Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2022, Section Consumer Health Informatics and Education

Abdulai AF, Tiffere AH, Adam F, Kabanunya MM
COVID-19 information-related digital literacy among online health consumers in a low-income country
Int J Med Inform 2021 Jan;145:104322

As health information is increasingly made available on the Internet, people frequently resort to online platforms including blogs, social media, websites, and virtual communities in search of information about specific medical conditions, symptoms of diseases, and support services. To make online health resources beneficial to the health of laypeople, the digital literacy of online health consumers’ needs to be improved to enable them to stay afloat in an era of misinformation. Such misinformation has been increasingly displayed on various social media platforms since the outbreak of COVID-19. While health professionals may be able to critically evaluate Internet-based information, the ability and skills of lay consumers in low and middle-income countries to find, appraise and apply appropriate Internet-based COVID-19 related information remain unknown. The purpose of this study was to examine the digital literacy of lay consumers of online COVID-19-related information in Ghana. The authors conducted a cross-sectional survey of people with access to the internet across five regions in Ghana. Using a multi-stage sampling, they randomly selected ten cities across the five regions. The five regions were in the lower, middle, and upper belts in Ghana. People with social media handles (i.e., Facebook and Twitter) indicating residence of the selected cities were contacted to participate in the study. A self-administered structured questionnaire was designed to measure participants’ ability to access, evaluate, integrate, and apply COVID-19 related information available on the internet. It was composed of two parts: questions on demographic information and questions of the eHealth Literacy Scale slightly adapted to COVID-19 resources instead of general resources as contained in the original instrument. Out of a total of 700 respondents sent with a link to the questionnaires, 325 were returned after one and a half months—representing a 46.4% response rate. Statements 1, 6 and 7 have mean scores less than 4. Statement 1 was “I know what COVID-19 resources are available on the Internet” (mean 3.4 SD 1.2). Statement 6 was “I have the skills I need to evaluate COVID-19 health resources I find on the Internet” (mean 3.7 SD 0.99). Statement 7 was “I can tell high-quality COVID-19 resources from low-quality resources on the Internet” (mean 3.3 SD 1.0). The findings indicated that being of a younger age, being male, searching for COVID-19 information half of the time, and most of the time, having some little or adequate knowledge of COVID-19, and using the internet for educational purposes were significant predictors of perceived digital literacy. Educational status, frequency of using the internet, and using the Internet for social media and entertainment purposes were not significant predictors of digital literacy related to online COVID-19 information. As a conclusion, Internet-based information alone may not be sufficiently effective to enhance prevention. The Internet may not be an effective communication channel for disseminating COVID-19 preventive information to the aged in low and middle-income countries. The findings also suggest that the majority of the respondents use the Internet daily and were mainly engaged in social media activities. The Internet can be used to improve lay people’s understanding of disease conditions and their health outcomes if they sharpen their interpretive and critical thinking skills to decipher right from fake or misleading health information.

Disparities in access to mobile devices and e-health literacy among breast cancer survivors
Support Care Cancer 2022 Jan;30(1):117-26

Over the past 5 years, interest in e-health and m-health interventions for people diagnosed with breast cancer has increased. Whilst the use of e-health to support women diagnosed with breast cancer continues to grow, little attention has been paid to the e-health literacy skills and technology access of these women. Issues with uptake and retention are common. Low uptake with e-health applications may be due in part to the age of breast cancer survivors, who may be less likely to have access to the necessary devices. Moreover, patients with lower health literacy were less likely to own and use a mobile phone for health-related purposes. The primary aim of this study was to explore e-health literacy and access to smartphones and tablets in a large sample of breast cancer survivors in the UK. Two study samples were constituted (study 1 and 2). The first one was composed of participants recruited from outpatient breast cancer clinics across 19 NHS Trusts in England and Wales. The second was composed of participants recruited through online advertisements on social media. e-Health literacy was assessed using the eHEALS scale. Access to a smartphone and/or tablet, were self-reported as well as sociodemographic and clinical variables including age, ethnicity, years of full-time education, and previous treatment. Study 1 results showed that the majority (80%) of the NHS-based population do report access to mobile devices, providing tentative support for e-health interventions. This was further supported by study 2 which showed that 94% of participants recruited online in the UK reported using mobile apps daily, and 49% reported using a health-related app in the past week. However, one-fifth of the NHS-recruited sample did not have access to either a smartphone or a tablet, meaning they may not be able to access or fully engage with mobile interventions. Women who were younger, who had more full-time education, and who were from less socioeconomically deprived areas were more likely to have access to these mobile devices. Older women were less likely to have access to mobile devices and had lower e-health literacy. Just under half of women over 65 did not have access to a smartphone; however, when looking across both devices, the percentage of women aged 65 + without access fell to
only 29%. As well as age, access to mobile devices was also associated with years of full-time education and lower deprivation levels. However, the relationship between deprivation and mobile device access does not appear to be linear, with the effects being most pronounced in the two most deprived quintiles. Compared to women in the least deprived area, those in the most deprived areas were around 60% less likely to have access to a device, although overall access was still high at around 75%. Whilst mobile device access differed across both socioeconomic status and education levels, e-health literacy remained fairly constant and moderately high across the different deprivation levels. Results also showed that White women were less likely to have access to mobile devices, and had slightly lower e-health literacy, than women from other ethnic groups. This is unlikely to be associated with socioeconomic status, as IMD deprivation scores were similar across ethnic groups. There is evidence of a digital divide across some groups. Online interventions should be developed with consideration of individuals who are less e-health-literate and less technologically adept in order to increase the likelihood of engagement.

Panko TL, Contreras J, Postl D, Mussallem A, Champlin S, Paasche-Orlow MK, Hill J, Plegue MA, Hauser PC, McKee M

The Deaf Community’s Experiences Navigating COVID-19 Pandemic Information
Health Lit Res Pract 2021 Apr;5(2):e162-e170

People who are deaf often face barriers receiving health information, contributing to significant gaps in health knowledge with disparities in preventive health. Adults who are deaf are more likely to have inadequate health literacy. These challenges may complicate the deaf community’s ability to access and/or comprehend COVID-19 information, even if written or captioned. The objective of the study was to compare COVID-19–related information access between deaf participants who used ASL and participants who can hear. Participants were originally recruited from the community in two metropolitan and surrounding area sites. Participants who were hearing and those who were deaf were contacted simultaneously and invited to participate in a brief survey on COVID-19. The telephone survey initially had 11 multiple choice, Likert scale, and open-ended questions including COVID-19–related behaviors such as testing and prevention, knowledge, and access to information. The survey items were translated into ASL through an iterative and collaborative process by interpreters on the team who are native ASL signers. All participants were interviewed remotely through video conference, a smartphone app, or telephone or videophone between April and July 2020. Participants who are deaf were interviewed by ASL-fluent staff who are deaf, whereas people who can hear were interviewed by staff who are hearing. The primary outcome was analyzed by comparing a positive response to having difficulty accessing information about COVID-19 between groups (deaf vs. hearing). Adjusted analysis using logistic regression was performed including covariates of group, race (white vs. person of color), age, health literacy, and study site. A total of 178 adults, including 104 ASL users who are deaf and 74 people who are hearing completed the survey. Twenty percent of participants who are deaf reported having difficulty accessing information regarding COVID-19, which was significantly higher than participants who are hearing (5.5%; p = .005). When controlling for race, age, and health literacy, participants who are deaf had 4.6 times higher odds of reporting difficulty in accessing COVID-19–related information than participants who are hearing (p = .013). Both groups of participants equally found COVID-19 information difficult to understand (26% vs. 19%; p = .27). Regarding information source, participants who are deaf were more likely to report getting their information from television/news (86% vs. 54%; p < .001) and social media (90% vs. 57%; p < .001) than their peers who are hearing. For the deaf community, the information on government-based platforms were often not accessible in ASL or from a source of trusted agents or entities that have consistently demonstrated caring for the needs of the deaf community and have established a relationship with them. Efforts in ensuring publicly available health information during COVID-19 have reached and educated the deaf community in terms of risk mitigation and COVID-19 symptom recognition. Additional education on recommended COVID-19 management and guidance on equitable health care navigation strategies are needed for the deaf community and health care providers, respectively.

Williamson A, Barbarin A, Campbell B, Campbell T, Franzen S, Reischl TM, Zimmerman M, Veinot TC

Uptake of and Engagement With an Online Sexual Health Intervention (HOPE Intervention) Among African American Young Adults: Mixed Methods Study
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Numerous consumer health informatics (CHI) interventions exist to prevent HIV and sexually transmitted infections (STIs) among African American youth. Nevertheless, previous experience with patient portals shows that CHI interventions may not achieve uptake and engagement among them. Moreover, there is limited understanding of what motivates uptake and engagement in African American young adults participating in CHI interventions to prevent HIV/STIs. This study aims to examine rates of uptake and ongoing usage, and factors influencing uptake, ongoing usage, and engagement for a CHI intervention for HIV/STIs prevention among African American young adults, using the diffusion of innovation theory (to identify variables that may predict uptake), trust-centered design framework (to inform technology design and implementation strategies), and O’Brien and Toms’ model of engagement (to analyze qualitative interview data). This mixed-methods, community-based participatory research (CBPR) study included surveys and interviews with African American young adults who attended a community-based HIV/STI prevention intervention called a HOPE party. HOPE parties were one-time, interactive, face-to-face HIV/STI prevention sessions hosted by African American young adults in their homes for their social networks. Attendees listened to didactic material, engaged in educational activities, and discussed safe
sex practices with demonstrations of safe sex tools. The eIntervention, available to HOPE party participants, aimed to reinforce information presented at the parties and foster commitment to HIV/STI prevention. The eIntervention consisted of a website with a blog, a Twitter account, and a Facebook page. The website was updated at least once monthly. Facebook content included status updates, external links, photos, sexual health information, and/or questions. Tweets offered safer sex advice and memes reinforcing safer sex norms. Three social media contests incentivized eIntervention information sharing via social networks. There were 57 HOPE parties over three years, with one to 12 participants at each who responded to surveys. The survey asked about demographic characteristics, social network information, and questions regarding use of the HOPE eIntervention. Surveys were developed to measure network assessments such as network composition (gender homophily), social influence of networks based on density, and type of social tie (ie, weak or strong) as predictors of HOPE website use. Interviews were conducted at least 1 year after each participant’s HOPE party (semi-structured interview guide that accommodated personalized follow-up questions). A set of 280 African American participants (164 – 58.6% were female, mean age of 21 years) responded to the survey, and 19 African American young adult interviewees (14 – 74% were female, mean age of 24 years) were drawn from this pool of respondents. Uptake and ongoing usage were low overall; website uptake increased as more participants entered the study but always remained low. The only marginally significant individual-level positive predictor of uptake was education. There was also a marginally significant positive relationship between party gender homophily and party-level uptake. Awareness and motivation to share information with others positively influenced uptake. Necessary conditions undermined uptake when absent; these included technology access, perceived lack of time, and technological trust, especially regarding social media–based discussions about HIV/STIs. Visual appeal of the website, information with the appropriate level of challenge, and interactivity positively affected ongoing usage, although the website was not interactive enough for some participants. A social media contest also increased re-engagement, with limited reach. Lack of novelty was linked to disengagement. As a conclusion, the model reinforces O’Brien and Toms’ inclusion of motivation, challenge/ease of use, esthetics/sensory appeal, and novelty as factors influencing engagement. To make the model more appropriate for this group, uptake was added. Factors driving uptake were identified through interviews (awareness and motivation) and survey data (education level and party network homophily). The model also newly incorporated necessary conditions and intervention context, including promotion efforts and the intervention’s platform on social media, which was linked to technological trust.