Latino(a), or Spanish origin	32 (2.3%)
Not Hispanic, Latino(a), or Spanish origin	786 (56.5%)
Unknown or declined to answer	572 (41.2%)

[a]Interquartile range.

Survey Design

We developed an online survey instrument to evaluate patients' impressions with open results, and implemented it using REDCap. The survey was adapted from a previously validated survey used to evaluate "open notes."[6,14] The survey evaluated the following domains: MHAV user role (i.e., patient vs. care partner), demographic information, ease of use, impact of immediate release, notification of results, impact of viewing results on health management, and importance of sharing results with others. For visual analog scale questions, the scale ranged from 0 to 100 where 0 is "Not important" and 100 is "Extremely important." The survey instrument in its entirety is available in the ►Supplementary Material (available in the online version) and is available for free re-use with attribution. During the introduction to the survey, patients were shown a screenshot to remind them of how results are presented in the EHR (see ►Supplementary Material for a complete copy of the survey, including the screenshot).

Analysis

Deidentified data were analyzed in aggregate using REDCap. We present descriptive statistics for multiple choice questions and visual analog scale questions and highlight key examples from free-text questions.

Results

During the study period, 25,359 patients who underwent COVID-19 PCR testing had logged into MHAV since the first test was ordered. Of this group, 1,390 (5.5%) had consented to direct contact about COVID-19 research opportunities and were invited via email to participate, had a valid email address, and were alive (per medical record) at the time of the survey. After the initial invitation (sent November 19, 2020), a single reminder email was sent later (January 27, 2021) to increase enrollment. There were 324 (23.3%) responses to the survey and 290 (21.0%) who confirmed they viewed the results of their COVID-19 PCR tests in MHAV. The full results for each question in the survey instrument are presented in the ►Supplementary Material (available in the online version). Highlights are described for each section below. User roles and demographics are presented in ►Table 2. Languages other than English and Spanish included French, Farsi, Arabic, Fante/Twi, and Dutch.

Ease of Use and Patient Confusion

When asked how confusing viewing their test result was on MHAV, 262 (95.2%) found the experience *not very confusing* or *not confusing at all.* Of the 13 (4.7%) respondents who expressed confusion, 11 reported difficulty interpreting their results and 2 could not find their results.

Impact of Immediate Release and Patient Worry

Of 275 who answered the question, 243 (88.4%) reported that they viewed their test result before discussing with a clinician. Of that 243, 99 (40.7%) stated viewing before discussing with a clinician *did not change* whether they were worried about their health, while 83 (34.2%) felt *less worried* and 12 (4.9%) felt *more worried*; 49 (20.2%) were never worried.

Notification of Results: Was It Useful for Patients?

Of 275 who answered the question, 234 (85.2%) found the default email reminder about their test result "A little useful," "Somewhat useful," or "Very useful," while 10 (3.6%) found it "Not at all useful." Thirty-one (11.3%) respondents (of 275) reported not seeing an email notification.

When asked how else users preferred to be notified besides email (multiple responses allowed), 119 (43.3%) did not prefer an alternative, while 120 (43.6%) preferred text messages, 58 (21.1%) preferred a phone call from a clinician, and 4 (1.5%) preferred to receive a letter in the mail.

Impact of Viewing Results on Health Management

Respondents were asked how important viewing their test result on MHAV was for *taking care of their health*, *making next steps in their care*, and *feeling in control of their care* using a visual analog score. Median response for *taking care of their health* was 86 (interquartile range [IQR]: 68–98), for *making next steps in their care* was 89 (IQR: 68–99), and for *feeling in control of their care* was 85 (IQR: 67–98).

Of 275 patients who responded to this section, 41 (14.9%) patients responded when asked: "Has something happened (good or bad) as a result of seeing your COVID-19 test result?" Of this group, 17 (41%) expressed relief, 6 (15%) reported affected work attendance, 6 (15%) expedited medical or surgical care, 4 (12%) changed quarantine (or nonquarantine) behavior, 4 (10%) expressed concerns about delays or validity of testing, 1 (2.5%) reported delayed surgical care, 1 (2.5%)

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Table 2 Demographic information for survey responders

Characteristic	*n* (%)	Characteristic (*cont.*)	*n* (%)
User role		Reported racial background	
Patient	310 (96.3%)	White	264 (90.7%)
Care partner	12 (3.7%)	Black or African American	14 (4.8%)
Language(s) spoken at home (multiple response)		American Indian or Pacific Native	1 (0.3%)
English	290 (99.0%)	Asian	5 (1.7%)
Spanish	11 (3.8%)	Native Hawaiian or Pacific Islander	0 (0.0%)
Spanish/Hispanic/Latino ethnicity		Other	10 (3.4%)
Yes	16 (5.5%)	Overall health	
No	277 (94.5%)	Excellent	80 (27.0%)
Other	6 (2.0%)	Very good	128 (43.2%)
Health care professional		Good	76 (25.7%)
Yes	38 (12.9%)	Fair	11 (3.7%)
No	256 (87.1%)	Poor	1 (0.3%)
Employment status		Education	
Employed for wages	179 (61.1%)	Some high school	1 (0.3%)
Self-employed	34 (11.6%)	High school or GED[a]	21 (7.1%)
Homemaker	10 (3.4%)	Some college, technical school, or 2-year degree	60 (20.4%)
Unemployed	12 (4.1%)	4-year college	99 (33.7%)
Retired	49 (16.7%)	Some graduate school	21 (7.1%)
Unable to work	3 (1.0%)	Masters or Doctorate	92 (31.3%)
Prefer not to answer	6 (2.0%)		

[a]General Educational Development certification.

reported changes in housing, and 1 (2.5%) reported using documentation for other purposes. Relief was expressed among both patients who self-reported negative and positive testing. Example responses from patients who tested negative are: *"Receiving a negative test result allowed my family (a) nd me to continue our normal daily lives. Very positive effect on my life,"* and *"Good, I was able to continue working and not worry about exposing someone."* Examples from patients who tested positive include: *"I was happy to at least know what was wrong with me"* and *"It was good to know I tested positive and needed to quarantine."*

Importance of Sharing Test Results with Others

Almost all respondents (259/286) reported sharing their COVID-19 test results with someone else (multiple response). Of that group, 235 (90.7%) shared with a family member or a relative, 147 (56.8%) with a friend, 80 (30.9%) with a health care provider, 24 (9.3%) with a large group of friends (e.g., through social media), and 51 (19.7%) with someone else. Of those 51, 49 (96%) provided additional information, with 46 (94%) sharing with an employer or a client, 2 (4%) with childcare providers, and 1 (2%) with a potentially exposed person.

When asked "How important is it to be able to share the results of your COVID-19 test with others?" using a visual analog scale, the median response was 77 (IQR: 50–97).

Of 300 respondents, 176 (58.7%) reported encouraging someone else to get tested as a result of receiving their test result. When asked about who they encouraged (of 174) (multiple response allowed), 103 (59.2%) encouraged non-household family and friends: 95 (54.6%) household contacts, 64 (36.8%) coworkers, 42 (24.1%) specific groups of friends, 36 (20.7%) neighbors, 9 (5.2%) social media, and 8 (4.6%) classmates of children.

Discussion

In a single-center survey of adult patients tested for COVID-19 who had logged into the MHAV patient portal and previously agreed to be contacted about COVID-19 research, patients and care partners expressed positive sentiments about the experience of receiving their test results on MHAV. Most users were patients themselves, with a very small proportion of respondents representing patient care partners. Very few users found the use of the patient portal confusing, and most were not more worried after seeing their results. While most users were comfortable with email as a primary notification tool, there were mixed preferences between email, text messaging, and discussion with a clinician prior to viewing results. This variety of patient preferences highlights the importance of patient portals supporting multiple notification options and the

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need for clinicians to counsel patients when ordering tests that will become available on a patient portal.

There were varied consequences of receiving test results online with employment, health care, and childcare implications. Many respondents reported a sense of relief from receiving the results via MHAV (with both negative and positive test results). None of those surveyed specified whether a positive test provided additional anxiety (and this question was not specifically asked). Users overwhelmingly believed viewing the test result on MHAV was important for taking care of their health, for making next steps for their health care, and for helping them feel in control of their health care. Most users shared their result with someone else, including family members, friends, health care providers, employers, childcare facilities, and large networks via social media. Users overall felt sharing was important, but less so compared with how important viewing results was for managing their health care. Many users encouraged others to get tested.

Overall, users perceived the receipt of COVID-19 PCR test results as beneficial in multiple domains. For our cohort, we believe the benefits far outweigh the risks. Clinicians practicing in an open results environment might avoid possible confusion by discussing the test result process with patients before ordering tests as a way of screening patients who need closer guidance.

There are several significant limitations to our study. We did not stratify these results based on test positivity, which due to a higher number of negative tests in the population may lead to missed sentiments from patients who tested positive. However, in the free response section, several users identified themselves as having tested positive and still found the experience useful and felt it empowered them to manage their health care and their lives.

Our survey population represents a very small sample of the overall number of patients who logged into MHAV during the study period and of patients who viewed their COVID-19 results on MHAV (since we limited contact to those who enrolled in the C2C registry). Further studies would benefit from contacting a broader fraction of the population.

Our population was less diverse than would be expected based on our overall patient population, with a very large proportion of white, primarily English-speaking, educated patients. This homogeneity particularly limited our ability to perform meaningful subgroup analyses that might identify preferences between patients belonging to different racial, ethnic, or language groups. This is especially important in the case of COVID-19, where there are known race-related outcome disparities.[15] The homogeneity of our population limits generalizability of our findings and raises concerns about inequitable access to patient portals among patients from underrepresented groups and with less education. Lack of trust in research may also have contributed (as our patients had previously agreed to be contacted for research). Since the survey instrument was disseminated via email, lack of access to technology or internet may also have contributed via systematic inequities. Finally, as the survey instrument was only distributed in English, language barriers may have also played a role. Further study is needed in each of these areas. Additionally, while this study provides evidence that patients are capable of handling sensitive test results communicated via online patient portals without immediate counseling, ongoing research into best practices when communicating these results is needed, especially for those groups who were poorly represented in our study.

To address the study limitations and bias in our results, the authors have started planning a larger, multicenter survey study, which will include a more diverse patient population and other testing modalities. In addition to generalized understanding, we hope this next study will allow for more robust subgroup analyses to better understand user-experience differences between patients and care partners with different ethnic, racial, and language backgrounds while using patient portals for open results. An additional feature of interest would be evaluating association between frequent patient portal use and comfort viewing open results.

Conclusion

Open notes is an established practice, but open results remains controversial. In this study, adult patients and care partners surveyed about the impact of open results for COVID-19 testing expressed that immediate access to results empowered them to better manage their health, personal lives, and professional lives with minimal increased worry. The skew toward non-Hispanic white, English-speaking, highly educated patients in this study highlights the need for future research on equitable access to patient portals and the acceptability of use in wider populations.

Clinical Relevance Statement

Overall, patients and care partners expressed positive sentiment about the use of open results for COVID-19 testing but expressed varied notification preferences. Given widespread access, clinicians should discuss the availability of test results with patients and counsel them in advance on anticipated next steps based on possible results. Patient portal developers and administrators should provide flexible notification options for users with varied preferences.

Multiple Choice Questions

1. Most patients felt that viewing their COVID-19 results via patient portal was:
   a. Very confusing.
   b. Somewhat confusing.
   c. Not very confusing.
   d. Not confusing at all.

   Correct Answer: The correct answer is option d. Most patients did not find accessing their test result on the patient portal confusing at all.

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2. How did most patients prefer to receive notifications about a result in the patient portal?
   a. Phone call from clinician.
   b. Text message from patient portal.
   c. Email from patient portal.
   d. Mix of the above.

Correct Answer: The correct answer is option d. Patients varied in the way they preferred to be contacted about results via the patient portal. This highlights the importance of discussing the use of online portals with patients before sending tests that will not return in real time.

Protection of Human and Animal Subjects

This study was reviewed by the Vanderbilt University Institutional Review Board and met 45 CFR 46.104 (d) category (2)(4) for Exempt Review.

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Conflict of Interest

None declared.

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