

Consumer Health Informatics for Racial and Ethnic Minoritized Communities: Minor Progress, Major Opportunities

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Summary

Objective: By reducing barriers to accessing health services and by supporting health management, consumer health informatics has the potential to reduce health disparities. Yet, technologies are still being designed without considerations for racial and ethnic minoritized populations. This paper reviews consumer health informatics research within this population to assess for whom and how such technologies are being designed.

Methods: We searched four databases from January 2020–December 2021 for literature focused on consumer health informatics and racial and ethnic minoritized populations. We extracted information about the study population, geographic location, stage of the design lifecycle, culturally tailored approaches, community engagement strategies, and considerations for the social determinants of health.

Results: Twenty articles were included in the review. Most of the included literature were original research articles that tested health management interventions focused on one racial or ethnic minoritized population primarily within a confined geographic area within the United States. Seven studies described the extent to which an intervention was culturally tailored, including modify-

ing the content, interface, functionality, and platform. Community engagement strategies varied, but few articles employed robust approaches. Lastly, seven studies detailed considerations for the social determinants of health, including providing hardware to access interventions and incorporating information about community-based resources within an intervention.

Conclusions: There has been moderate progress in consumer health informatics focused on racial and ethnic minoritized populations and many opportunities remain for these technologies to be used as an approach to address health disparities. Future research should utilize community engagement strategies to design interventions that are attune to multiple racial and ethnic minoritized populations across geographic regions in addition to numerous intersectional identities and multiple co-morbidities.

Keywords

Consumer health informatics; health equity; ethnic and racial minorities; review

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1 Introduction

The use of consumer health technology has the potential to improve health outcomes and reduce health care spending by increasing access to health information and health care professionals as well as providing individuals the tools to manage patient work across home, community, and clinical settings [1, 2]. Consumer health informatics includes a “wide range of hardware, software, and web-based applications that allow patients to participate in their own health care via electronic means” [3]. The benefits of these technologies may not be equitably

distributed as most current technologies implemented are not designed with considerations for the full contexts in which they are embedded, including but not limited to diverse social, cultural, and economic contexts [4, 5]. Although the digital divide across racial and ethnic groups in terms of technology ownership is closing [6], individuals from minoritized populations are less likely to use health technology such as patient portals [7]. Moreover, health informatics interventions have historically tended to benefit those who are most socially advantaged [8]. For example, wearable devices that use photoplethysmographic

green light signaling are less accurate for those with darker skin tones [9]. Thus, there is an ethical imperative to include consideration of the experiences of racial and ethnic minoritized populations in the design of consumer health technology. As the experience of being in a racial and ethnic minoritized population is not uniform and can also differ based on other identities (e.g., gender identity, sexual orientation, disability status, socioeconomic status, and geographic setting), there is also a need to become more sophisticated in our approaches to designing consumer health technologies that are appropriate across and at the intersections of cultures and identities.

To appropriately address the needs of racial and ethnic minoritized populations in consumer health informatics, it is necessary to understand the range of lived experiences and social determinants of health shaping the experience of health and health care [10]. Participatory design methods can begin to elucidate these experiences by including the perspectives of the intended end users in the design process. Though to meaningfully engage historically marginalized populations in research, tenets from community-based participatory research can be used to create appropriate consumer health informatics interventions that are more likely to be accepted and utilized by the intended users. This approach from the health sciences engages researchers and community stakeholders as equal partners in all steps of the research process [11]. To provide a survey of how consumer health technologies are currently being designed with considerations for racial and ethnic minoritized populations, this review will evaluate recent consumer health informatics literature with a focus on these

populations. This review provides a synthesis of the recent advances and opportunities for the informatics community in terms of creating and evaluating technologies that incorporate the needs and preferences of racial and ethnic minoritized populations.

2 Methods

We conducted a literature review on consumer health information technology with a focus on racial and ethnic minoritized populations. With assistance from a health sciences librarian, we searched the literature from 2020 through mid-December of 2021 in the following databases: Association for Computing Machinery Digital Library, Cumulative Index to Nursing and Allied Health Literature, PubMed, and Web of Science. The following concepts informed the specific search terms: consumer health informatics; equity, bias, and literacy; and racial and ethnic minoritized populations. Examples of the search terms are available in Table 1 and were modified to fit with the specific ontologies of the search databases (e.g., MeSH terms as used in PubMed). The search terms were restricted to only the title and abstract. Categories for data extraction were derived from both deductive (e.g., study population) and inductive (e.g., culturally tailored approaches, community-based methods, and considerations for the social determinants of health) approaches to qualitative content analysis [12].

3 Results and Discussion

3.1 Overview

A total of twenty articles were included in the review [13–32]. A significant portion of the included articles were original research (n=18) [13, 15–26, 28–32]. One perspective piece and one review were also included [14, 27]. The publication venues were mostly in journals focused on medicine and public health [13–17, 19, 20, 22–25, 28, 30, 32], with only four of the included articles published in traditional informatics journals [18, 21, 27, 29] and two published in the proceed-

Table 1 Search terms.

Concept	Search Terms
Consumer health informatics	Consumer health Consumer health informatics Consumer health IT Consumer health information technology Consumer HIT Consumer health information
Equity, bias, and literacy	Bias Co-design Community based participatory research Community engagement Cultural informed design Culturally-responsive Disparities Disparity Equality Equities Equity Inclusion Inclusive Inequal Inequity Justice Literacy Participatory Representation Unequal Universal design Universalism
Racial and ethnic minoritized populations	Anti-racism BIPOC Ethnic Ethnic Groups Marginalized Minority Race Race Factors Race Relations Racial Groups Racism Underrepresented

ings of computing-related conferences [26, 31]. The relatively few articles published in the informatics literature suggest that research focused on this intersection of consumer health IT and racial and ethnic minoritized populations has yet to become an integral part of the conversation in this field.

3.2 Populations and Topics

Most of the included literature focused on a specific racial or ethnic group, rather than focusing on creating more broadly generalizable interventions incorporating the needs of multiple minoritized communities. The articles that focused on general technologies explored the inclusion and specific views of

racial and ethnic minoritized populations [18, 19, 27]. Though most literature had a particular emphasis on African Americans [13, 14, 16, 21, 23–25, 28], there is still a dearth of literature focused on designing consumer health IT for this community. There were significantly fewer articles focused on indigenous communities [15, 17, 20, 30, 31] and Hispanic populations [22]. Moreover, the primary setting of the literature reviewed was in the United States [13–25, 28, 30, 32], with most articles focused on a specific region within the United States. As such, there is an opportunity for informatics research to expand to other populations as well as global regions, such as Asian Americans in the United States and refugees across countries.

Though the literature reviewed included a range of health conditions studied, including chronic conditions, sexual and reproductive health, maternal health, alcohol and substance abuse, and mental health, the articles had a singular focus on a particular condition. As a result, there is a need to understand how informatics can support multiple types of conditions. Often racial and ethnic minoritized populations experience disparities across multiple types of conditions and many individuals live with multiple conditions simultaneously. Future work should focus on designing for a myriad of comorbidities that are highly prevalent within racial and ethnic minoritized communities (e.g., diabetes, hypertension, and depression in the African American community [33]).

There is a not only a clear need to expand informatics work beyond the typical populations and conditions studied but also a need to understand how informatics can support those with multiple minoritized identities. Some of the articles included focused on the intersections of race and ethnicity with other identities such as age and income status [16, 26, 29, 32]. In particular, one study explored the intersections of ethnicity, gender identity, and sexual orientation [22]. With a concentration on improving HIV knowledge and testing among Hispanic sexual minority men and transgender women, this study provided design guidance for a particularly marginalized and hard to reach population, demonstrating the ways informatics can address multiple marginalized identities at

once. Creating technologies that are more attune to the full range of identities and life experiences is essential for limiting intervention generated inequities [8]. As such, there is a need for the informatics community to examine how best to adapt and scale interventions that were originally designed for individuals holding a particular identity within a circumscribed geographic location. There is also need for new informatics initiatives to begin the design process with multiple intersectional identities and geographic locations in mind.

3.3 Stage of the Design Lifecycle

Along an intervention development continuum, the included articles discussed interventions at different stages of the design and evaluation lifecycle, from needs assessment to randomized controlled trials. The interventions that were at the needs assessment phase described formative qualitative research to produce initial design guidance [15, 17, 31]. Many of the articles reviewed were pilot feasibility studies [13, 16, 21–23, 25, 26, 28, 32]. A significant proportion evaluated the feasibility and acceptability of mobile health, including both text-based and app-based interventions [13, 16, 22, 23, 25, 26, 32]. A few evaluated telehealth systems [21, 28]. Two of the articles included were randomized controlled trials (RCTs), with one testing a computer-based intervention [24], and the other a text-based intervention [30]. As most of the studies included were in the pilot phase, we would expect to see more RCTs in the coming years to better understand the effectiveness of these interventions through clinical and behavioral outcomes. Yet, we are only beginning to gain a meaningful understanding designing for racial and ethnic minoritized populations. As such, there remains a pressing need for a growing number of studies to focus on the needs assessment phase of the design and evaluation lifecycle to ensure the appropriateness and acceptability of future consumer health IT interventions.

There is an opportunity for our needs assessment efforts to draw on a plurality of methods as most of the included studies described using interviews and focus groups.

Additional qualitative methods should be used to grow our understanding of needs and preferences across racial and ethnic minoritized communities. For example, journaling can be used to gain insights over time about an individual's experience in ways that limit recall bias and capture variability over time [34]. Similarly, body mapping can be used with community members to explore how to broader contextual factors shape health [35]. Other suggested methods include systems mapping [36], observations (including participant observation) [37], photo elicitation [38], and task analysis [39]. Mixed methods approaches should be incorporated to produce a comprehensive view of the topic being studied as well as to triangulate findings. As an example, qualitative interviews that use maximum variance sampling across racial and ethnic groups can inform larger scale sample surveys that purposefully oversample racial and ethnic minoritized groups to understand similarities and differences in needs and preferences for consumer health IT [40]. Remote sensing data could also inform topics for qualitative inquiry by providing information on behaviors such as locations visited, time spent exercising, and interactions with others.

Most of the pilot feasibility studies and RCTs reported relatively high retention and technology acceptability and usability rates. One study that had especially high retention rates among American Indian and Alaska Native teens leveraged social media platforms already familiar to the population [30]. Conversely, one intervention among postpartum African American mothers lost about half of the participants during the course the study [23]. The authors speculated that issues with retention may have been due in part to competing daily life activities. Other difficulties with continued use of an intervention technology included discomfort in using the technology, dexterity limitations, and general technical issues [16, 32]. Following human factors principles, interventions should be aligned with existing patient work systems, meaning that they should fit into established daily workflows and be adapted to the contextual factors in an individual's environment [41]. These interventions should also be designed for universal accessibility across disability types.

Studies focused on patient-provider communication technologies reported lower engagement of using technology among racial and ethnic minoritized populations [18, 19]. One study that explored language preference and communication reported that Chinese-speaking participants were less likely to use texting to communicate with health care professionals and Spanish-speaking participants were less likely to use apps [18]. In another study examining eHealth use, Black, Hispanic, and Asian individuals were more likely than non-Hispanic White individuals to use social media for eHealth purposes [19]. These studies show that there are disparities in engagement in health communication platforms as well as differential use across racial and ethnic minoritized populations. Technologies that are for a general population should be designed in ways that are appropriate for a diverse range of users and more targeted interventions should leverage existing platforms that have been shown to have high engagement among the population of interest.

3.4 Cultural Tailoring

Of the original research articles included, few mentioned tailoring the technology to the culture of the study population [14, 15, 21–23, 25, 30]. Most of these articles did not provide a detailed description as to how the technology was culturally tailored, though some did report that cultural tailoring was based on evidence from previous studies [15, 22]. Of the studies that included details on cultural tailoring, tailoring occurred across four areas: content, functionality, interface, and platform. Content was designed to incorporate cultural norms and values, promote cultural pride, and be available in a user's preferred language [21, 22, 30]. Specific functionalities included having the option to connect to an online peer network [14, 23] and other culturally tailored resources [30]. In terms of interface, one study discussed incorporating branding with which the intended user population identified with [23]. Other considerations for cultural tailoring included using a platform that would be accepted by the study population, such as a preference for text messages [22, 25]. With

regards to evaluating cultural tailoring, one study reported that the participants thought the intervention was ethical and appropriate for the intended population [22]. In another study, some participants questioned why the technology was designed to focus on a specific population rather than being designed to be used more broadly while incorporating needs reflective of their community [25]. In some cases, there were cultural norms that the designers found difficult to address through technology design, such as the acceptability of breast feeding in public [25] and youth sex education [21].

With a dearth of detailed reporting of how consumer health technologies are culturally tailored for and received by a specific population, it is not only difficult to apply these modifications and lessons learned to other interventions but also to know what is ineffective and even potentially inappropriate. It is also hard to extrapolate commonalities within and across racial or ethnic groups as well as across geographic areas and intersectional identities. As such, currently it would be challenging to design appropriate consumer health informatics solutions to be utilized across multiple different racial and ethnic minoritized populations without additional studies. Therefore, reporting on consumer health IT research designed for specific racial and ethnic minoritized populations should be thorough in describing the process of determining if and how to tailor, what aspects of a technology were tailored, and the impact of such tailoring.

3.5 Community Engagement

Within the field of health sciences, the value of working collaboratively with stakeholders to design and implement interventions has been increasingly recognized and put into practice [42]. The importance of community-based work has also been recognized broadly within the informatics community [43]. This idea continues to be recognized within this review as one perspective piece emphasized the need to involve community-based organizations and community members specifically in the design of mHealth interventions to address sexual and reproductive health for Black women

[14]. However, about half of the original research articles focused on racial and ethnic minoritized populations published in the last two years used community engagement strategies for the development and implementation of consumer health IT interventions [16, 18, 21, 22, 24–26, 28, 31, 32]. The extent to which the community was engaged in the research varied. Studies that only adopted limited aspects of community-oriented research recruited participants from community-based sites and events [16, 18, 21, 22, 24, 32] and received permission from community leaders to conduct the research [31]. More holistic approaches to community engagement included forming community advisory boards [25] and facilitating multiple participatory design sessions with community stakeholders [25, 26]. The most holistic approaches were entirely community-led as in one study, a community-based organization initiated a partnership with an academic institution to create virtual health ministries to address the effects of the Covid-19 pandemic on an urban African American community [28]. Since most studies included in this review did not do any community engagement, there is a clear opportunity to further invest more in community-based work within informatics. Moreover, there is an opportunity to use more holistic approaches to community engagement as majority of the studies did not use community engagement strategies to their full extent. Beyond engaging one community in a research study, we need to begin thinking about models that can produce more scalable solutions without compromising appropriateness for racial and ethnic minoritized populations. Initiatives could include creating larger scale projects that bridge multiple academic institutions and communities to create coalitions that would inform broader reaching interventions. At a greater scale, new models of engagement are emerging, such as citizen science [44], that further democratize research and provide options for scalability. As scalability is a challenge with community-based research and culturally tailored interventions, informaticians should continue to innovate methodologically to create interventions that are appropriate for multiple populations across geographic regions and intersecting identities.

3.6 Considerations for the Social Determinants of Health

The social determinants of health, which are the elements of the physical, social, and organizational environment that affect wellbeing, have been increasingly attended to in health interventions. Some of the articles included in this review argue that consumer health IT helps to address some determinants of health, such as cost and transportation, as it expands access to health care and facilitates health management outside of clinical settings. As an example, two of the included articles described how telemedicine and telepsychiatry interventions expanded access to specialty care and increased the availability of health care resources in rural Alaska Native communities [17, 20]. To achieve this promise, consumer health IT needs to be adapted for the realities of peoples' lives. For example, in some of the included articles, factors such as cell phone ownership, technology literacy, adequate cell phone signal, and having access to a place to charge a cell phone affected the ability to consistently use consumer health IT and thus retention rates [26, 32]. Therefore, proactive approaches to accounting for the social determinants of health should be incorporated into interventions. Two interventions included in this review accounted for low literacy in the study population by including an audio narration feature within the intervention [24, 26]. Another intervention recognized that the study population did not have consistent access to devices that could access the internet and designed the intervention to take place on a computer in a private room in a community-based clinic [24]. These articles reiterate ongoing conversations in the informatics community about the need to create interventions that align with the physical, social, and organizational contexts in which patient work is performed [8, 41, 45]. Consumer health IT can also help to address the social determinants of health by integrating information that connects individuals to community-based services. In particular, two of the included articles incorporated existing platforms into the intervention that provided information on community-based resources, such organizations that provide financial assistance [25, 28]. Taken together, there is a need to understand not only the cultural elements of a population

but also the broader contexts of the community in which that population lives when designing and implementing informatics interventions for racial and ethnic minoritized communities. Working with community partners is essential to identify these factors and how they should be incorporated into the design and implementation of consumer informatics.

3.7 Limitations

This review included literature from the past two years to provide a recent survey in this area. It is not inclusive of all literature on consumer health informatics focused on racial and ethnic minoritized populations. Additionally, the search may have been limited by only using terms that included "consumer."

4 Conclusion

As there is growing discourse surrounding racial and ethnic justice globally, there is emerging work within the informatics community to design consumer health informatics interventions that are responsive to the needs of racial and ethnic minoritized populations. From a review of the literature from the past two years, consumer health informatics focused on racial and ethnic minoritized populations is an emerging space within our field and there remains a plethora of opportunities for growth and development.

Though some of the existing work in this space is moving towards later phases in the design and evaluation process as many of the included articles were either pilot feasibility trials or randomized controlled trials, significant formative research is still needed. Since most of the articles included in this review concentrated on one health condition within one racial or ethnic minoritized population in one circumscribed geographic area in the United States, future work should encompass multiple racial and ethnic minoritized populations in multiple geographic communities within a global context. It should also attend to the intersection of multiple identities and health conditions. Design considerations for racial and ethnic differences also need to be foregrounded in technologies that are designed to be used by the general population.

To design technologies in such a way, more knowledge about how to appropriately incorporate cultural elements into consumer health informatics is necessary. Employing community engagement strategies throughout the research process, from engaging community members in the design process to creating larger coalitions across academic institutions and communities, can result in designing interventions that are responsive to the needs and desires of the intended users. Moreover, by understanding these factors, more information about the physical, social, and organizational contexts within which a technology will be implemented in can be gleaned. By accounting for these broader factors that might hinder technology adoption, the promise of consumer health informatics to address health disparities by expanding access to appropriate care may be realized.

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