

Consuming Health Information and Vulnerable Populations: Factors of Engagement and Ongoing Usage

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Summary

Objective: To summarise the state of the art during the year 2021 in consumer health informatics and education, with a special emphasis on “Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems”.

Methods: We conducted a systematic search of articles published in PubMed using a predefined set of queries. In order to build queries, we have used a common understanding of digital inclusion. Leaving no one behind in the digital age requires not only reaching the most vulnerable populations, but also those people and population groups that are not digitally literate. It implies appropriate access, digital skills, and usability and navigability aspects in the development of technological solutions. Thus, we identified 126 potential articles for review. These articles were screened according to topic relevance and 13 were selected for consideration of best paper candidates, which were then presented to a panel of international experts for full paper review and scoring. The top five papers were discussed in a consensus meeting. Four papers received the highest score from the expert panel, and these papers were selected to be representative papers on consumer informatics for exploring inclusive digital health in the year 2021.

Results: Bibliometrics analysis conducted on words found in abstracts of the candidate papers revealed five clusters of articles, where the clustering outcomes explained 93.58% of the disper-

sion. The first cluster analysed the use of mobile apps to improve quality of communications between racial subgroups (e.g., Black patients and their family members) and healthcare professionals, and reduce racial disparities in core palliative care outcomes.

The second cluster revealed studies reporting health literacy and experience of patients with specific diseases or impairments (e.g., type 2 diabetes, asthma and deaf people). The third focused assessing the effectiveness of interactive social media interventions on changing health behaviors, health outcomes and health equity in the adult population. The fourth targeted people with limited health literacy, as well as potentially disadvantaged or marginalized groups (people with cerebrovascular or cancer problems, students with mental problems, African American Young adults), and explored how social media may help reduce health disparities and improve health outcomes. The last explored health literacy levels among groups who experience difficulties with health service engagement and retention (patients with cancer or lay consumers of online disease information).

Conclusion: Although the query was built to address consumer inclusiveness and digital health, without specifying any health status or disease, COVID-19 was the topic in a lot of retrieved papers. Beyond the classic health issues targeted by social media (e.g., influencing health behaviors, from smoking and diet adherence to preventative screening and exercise habits), the pandemic

has exposed many situations of vulnerability and health inequality. There is universal agreement on the necessity of a healthcare policy that addresses issues of gender, age, sexual orientation, and different cultures to ensure health equity for all, regardless of age or resources available. The place of digital health is studied both as a solution and a possible factor of accentuating healthcare disparities, inequalities, and exclusions. Healthcare providers should implement a digital health literacy plan to make sure health information technology is an option for everyone. Public health policies and health promotion strategies must focus on strengthening and adapting the digital health literacy in known vulnerable subgroups (ethnic and racial minorities, sexual and gender minorities, children and adolescents, elderly people, students population, impaired people, patients with cancer and chronic diseases) increasing citizen technology engagement and guaranteeing equity in access to information and in the skills to manage, discriminate, and apply information to health.

Keywords

Consumer health informatics; health literacy; healthcare disparities; minority groups

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1 Introduction

For this 31st edition of the Yearbook of Medical Informatics, the topic of “Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems” comes as the COVID pandemic exposes the vulnerability of communities enduring the many circumstances that make it difficult to live healthy lives.

The health and economic crisis stemming from the coronavirus crisis has magnified systemic barriers to health, especially for

marginalized groups in the community. As telehealth gets rapidly adopted during the pandemic, it is particularly important to acknowledge the existence of a “digital divide”. Some communities have less ability to access or benefit from the technology, such as those who do not have access to the Internet, or those who have hearing impairment and may experience obstacles to participating over the telephone to access healthcare. Many issues related to the upstream causes of “hallway health care” (e.g., overcrowded emergency

departments, unavailable specialized post-acute hospital care) cannot be solved by technology. Cultural appropriateness should be central to the design of technologies to ensure they are relevant to the communities they serve. Moving forward, as we contemplate a redesign of the health system, we need to ensure new digital tools do not lead to a more fragmented system, and that data collection and data sharing is in alignment with the needs and wishes of patients and communities, especially the indigenous pop-

ulations. Instead of resorting to digitalizing traditional models of healthcare delivery, needs of vulnerable or underrepresented populations must be evaluated and understood to create tailor-made digital solutions that will deliver focused health interventions to the communities it aims to serve.

In this synopsis, we will explore the literature describing the role of consumer informatics as a means to empower consumers to fight against health inequities. Specifically, we will identify how research in the past year has addressed innovative uses of social media to improve consumer engagement during the COVID-19 pandemic, especially those from marginalised communities.

2 Methodology

2.1 Search Strategy

We used PubMed to conduct our search, capturing papers on consumer-using technologies and inclusive digital health concerned published in the year 2021. The search strategy was based on the PICO framework ((P-Population/Problem, I-Intervention, C-Comparison, O-Outcome), where “Population” refers to patient, client, consumer, “Problem” refers to inclusive healthcare and resilience, “Intervention” refers to social media and information technology, “Comparison” refers to digital exclusion and health inequalities, whereas “Outcome” is not included. We started from a core query adopted in previous work. The syntax “[All Fields]” was used wherever possible to ensure our search strategy was comprehensive. The final search query is listed below:

((2021/1/1:2021/12/31[DP] NOT “Epub ahead of print”) NOT Bibliography[pt] NOT Comment[pt] NOT Editorial[pt] NOT Letter[pt] NOT News[pt] NOT Case Reports[pt] NOT Published Erratum[pt] NOT Historical Article[pt] NOT Legal Case[pt] NOT legislation[pt] NOT (“review”[pt] OR “review literature as topic”[MeSH Terms] OR “literature review”[All Fields]))

AND

(“patient”[All Fields] OR “client”[All Fields] OR “consumer”[All Fields] OR “consumer health informatics”[MeSH Terms] OR “consumer health information”[MeSH Terms] OR “consumer behavior”[MeSH

Terms] OR “consumer attitude”[All Fields] OR “consumer organizations”[MeSH Terms] OR “Direct-To-Consumer Screening and Testing”[MeSH Terms] OR “Direct-To-Consumer Advertising”[MeSH Terms] OR “customer experience”[All Fields] OR “rural healthcare”[All Fields] OR “primary healthcare”[All Fields] OR “secondary healthcare”[All Fields] OR “tertiary healthcare”[All Fields] OR “homecare”[All Fields] OR “workplace”[All Fields] OR “proactive healthcare”[All Fields] OR “resilient healthcare”[All Fields] OR “inclusive healthcare”[All Fields] OR “chronic care”[All Fields] OR “care delivery”[All Fields] OR “self-care”[All Fields] OR “prevention”[All Fields] OR “wellness”[All Fields])

AND

(“ehealth”[All Fields] OR “e-health”[All Fields] OR “mhealth”[All Fields] OR “m-health”[All Fields] OR “mobile health”[All Fields] OR “information technology”[All Fields] OR “communication technology”[All Fields] OR “mobile technology”[All Fields] OR “mobile”[All Fields] OR “online systems”[All Fields] OR “internet”[All Fields] OR “web”[All Fields] OR “website”[All Fields] OR “app”[All Fields] OR “smartphone”[All Fields] OR “tablet”[All Fields] OR “laptop”[All Fields] OR “digitalization”[All Fields] OR “digital solution”[All Fields] OR “digital technology”[All Fields] OR “digital health technology”[All Fields] OR “digital health applications”[All Fields] OR “electronic medical record”[All Fields] OR “personal health record”[All Fields] OR “electronic patient record”[All Fields] OR “patient portal”[All Fields] OR “cell phone”[All Fields] OR “short message service”[All Fields] OR “interactive voice recognition”[All Fields] OR “mobile platform”[All Fields] OR “artificial intelligence”[All Fields])

AND

(“social media”[All Fields] OR “facebook”[All Fields] OR “twitter”[All Fields] OR “youtube”[All Fields] OR “instagram”[All Fields] OR “social network site”[All Fields] OR “social web”[All Fields] OR “online social network”[All Fields] OR “discussion group”[All Fields] OR “support group”[All Fields] OR “forum”[All Fields] OR “social support”[All Fields] OR “community network”[All Fields] OR “online community”[All Fields])

AND

(“digital inclusion”[All Fields] OR “digital exclusion”[All Fields] OR “digital divide”[All Fields] OR “resilience, psychological”[MeSH Terms] OR “health equity”[All Fields] OR “health inequalities”[All Fields] OR “health disparities”[All Fields] OR “underserved communities”[All Fields] OR “rural communities”[All Fields] OR “equitable”[All Fields] OR “sustainable”[All Fields] OR “health literacy”[All Fields] OR “digital literacy”[All Fields] OR “digital health literacy”[All Fields] OR “digital readiness”[All Fields] OR “clinical decision support”[All Fields] OR “data collection”[All Fields] OR “data sharing”[All Fields])

2.2 Bibliometrics Analyses

To understand the state of the literature, we applied various bibliometrics tools onto the original set of articles returned from the search query. The “Bibliometrix” package from R [2] was used on the citation set of retrieved articles. We reported frequency of keywords. We illustrated the analysis of abstracts (measure of word frequency) by a word cloud drawing feature. We analysed keywords to uncover links between concepts through co-occurrences network. We also plotted a thematic map to analyse these clusters according to the quadrant in which they are placed [3]:

- Themes in the *upper-right* quadrant are both well-developed and important for the structuring of a research field. They are known as the motor-themes of the specialty given that they present strong centrality and high density;
- Themes in the *upper-left* quadrant have well-developed internal ties but less-developed external ties and so are of only marginal importance to the field. These themes are very specialized and peripheral in character;
- Themes in the *lower-left* quadrant are both weakly-developed and marginal. The themes of this quadrant have low density and low centrality, mainly representing either emerging or disappearing themes;
- Themes in the *lower-right* quadrant are important for a research field but are not as well-developed. Each theme is represented as a sphere, its volume being proportional to the number of documents associated with the theme.

3 Results

3.1 State of the Literature

A descriptive analysis of 126 articles was conducted, reporting the frequency of keywords, and the frequency of words in titles and abstracts. Four hundred and nine distinct keywords were used, 737 distinct words in titles and 4,538 words in abstracts. Figure 1a lists the 50 most-frequently cited keywords ranked from most-frequently to least-frequently reported. Table 1 shows how the most-frequently cited keywords (10 or more occurrences) can be reorganised to describe the structure of the initial query. Figure 2 shows a triangle-shaped words cloud created from the analysis of abstracts. Along the tip of the triangle, we can see keywords such as “objective, interventions, support”; and along the base of the triangle, we can see keywords such as “participants, care, media, data, intervention” and “covid, literacy, digital, patients”. Regarding the conceptual structure of the set of 126 articles, Figure 3 shows the co-occurrences of keywords. It identifies the relationships between keywords in accordance to the groups reported in Figure 2.

Regarding thematic maps of keywords found in Figure 4, clusters according to centrality (relevance degree) and density (development degree) are reported in each quadrant. Most common themes found across papers are related to social media, mobiles applications and internet to deploy health literacy studies towards all age categories. Next set of frequently reported themes focus on “health behavior and treatment outcome”. Niche themes revealed by this analysis are represented by medicare in united states. The cluster “rural population, health education and self-management” seems to be classified as an emerging theme.

The analysis of these first metrics allows us to see that the terms linked to the Covid pandemic are found in first position, while the query did not specify any specific health situation. Studies addressing health literacy as a characteristic linked to health inequalities and resilience of disadvantaged populations continue to focus on COVID-19. Other health problems (such as cancer), health impairments

(such as deafness) or health actions (HIV prevention) have been identified as topics in the original selection.

3.2 Best Paper Selection

To identify the 13 candidate papers, the co-editors independently assessed the 126 retrieved papers using the Rayyan web-tool [4], followed by discussion. Elements that were considered in the screening decision include: (1) level of relevance regarding the 2022 Yearbook topic “Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems”; (2) whether the study was focused only on patients and consumers; (3) nature of the issues addressed; and (4) level of innovative approach. Section co-editors’ agreement was measured with Cohen’s kappa coefficient: $\kappa=0.9461$ 95%CI [0.7718;1.12] (strong agreement). The 13 articles were then presented to a panel of international experts for full paper review and scoring according to the IMIA Yearbook best paper selection process. The final selection of best papers is completed after discussions at the annual IMIA Yearbook board meeting.

We applied the same metrics in the best paper selection. A set of 76 distinct keywords were used, 124 distinct words in titles, and 1,224 words in abstracts. Figure 1b lists the 50 frequently-cited keywords ranked from most-frequently to least-frequently reported. Figure 5 shows the factorial map of the candidate best papers, based on words in abstracts (76 terms), revealing four clusters. The result clustering explains 93.58% of the dispersion. This clustering was blinded to the reviewers.

- Cluster 1 is composed of one article relating to the use of a mobile App to improve the quality of ICU-based communication among racial subgroup. Cox *et al.*, [5] investigated the effects of a new mobile app intervention (called ICUconnect) for ICU clinicians and family members that assists with delivering need-based care. They designed a clustered randomized trial to compare ICUconnect vs. usual care to determine: (1) the clinical impact of the ICUconnect intervention in improving

outcomes overall, and (2) for each racial subgroup on reducing racial disparities in core palliative care outcomes over a 3-month follow up period. They identified four key gaps that limit improvement in the quality of ICU-based palliative care: the infrastructure gap (delays due to small specialist workforce), the family engagement gap, the needs gap, and the clinician communication content gap;

- Cluster 2 is composed of three studies reporting health literacy and experience of patients with specific diseases or impairments [6-8]. Panko *et al.*, [6] compared COVID-19-related information access between participants who are deaf and participants who have normal hearing. Sjöström *et al.*, [7] study aimed to explore online COVID-19 information acquisition experiences among persons with type 2 diabetes and varying eHealth literacy. Salim *et al.*, [8] developed and tested a prototype asthma self-management mobile app tailored to the needs of people with limited health literacy through a web-based workshop;
- Cluster 3 is composed of one systematic review [9] assessing the effectiveness of interactive social media interventions, in which adults are able to communicate directly with each other, on changing health behaviors, body functions, psychological health, well-being, and adverse effects;
- Cluster 4 is composed of four articles targeting at people with limited health literacy, as well as disadvantaged or marginalized groups, and exploring how social media may help reduce health disparities and improve health outcomes [10-13]. Williamson *et al.*, [10] examined rates of uptake and ongoing usage, and factors influencing uptake, ongoing usage, and engagement for a consumer health informatics (CHI) intervention for HIV/sexually transmitted infection (STI) prevention among African American young adults. Noser *et al.*, [11] study aimed to address social inequities in cerebrovascular health through the identification of race- or ethnicity-specific health needs and the provision of in-person stroke prevention screening during two community events. Valera *et al.*, [12] documented the process of adapting the content from the

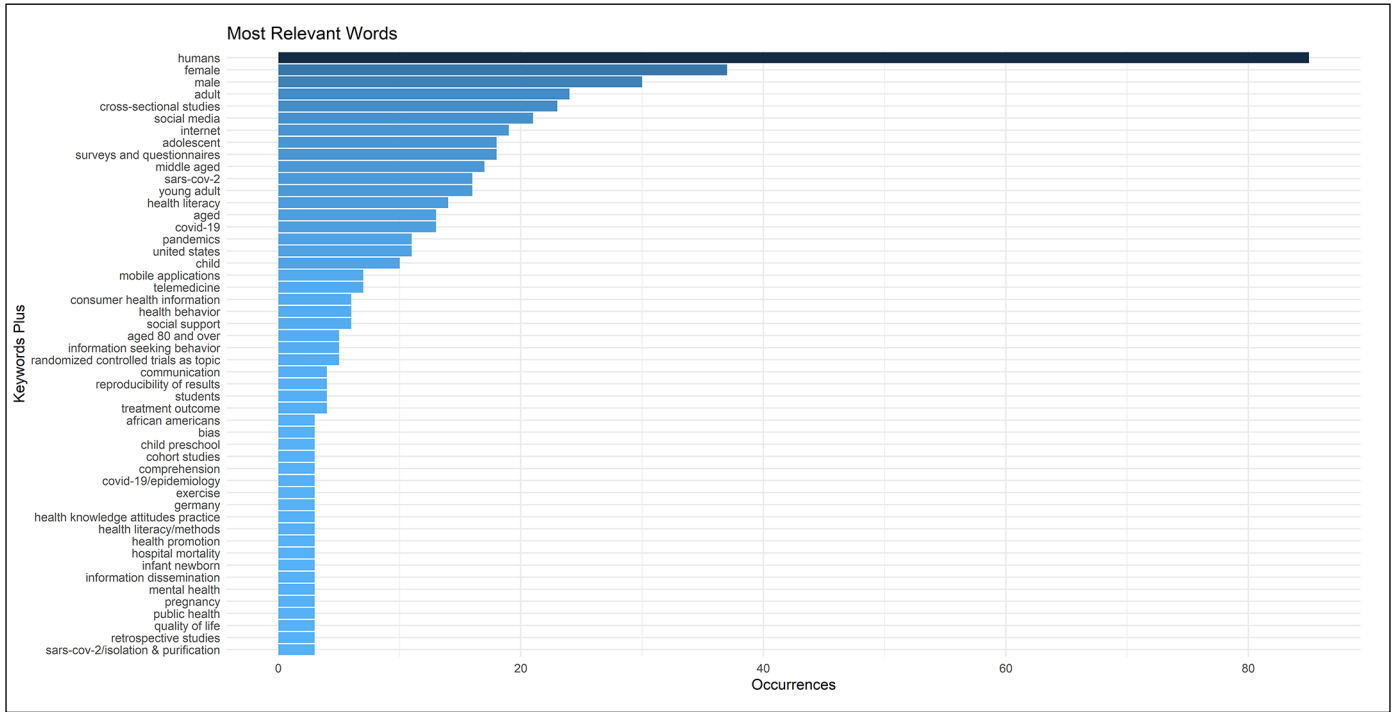


Fig. 1a Occurrences of keywords in the first selection of 126 papers.

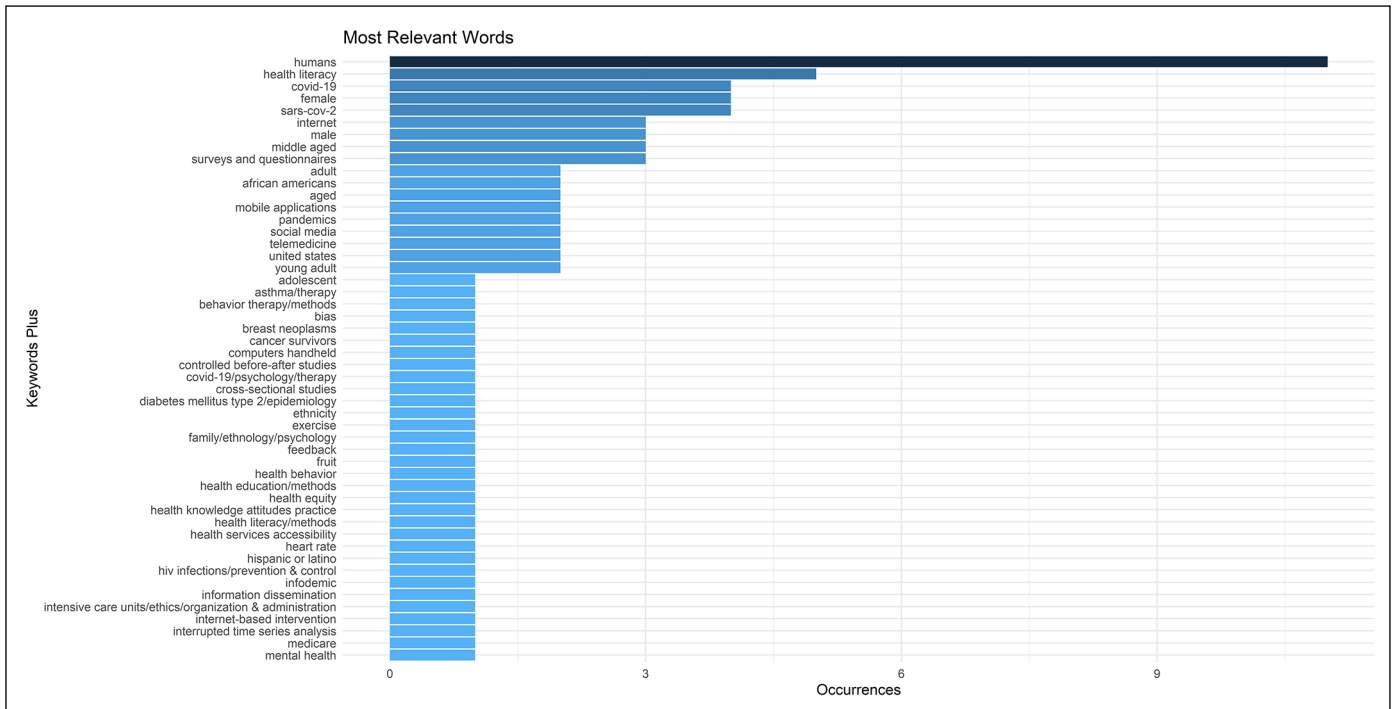


Fig. 1b Occurrences of keywords in the second selection of 13 candidate best papers.

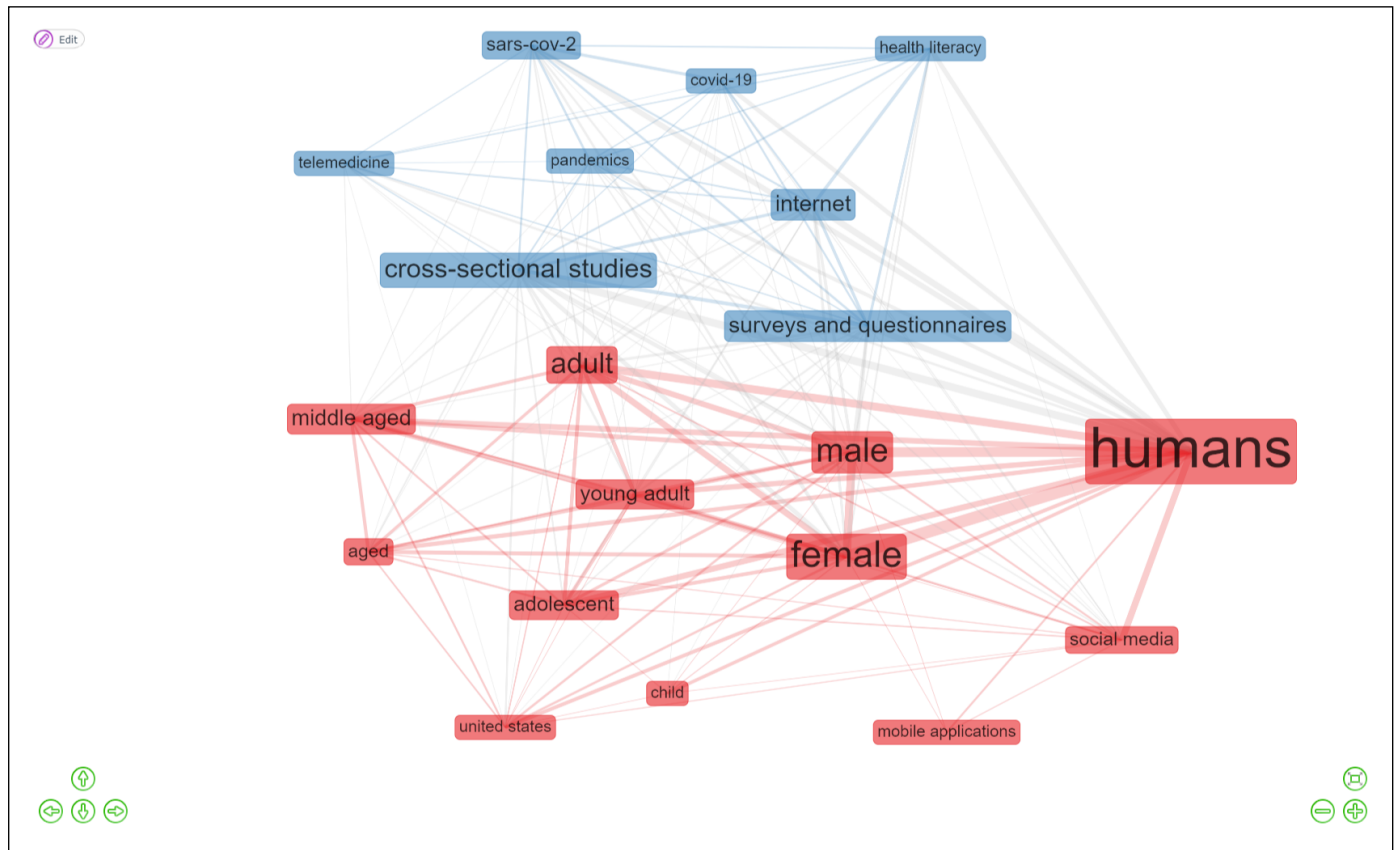


Fig. 3 Co-occurrence network of the 20 most frequent keywords (original set of 126 papers).

4 Conclusions

Barriers to digital access and inclusion are well-known, such as: poverty, older age, low literacy, low digital skills and confidence, communication needs and preferences, complex or precarious lives, disability and some health conditions, lack of privacy, fears, and mistrust of technology and/or of institutions. COVID-19 has increased the level of situational vulnerability. Digital skills and confidence – as well as motivation to use digital technology – needs to improve in healthcare, community, and wider sectors. If technical elements are put forward to make applications accessible to all, the challenge persists to create content that includes the patient experience and consumption considering physical limitations disabilities, or other health issues that could impair their vision, hearing, speech, processing, or

memory. Bias across economic and racial groups must be recognized with strategies to reduce their disparities by incorporating inclusive design approaches.

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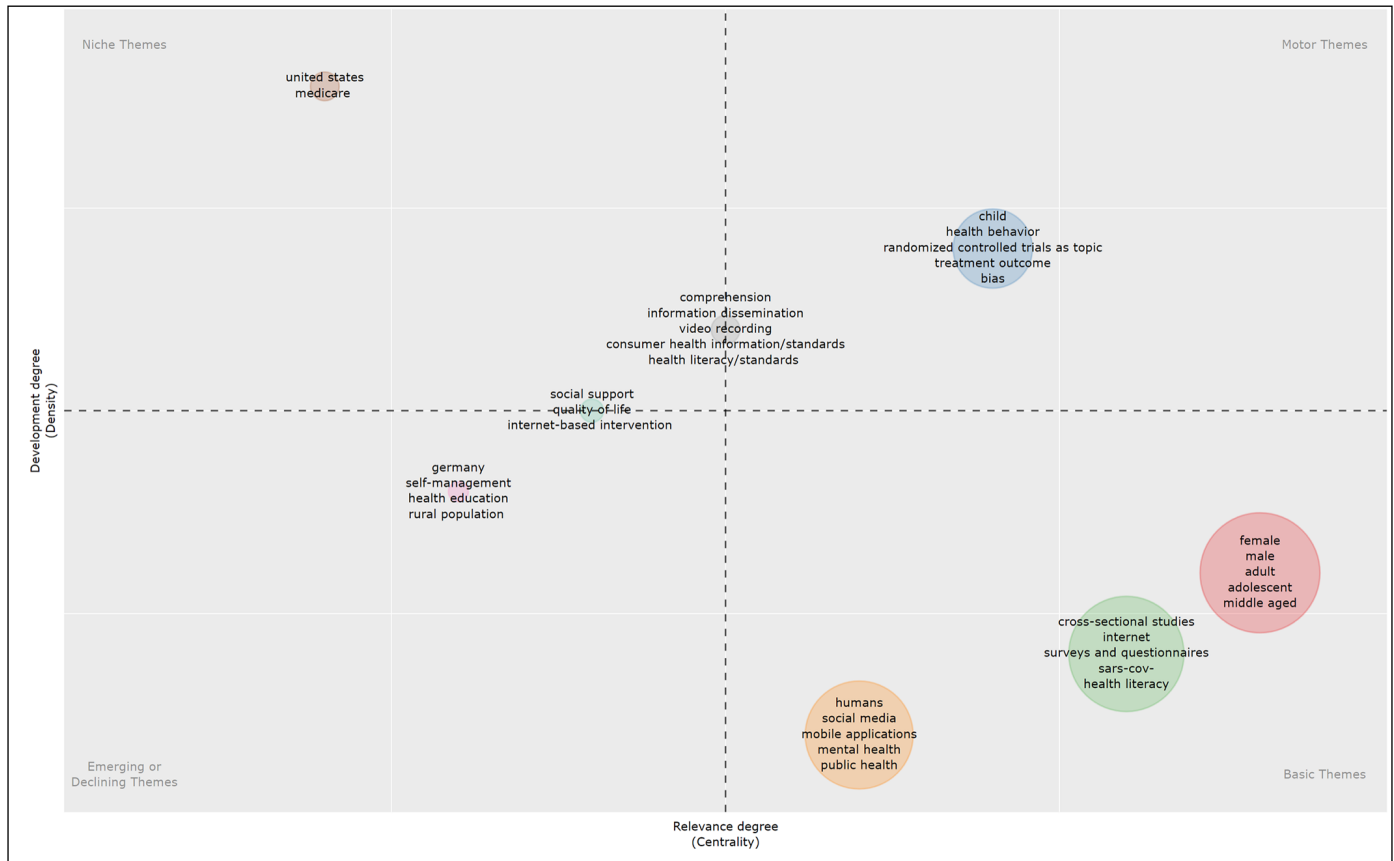


Fig. 4 Thematic map of clusters of keywords (original set of 126 papers).

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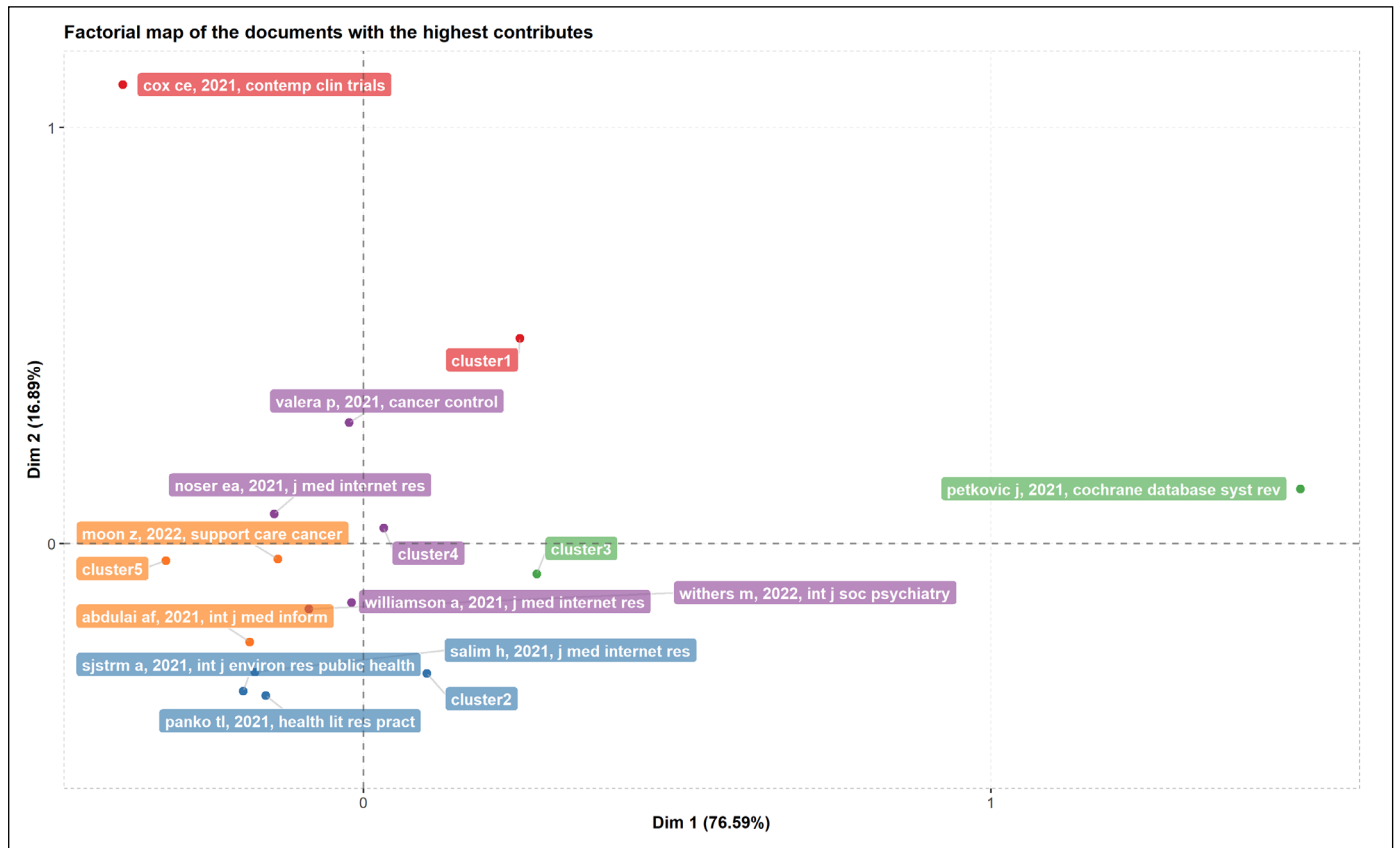


Fig. 5 Factorial map of papers, based on words in abstracts of the 13 best candidate papers (multiple correspondence analysis based on abstract terms).

Table 2 Best paper selection of articles for the Consumer Health Informatics and Education section of the IMIA Yearbook of Medical Informatics 2022. The articles are listed in alphabetical order of the first author's surname.

Section
Consumer Health Informatics and Education
<ul style="list-style-type: none"> ▪ Abdulai AF, Tiffere AH, Adam F, Kabanunye MM. COVID-19 information-related digital literacy among online health consumers in a low-income country. <i>Int J Med Inform</i> 2021 Jan;145:104322. ▪ Moon Z, Zuchowski M, Moss-Morris R, Hunter MS, Norton S, Hughes LD. Disparities in access to mobile devices and e-health literacy among breast cancer survivors. <i>Support Care Cancer</i> 2022 Jan;30(1):117-26. ▪ 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. <i>Health Lit Res Pract</i> 2021 Apr;5(2):e162-e170. ▪ 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 eIntervention) Among African American Young Adults: Mixed Methods Study. <i>J Med Internet Res</i> 2021 Jul 16;23(7):e22203.