ORIGINAL RESEARCH ARTICLE Volume 4 (2023), No. 2, pp. 20-28 DOI: 10.15367/ch.v4i2.635

Addressing Digital Health Equity Through Diverse User Personas

ASLI MCCULLERS, BS,¹ NAHEED AHMED, PHD, MA² 1 University of Delaware; MedStar Health Research Institute 2 Grossman School of Medicine, New York University

Correspondence: amccul@udel.edu (Asli McCullers)

With patient portals emerging as a powerful digital health innovation, the work described in this manuscript strives to ensure that these innovations occur with health equity at the forefront. This work approaches this uniquely through the data-informed development of user personas. This will be particularly useful for developers and healthcare institutions when considering the diverse needs of potential patient portal users of historically marginalized backgrounds.

Keywords: Patient portals, User personas, Health equity, Digital Health, Health care innovation

Introduction

There are numerous benefits to patient portal platforms including facilitation of provider-patient communication and improved patient health outcomes.1 Research shows that patients who enroll in and use patient portal accounts have improved health outcomes and are more engaged in their health.^{2, 3} However, patient portal usage data indicates significant disparities by patient subpopulations, specifically among elderly, racial and ethnic minorities, lower technology and health literate, and safety-net populations.4,5,6 There is an urgent need for healthcare systems and

Background

While designing these user personas, we have considered various barriers that influence patient portal usage. Low digital literacy has been evidenced as a strong barrier to patient portal usage, as navigating online systems can be arduous for those who are not adept in accessing digital resources.^{7,8,9} Low health literacy serves as an additional barrier, as those with low health literacy are less likely to find health information

developers to close these gaps in usage, so that patient portal platforms are accessible and approachable for these patient subpopulations. To facilitate the design and operation of inclusive patient portal platforms, we present user personas incorporating different patient subpopulations, and how to meet the technology and health needs of each persona. These user personas were developed based on research and a review of the literature to maximize patient portal usage across patient subpopulations.

technology useful due to limited understanding of the implications and best uses of these resources.⁹ Limited access to computers, smart phones, or the Internet may also prevent full uptake to patient portals, as these tools are largely web-based. People with disabilities, lowincome communities, older populations, and racial and ethnic minorities are the most at risk to being impacted by these barriers, as the marginalization of these groups have led to differing levels of education, health and digital literacy, internet access, and other determinants of health that shape their access to

Methods

The user personas we designed are collectively informed by two patient portal studies performed by a medium academic healthcare system in the Mid-Atlantic region, which both contained data on patient portal users and non-users. We additionally developed these personas based on findings from an environmental scan of peer-reviewed and grey literature.

The first study we leveraged to inform our user personas aimed to examine demographic differences between patient portal users and non-users, as well as examine health literacy, patient self-efficacy, technology usage and media and technology attitudes between patient portal users and non-users.12 This data was collected from an online survey completed by a sample of 489 Amazon Mechanical Turk (MTurk) workers from December 2021 to January 2022. Data were analyzed using latent class analysis (LCA) and multivariate logistic regression models. Among the most relevant findings for the current analysis on user personas were indications that patient portal usage was high among patients with health insurance, a primary care provider, and patients with comorbid disorders.¹²

The second study we used to inform our user persona designs aimed to examine patient portal usage from pre- to post-onset of the COVID-19 pandemic, as well as to assess differences in portal usage by chronic disorders from pre- to post-onset of the pandemic.¹³ Patient portal data were extracted and analyzed from a sample of 153,628 unique patients with patient portal account receiving care in a medium, Mid-Atlantic-based academic healthcare system. Patient portal usage from pre-onset (March 2019-February 2020) to postonset of the COVID-19 pandemic (March contemporary care resources such as patient portals.^{10,11}

2020-February 2021). A demographic analysis and a series of mixed effects models confirmed that patient portal usage was higher among these patient populations (insured, have primary care provider, have comorbidities of any type) and among patients with a disability, high levels of patient self-efficacy, and positive attitudes toward use of technology.¹³ Other results relevant to our user personas evidenced in both studies include higher income and education levels among patient portal users, more users living in urban locations, and high health literacy among non-users.^{12, 13}

An environmental scan of the peerreviewed and grey literature aligned with the findings from these two studies. This scan also provided additional details on differences among patient portal users and non-users beyond the scope of the two studies. This scan included studies found using PubMed and Google Scholar, as well as other scholarly content found in standard Google search engine. This scan included a global array of studies, including research based out of the United States, Australia, Canada and the Netherlands. Our search terms, which were adapted depending on database or search engine type, included phrases such as: "user personas"; "patient portal users"; "patient portal nonusers"; "patient portal characteristics"; "patient portal disparities"; "digital health equity" and others. The additional information we found included data suggesting that women more often identify as users when compared to men, and that average users are typically younger than non-users.14,15 Racial differences have also been noted, as White and Asian-Americans are more likely to utilize patient portals than Hispanic/Latinx or African Americans.^{10, 11, 16}

Use Personas

A total of three patient portal user personas were developed (Table 1). These personas are defined by health utilization patterns, technology barriers, and email and computer usage.

Use Fersonas	User Persona 1	User Persona 2	User Persona 3
Healthcare Utilization	 No primary care provider No health insurance Low use of healthcare services 	 Has primary care provider Has health insurance Inconsistent use of healthcare services 	 Has primary care provider Has health insurance Regular use of healthcare services for preventative and/or screening appointments, and/or management of acute and chronic condition
Technology Barriers	 None or limited access to technological devices None or limited access to Internet Limited comfort with use of technology Prefers receiving physical copies of medical records or paperwork 	 Moderate access to technological devices and Internet Out-of-date or poor quality technological devices Limited comfort with use of technology Mixed preferences about modality of receiving medical records and paperwork 	• No to minimal barrier
Email and Computer Usage	• No active email account	 Has active email account Email account used inconsistently 	 Has an active email account Email account used regularly Can access email via multiple devices (cellular device, computer, tablet, etc.)

Healthcare System	Technology assessment of patient		
mputs	• Provide resources (internal and external) to address barriers		
	• Technology support		
	o Assistance with setting up email and patient portal accounts		
	o Support for issues with patient portal accounts		
	 Provide secure access to device for patients in provider waiting room/lobby/office 		
Developer Inputs	• Integrate accessibility features into patient portal accounts for patients with vision, hearing and other disabilities		
	• Pilot test patient portal platform with patients from different backgrounds (low to high technology and health literacy; patients with vision, hearing, and other disabilities; low to high income; low to high education levels; diverse racial and ethnic backgrounds; diverse age groups; diverse gender/sexuality representation).		
	• Survey potential users from different backgrounds regarding which features may be of most useful		
	may be of most useful		

Type #1

The first user persona is someone who faces significant barriers to accessing technology and healthcare services. Barriers to healthcare include lack of health insurance which severely limits use of healthcare services due to high out of pocket fees and patients typically do not have a primary care provider. Technology barriers include none to minimal access to devices needed for patient portal usage (e.g. computer, tablet, smart phone) and none to limited access

Туре #2

The second user persona faces some barriers in accessing technology and healthcare services but has more points of access when compared to the first user. Though this user has both health insurance and a primary care provider, their healthcare utilization behaviors are inconsistent due to barriers such as lack of transportation, inability to take time off from work, and medical mistrust. These users have to Internet. These technology barriers are shaped by structural factors, such as limited finances to purchase devices and pay for Internet services and contribute to low technology literacy and comfort with technology. The absence of an actively used email account is another barrier, which complicates enrollment and usage of patient portal platforms.

moderate access to technology including both Internet and personal internet-accessible devices for access to patient portals. However, their device is slow and outdated, which makes checking emails and using patient portals frustrating. Thus, these users tend to prefer printed copies of medical records and other health status updates.

Туре #3

The third user persona faces minimal barriers to patient portal use. These users have a trusted primary care provider, as well as reliable health insurance. These users regularly use healthcare services for preventive and/or screening appointments to manage acute and chronic conditions. These users are well

We also provide insights on critical healthcare systems and developer inputs for consideration of a maximally equitable patient portal design. On the healthcare system level, we posit that a technology assessment of patients, including identification of access barriers as well as provision of internal and external resources, should be performed. We also recommend technical support, including assistance with setting up both email and patient portal accounts, support for any issues with patient portal accounts and provision of secure devices for use in the waiting room, lobby, or office. Developer inputs should include integration of accessibility features within patient portal accounts for patients with vision, hearing and other disabilities. Specifically, these features could potentially include simple, effective text enlargement features and high-quality text-to-

Discussion

Our work explores the development of equity-oriented user personas for patient portal use. This work intends to serve as a launchpad for development and innovation as digital health moves to the forefront of medical care. The development of user personas provides thoughtful insights of the situational details that may explain trends in patient portal usage. While user personas are unable to directly define the authentic lived experiences of potential users, they are pivotal in ensuring accessibility, diversity and inclusion are well embedded into the design of patient portals. adjusted to technology use, with strong internet access and an up-to-date array of Internetaccessible devices (e.g. smartphone, computer, tablet). These users regularly monitor their emails and are open to downloading and using patient portal applications.

speech and voice typing capabilities. We recommend that developers pilot test the patient portal platform among a diverse sample of users, with intentional effort to include the following demographics; those with both low to high technology and health literacy; patients with vision, hearing, and other disabilities; patients with various income levels; patients with various education levels; diverse racial and ethnic backgrounds; diverse age groups and diverse gender/sexuality groups. Potential users from these groups should be surveyed regarding which particular patient portal features (i.e., admission summaries, records access, messaging provider, etc.) would be most useful to them. Centering feedback from a diverse group will allow for an equity-focused approach in the patient portal design.

This study is uniquely informed by patient portal usage studies conducted out of a Mid-Atlantic based medical system, and a scan of the peer reviewed and grey literature. Insights from these sources provided comprehensive data on diverse patient subpopulations and healthcare needs related to technology. Our user personas speak to a multitude of both barriers and facilitators to engaging in patient portals, including access to Internet-accessible devices, insurance status and primary care. We contextualized this further by noting that psychosocial factors such as medical mistrust, inability to take time off of work and digital

hesitancy or frustration in the characterization of these personas. In continued work, we encourage developers, alongside researchers and providers, to be intentional about amplifying the feedback of historically marginalized populations, including people with disabilities, racial and ethnic minorities, and LGBTQIA+ identifying individuals in the early design stages of patient portals. In doing so, patient portals and digital health at-large may evolve to be optimally inclusive and equity oriented.

The limitations of this analysis should be considered in future directions for this work. Our personas could certainly be improved with increased dimensionality to authentically speak to the complexities of health inequity. In future analysis, these user personas should be strengthened through use of driving factors, facilitated dialogue and modeling to extend their reach beyond surface-level variables we have centered, such as race, insurance status and

Conclusion

With digital health being increasingly adopted in healthcare, it is critical for inequalities to be considered in the design of tools like patient portals. Our data addresses this need through the development of uniquely informed user personas that highlight the diverse social, technological, and health related

income level. More dynamic, highly tailored preferences should also be included to make future persona designs maximally engaging, inclusive and rooted in advocacy and equity, including patient's personal care goals, considerations, occupational personality attributes and lived experiences with discrimination that shape a patient's journey in pursuing care. We also note that this work should be further grounded in other elements of innovative strategies for health technology research, including User Experience (UX) and Customer Experience (CX) research strategies. Lastly, these studies were partially informed by an environmental scan, which may not have produced as robust of a basis as a systematic literature review, for example. Future studies should aim to be more systematic in the grounding of literature to ensure that personas have a maximally strong foundation.

needs that many real patients may resound with. In this, we encourage developers, researchers and providers alike to center health equity in ongoing activities that contribute to the expansion of digital health and medicine.

Acknowledgments

We would like to acknowledge Jason Brown, PhD, RN for his contributions to this project.

Conflicts of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Funding Sources

This study was funded by Grant Number R03HS026298-02 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

Statement of Contributions

These authors contributed equally to the writing of this manuscript. Asli McCullers played the primary role in developing this work into a publishable manuscript, and wrote the abstract, background, segments of the "User Persona" section, discussion and conclusion. Naheed Ahmed conceptualized the vision for this paper, and wrote the introduction, methods and segments of the "User Personas" section.

References

- 1. Sorondo B, Allen A, Fathima S, Bayleran J, Sabbagh I. Patient portal as a tool for enhancing patient experience and improving quality of care in primary care practices. *eGEMs (Generating Evidence & Methods to improve patient outcomes).* 2017;4(1):31. doi:10.13063/2327-9214.1262
- 2. Irizarry T, Shoemake J, Nilsen ML, Czaja S, Beach S, DeVito Dabbs A. Patient portals as a tool for Health Care Engagement: A mixed-method study of older adults with varying levels of health literacy and prior patient portal use. *Journal of Medical Internet Research*. 2017;19(3). doi:10.2196/jmir.7099
- 3. Urowitz S, Wiljer D, Dupak K, et al. Improving diabetes management with a patient portal: A qualitative study of diabetes self-management portal. *Journal of Medical Internet Research*. 2012;14(6). doi:10.2196/jmir.2265
- Ronda MCM, Dijkhorst-Oei L-T, Rutten GEHM. Reasons and barriers for using a patient portal: Survey among patients with diabetes mellitus. *Journal of Medical Internet Research*. 2014;16(11). doi:10.2196/jmir.3457
- Nijland N, van Gemert-Pijnen JEWC, Kelders SM, Brandenburg BJ, Seydel ER. Factors influencing the use of a web-based application for supporting the self-care of patients with type 2 diabetes: A longitudinal study. *Journal of Medical Internet Research*. 2011;13(3). doi:10.2196/jmir.1603
- 6. Zarcadoolas C, Vaughon WL, Czaja SJ, Levy J, Rockoff ML. Consumers' perceptions of patientaccessible electronic medical records. *Journal of Medical Internet Research*. 2013;15(8). doi:10.2196/jmir.2507
- Baldwin JL, Singh H, Sittig DF, Giardina TD. Patient portals and health apps: Pitfalls, promises, and what one might learn from the other. *Healthcare*. 2017;5(3):81-85. doi:10.1016/j.hjdsi.2016.08.004
- 8. Kemp E, Trigg J, Beatty L, et al. Health Literacy, Digital Health Literacy and the implementation of Digital Health Technologies in Cancer Care: The Need for a strategic approach. *Health Promotion Journal of Australia*. 2020;32(S1):104-114. doi:10.1002/hpja.387
- 9. Tieu L, Sarkar U, Schillinger D, et al. Barriers and facilitators to online portal use among patients and caregivers in a safety net health care system: A qualitative study. *Journal of Medical Internet Research*. 2015;17(12). doi:10.2196/jmir.4847
- 10. Walker DM, Hefner JL, Fareed N, Huerta TR, McAlearney AS. Exploring the digital divide: Age and race disparities in use of an inpatient portal. *Telemedicine and e-Health*. 2020;26(5):603-613. doi:10.1089/tmj.2019.0065
- 11. Gordon NP, Hornbrook MC. Differences in access to and preferences for using patient portals and other eHealth Technologies based on race, ethnicity, and age: A database and survey study of seniors in a large health plan. *Journal of Medical Internet Research*. 2016;18(3). doi:10.2196/jmir.5105
- 12. Ahmed N, Brown J, Parau C, McCullers, A, Sanghavi K, Littlejohn R, Wesley D. Bridging the Digital Health Divide: Characterizing Patient Portal Users and Non-Users in the U.S. *In Press, Medical Care.* 2023.
- 13. Ahmed N, Sanghavi K, Mathur S, McCullers A. Patient Portal Use: Persistent Disparities from Pre- to Post-Onset of the COVID-19 Pandemic. *Under Review*. 2023.

- Oest SER, Hightower M, Krasowski MD. Activation and utilization of an electronic health record patient portal at an Academic Medical Center—impact of patient demographics and geographic location. *Academic Pathology*. 2018;5:2374289518797573. doi:10.1177/2374289518797573
- 15. Huang J, Chen Y, Landis JR, Mahoney KB. Difference between users and Nonusers of a patient portal in health behaviors and outcomes: Retrospective cohort study. *Journal of Medical Internet Research*. 2019;21(10). doi:10.2196/13146
- 16. Foster B, Krasowski MD. The use of an electronic health record patient portal to access diagnostic test results by emergency patients at an Academic Medical Center: Retrospective Study. *Journal of Medical Internet Research*. 2019;21(6). doi:10.2196/13791