

Designing Health Recommender Systems with a Health Equity Lens

Caroline Figueroa, Helma Torkamaan, Ananya Bhattacharjee, Hanna Hautpmann, Kathleen Guan, Gayane Sedrakyan

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Abstract

Health Recommender Systems (HRS), which use Artificial Intelligence (AI), have made great strides for human-centered care and prevention by providing personalized health advice on personal digital devices. HRS have demonstrated a unique role in the digital health field because they can offer relevant recommendations, not only based on what users themselves prefer and may be receptive to, but also using data about wider spheres of influence over human behavior, from peers, families, communities, and societies. Using the socioecological model, we identify how HRS could play a unique role in decreasing health inequities by targeting the interconnectedness of individuals and their environments. We then discuss the challenges and future research priorities. Despite the potential for targeting more complex systemic challenges in obtaining good health, current HRS are still focused on individual health behaviors, do not integrate lived experiences of users, and have had limited reach and effectiveness for individuals from low socioeconomic status (SES) and racial/ethnic minoritized backgrounds. In this perspective, we argue that a new design paradigm is necessary, in which future HRS focus on incorporating structural barriers to good health in addition to user preferences, and are designed from decolonial perspectives. If these steps are taken, HRS could play a crucial role in decreasing health inequities.

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Original Manuscript

Designing Health Recommender Systems to Promote Health Equity: a socio-ecological perspective

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Keywords: Digital health; Health Promotion; health recommender systems; artificial intelligence; health equity.

Abstract

Health Recommender Systems (HRS), which use Artificial Intelligence (AI), have made great strides for human-centered care and prevention by providing tailored health advice on personal digital devices. HRS have demonstrated a unique role in the digital health field because they can offer relevant recommendations, not only based on what users themselves prefer and may be receptive to, but also using data about wider spheres of influence over human behavior, from peers, families, communities, and societies. Using the socioecological model, we identify how HRS could play a unique role in decreasing health inequities by targeting the interconnectedness of individuals and their environments. We then discuss the challenges and future research priorities. Despite the potential for targeting more complex systemic challenges in obtaining good health,

current HRS are still focused on individual health behaviors, do not integrate lived experiences of users in the design, and have had limited reach and effectiveness for individuals from low socioeconomic status (SES) and racial/ethnic minoritized backgrounds. In this perspective, we argue that a new design paradigm is necessary, in which HRS focus on incorporating structural barriers to good health in addition to user preferences, and are designed from decolonial perspectives. A shift in design is needed for HRS to play a crucial role in decreasing health inequities.

Introduction

Health Recommender Systems (HRS), which use Artificial Intelligence, are an increasingly popular method to provide patient-centric personalized health services [1][2][3]. HRS predict the relevance of recommendations (e.g. for exercise, healthy foods, mental health exercises) for a given user profile [4]. HRS base recommendations on what the user might like typically using various sources of data such as personal (e.g. age, gender, socioeconomic status), health (e.g. medical history, health surveys), contextual (e.g. time, weather, location) and interaction data (e.g. information searched, liked/rated) [1][5]. HRS can minimize the burden of delivering recommendations by only doing so when there is a real benefit and can target multiple behaviors at once (e.g. diet, physical activity, and mental health). With increasing interest in using AI to improve health promotion and prevention, and more than 50% of individuals using the internet to find health information[6], the use of HRS is expected to grow in digital health[7,8].

However, digital health interventions, including HRS, are often not developed from a health equity lens. For instance, they have scarcely been tested in populations that are marginalized, such as those belonging to low socioeconomic status (SES), and racial and ethnic minoritized individuals[9]. This is a widespread issue, since those with higher education levels, income, English proficiency, and non-Hispanic white individuals tend to have higher access to and use DHTs more often[10]. There is a lack of attention to issues of equity and inclusion, and a tendency to develop from a technology centered instead of a human centered perspective in the HRS field[2].

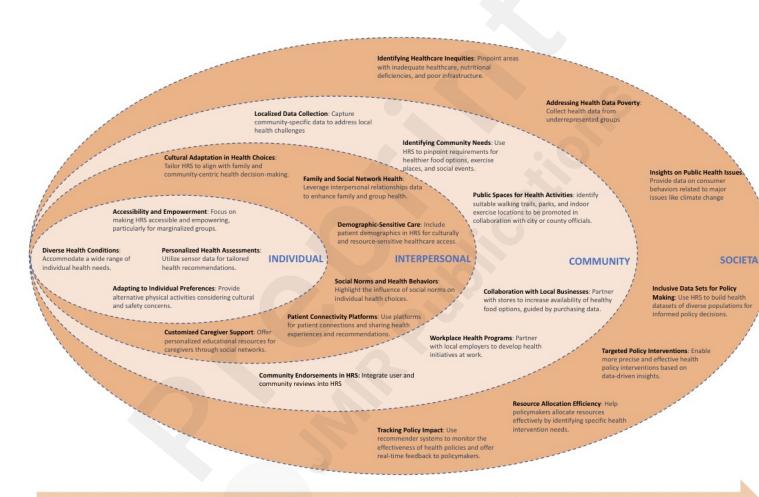
In this perspective, we illustrate the unique potential of HRS to contribute to health equity through collecting data and targeting health at the level of individuals, families/peers, communities, and societies. We use the socio-ecological model—a conceptual framework depicting spheres of influence over human behavior. This model has frequently been applied for understanding the interconnectedness of individuals and their environments to enable more effective public health interventions for complex social issues[11], and has been adapted for digital health equity [9,12]. Previous work in digital health equity however, has not been applied to HRS, which have a unique role in the field because of their data-driven personalization. We provide selected examples of prior work that could contribute to different layers of the framework, discuss challenges, and provide future research opportunities. Given the increasing use of recommender systems in medicine and public health[2], growing societal health inequities, and the World Health Organization's recent call for

equitable participation in a digital world[13], investing in equitable use of this technology is essential now.

The potential of HRS using the socioecological model.

Below we describe the potential of HRS for decreasing health inequities based on the socioecological model (individual, interpersonal, community and society), **Figure 1.**

Figure 1. How HRS can contribute to decreasing health inequities, illustrated within layers of the socioecological model.



Increased individual, interpersonal, community, and societal relevance

Individual level

Using data from diverse sources, including high-frequency and high-resolution data from phones and wearables, HRS can provide personalized suggestions, including about overcoming structural barriers to good health to enhance equity. For example, for lower SES individuals, HRS for nutrition can combine budgetary restrictions with health and familiarity motives (i.e. food associated with cultural traditions, or a sense of safety and comfort), which are more important to individuals with fewer resources[14]. For individuals living in areas where outdoor activities may be unsafe or impossible because of weather conditions, physical activity HRS could offer alternative options, such as indoor exercises, community-centered physical activities, or free

online classes. Further, HRS can also empower users through prioritizing user decisions over system performance. For example, in a previous study, a HRS for health coaching allowed participants to pick their own health domain to work on, and only use the information they wanted to provide, such as not using sensors or answering all health-related questions[15]. Thus, the use of HRS can lead to more equitable healthcare recommendations and empowered health decisions.

Interpersonal Level

HRS can positively influence the health of families, households, work-environments, and other small social networks by leveraging the data of interpersonal relationships[16]. For example, HRS can provide recommendations based on what worked for others with similar health[17]. HealthNet, a patient social network platform, used a recommender system to allow patients to find others with similar conditions, learn about what treatments were useful for them, and suggest health facilities or doctors consulted by patients with a similar health status[18]. However, the demographic background of patients, and the incorporation of this information into the HRS, was not reported. Basing recommendations on others with similar socio–economic or ethnic/racial minoritized backgrounds may make HRS even more effective. Further, social media network data can be used, as shown by Oliva-Felipe and colleagues, who developed a HRS with educational contents tailored to their specific profile of dementia caregivers[19]. HRS could also leverage peer-endorsements, allowing users to see recommendations or reviews from their social connections or members of a community with similar health goals[16]. Tapping into the power of social influence and community may specifically benefit lower SES individuals by making recommendations more relevant to them and trustworthy.

Community level

HRS can play a pivotal role in facilitating health promotion and preventive strategies tailored to community-specific risk and protective factors by capturing data specific to a community (i.e. localized data collection). For example, Wayman and Madhvanath (2015) describe a HRS that makes dietary recommendations based on grocery receipt data[20]. Leveraging this kind of data, HRS developers could collaborate with local businesses, such as grocery and convenience stores, to tailor the amount of fresh fruits and vegetables guided by food purchasing data[21]. HRS developers can also work with local governments to develop systems that allow low-income residents to receive recommendations on where to shop for healthy and affordable foods. The data collected from HRS can also be used to work with the city or county to identify the most suitable walking trails, parks, and indoor exercise sites, and publicize these to the community. Thus, HRS' ability to leverage localized data provides ample opportunities for community level interventions.

Societal level

HRS can contribute to building inclusive data sets with trends in health behaviors on a population-level, which can be leveraged for policy making. Currently, individuals of lower SES and ethnic/racial marginalized

individuals are systematically underrepresented in (open) health datasets (for example, the UK biobank, with half a million UK participants)[22]. By collecting data on the health of these marginalized populations in combination with contextual data, HRS can help to solve the problem of 'health data poverty', the inability of individuals, groups, or populations to benefit from discovery or innovation due to a scarcity of adequately representative data[23]. Policymakers can, for example, use this data to better pinpoint inadequate healthcare facilities, nutritional deficiencies, or insufficient infrastructure for healthy living.

Regarding major public health issues like climate change, which disproportionately affects the health of marginalized populations[24], HRS could provide insight into human behavior that leads to high carbon emissions, such as food waste, or actions that can promote sustainable food consumptions[25]. HRS can thus help policymakers allocate resources more efficiently by identifying areas or populations in need of specific public health interventions. Further, after implementing health policies, recommender systems can track their impact on health outcomes, and provide policymakers with real-time feedback on the effectiveness of their policies[26]. Data insights collected through HRS could form the basis for more targeted policy interventions to reduce health inequities.

Recommendations for Research priorities

Though HRS have immense potential in decreasing health inequities, they are currently not designed from a health equity lens. For HRS to be more useful and accessible to marginalized populations, we need new design guidelines. Below we describe future research priorities.

Incorporate structural barriers to good health in personalization

Despite the potential we explained above, most HRS do not integrate factors associated with the social determinants of health, despite their importance for the efficacy of health interventions and overall health outcomes[27]. Most HRS aimed at enhancing well-being and advocating healthy lifestyles primarily use basic demographic information like age and gender, as well as individual health behaviors for tailoring recommendations[2]. This oversight could exacerbate health inequities, as marginalized individuals are less likely to benefit from interventions focused on behavioral factors, because of limited resources and competing priorities, which are greater in these populations[9]. Future research should explore the integration of the social determinants of health into HRSs, such as socio-economic status, healthy food scarcity, and digital and health literacy.

Decolonial perspectives in HRS design

Because of their flexibility in incorporating diverse data-sources, HRS are very suitable to be designed to contextualize, recognize, and incorporate diverse perspectives. Scientific knowledge in the digital health field is however currently predominantly produced through the lens of Western scholars, which marginalizes

diverse and Indigenous health perspectives. In the case of HRS, users themselves have been scarcely involved in the design process. For example, in a recent review of 51 health recommender systems, only 10% included user testing, and the majority did not define the target group of the HRS intervention[2]. Further, the majority of HRS studies is conducted in the USA and China, and low-income countries are underrepresented[2].

Because of the underrepresentation of marginalized groups and lack of geographical diversity, HRS likely have cultural biases, which can make them less relevant to underrepresented groups. For example, mental health support integrated with religious or spiritual practices may be more accessible and relevant for some underrepresented groups, but it contrasts the body-mind separation of mental health dominant in a Western biomedical paradigm[28].

Decolonization involves critically reevaluating interventions to remove these biases[29]. It involves centering intervention designs in the lived experience of the potential users. Thus users, especially those from marginalized backgrounds, should be included in the design and testing of HRS through participatory research methods, including feature design, testing, and analysis of predictive results[29]. Decolonization also involves examining power relationships that may underlie the use of their technologies and structural and cultural factors that may broadly influence wellbeing[29]. Besides user involvement, technological collaborations with traditional health practitioners such as herbalists or local healers[28] community or faith-based organizations could help to understand and mitigate these power imbalances[30].

Evaluate the impact of HRS on health equity.

HRS researchers and developers should critically evaluate and report how their AI may impact health inequities (e.g. what disadvantage or privileges the research may create)[31,32]. For example, automated advice by HRS has a risk of being used to save resources on human healthcare providers[33]. In addition, successful implementation and deployment of HRS at the community level depends on structural factors such as consistent and high quality internet access, which may be particularly challenging for resource constrained areas[9]. If data is not available in sufficient detail or quantities, this will impact the effectiveness of HRS, leading to their lower effectiveness for marginalized populations.

Further, beyond the design phase, funding for planning and delivery of HRS to marginalized populations is necessary, to avoid that successful HRS projects fail to scale up to maturity to impact health. Additionally, we also need the data to track the reach and effectiveness of HRS in decreasing health inequities (metrics beyond health outcomes)[34], and advocate for policy changes based on this data[35]. Addressing these structural challenges and advocating for inclusive research are essential steps towards ensuring the equitable deployment and effectiveness of HRS in marginalized communities.

Conclusion: HRS have great potential in decreasing health inequities through accessible personalized health promotion interventions, which can influence the individual, intrapersonal, community, and societal level. HRS can leverage data from various sources to enable deep personalization of health promotion strategies based on the wider sphere of influence of health behavior, and through localized data collection, provide actionable insights for policymakers on population health. However, we argue that future research should focus on new design paradigms, including incorporating data on the social determinants of health, design from a lens of decolonizing HRS, ensuring social justice. If these steps are taken, HRS could play a crucial role in access to health promotion, improving the health of marginalized groups, and decreasing health inequities.

Conflict 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.

Author Contributions

CAF wrote the first draft of the main manuscript. All authors contributed to the writing and editing of the scientific manuscript. KG prepared the figure. All authors reviewed the manuscript.

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Data Availability Statement

NA

References:

- 1. De Croon R, Van Houdt L, Htun NN, Štiglic G, Vanden Abeele V, Verbert K. Health Recommender Systems: Systematic Review. J Med Internet Res. 2021;23: e18035.
- 2. Sun Y, Zhou J, Ji M, Pei L, Wang Z. Development and Evaluation of Health Recommender Systems: Systematic Scoping Review and Evidence Mapping. J Med Internet Res. 2023;25: e38184.
- 3. Schäfer H, Hors-Fraile S, Karumur RP, Calero Valdez A, Said A, Torkamaan H, et al. Towards Health (Aware) Recommender Systems. Proceedings of the 2017 International Conference on Digital Health. New York, NY, USA: Association for Computing Machinery; 2017. pp. 157–161.
- 4. Bhatt P, Liu J, Gong Y, Wang J, Guo Y. Emerging Artificial Intelligence-Empowered mHealth: Scoping

- Review. JMIR Mhealth Uhealth. 2022;10: e35053.
- 5. Etemadi M, Bazzaz Abkenar S, Ahmadzadeh A, Haghi Kashani M, Asghari P, Akbari M, et al. A systematic review of healthcare recommender systems: Open issues, challenges, and techniques. Expert Syst Appl. 2023;213: 118823.
- 6. Eurostat. EU citizens: over half seek health information online. In: Eurostat [Internet]. 6 Apr 2022 [cited 31 Oct 2023]. Available: https://ec.europa.eu/eurostat/web/products-eurostat-news/-/edn-20220406-1
- 7. Chinnasamy P, Wong W-K, Raja AA, Khalaf OI, Kiran A, Babu JC. Health Recommendation System using Deep Learning-based Collaborative Filtering. Heliyon. 2023;9: e22844.
- 8. Ayenigbara IO. The evolving nature of artificial intelligence: role in public health and health promotion. J Public Health . 2023. doi:10.1093/pubmed/fdad240
- 9. Richardson S, Lawrence K, Schoenthaler AM, Mann D. A framework for digital health equity. NPJ Digit Med. 2022;5: 119.
- 10. Health Organization W. Equity within digital health technology within the WHO European Region: a scoping review. Equity within digital health. 2022. Available: https://pesquisa.bvsalud.org/portal/resource/pt/who-365326
- 11. Lee BC, Bendixsen C, Liebman AK, Gallagher SS. Using the Socio-Ecological Model to Frame Agricultural Safety and Health Interventions. J Agromedicine. 2017;22: 298–303.
- 12. Lyles CR, Nguyen OK, Khoong EC, Aguilera A, Sarkar U. Multilevel Determinants of Digital Health Equity: A Literature Synthesis to Advance the Field. Annu Rev Public Health. 2023;44: 383–405.
- 13. Widening inequities, declining trust they are inextricably linked, with significant impacts on health, finds new WHO/Europe report. [cited 26 Jan 2024]. Available: https://www.who.int/europe/news/item/12-07-2023-widening-inequities--declining-trust---they-are-inextricably-linked--with-significant-impacts-on-health--finds-new-who-europe-report
- 14. Konttinen H, Sarlio-Lähteenkorva S, Silventoinen K, Männistö S, Haukkala A. Socio-economic disparities in the consumption of vegetables, fruit and energy-dense foods: the role of motive priorities. Public Health Nutr. 2013;16: 873–882.
- 15. Orte S, Migliorelli C, Sistach-Bosch L, Subías-Beltrán P, Cecilia Fritzsche P, Galofré M, et al. BECOME: A modular Recommender System for coaching and promoting empowerment in healthcare. In: Stawicki DSP, editor. Recommender Systems [Working Title]. London, England: IntechOpen; 2023.
- 16. Sedrakyan G, Gavai A, van Hillegersberg J. Design Implications Towards Human-Centric Semantic Recommenders for Sustainable Food Consumption. Advances in Conceptual Modeling. Springer Nature Switzerland; 2023. pp. 312–328.
- 17. Dempsey RC, McAlaney J, Bewick BM. A Critical Appraisal of the Social Norms Approach as an Interventional Strategy for Health-Related Behavior and Attitude Change. Front Psychol. 2018;9: 2180.
- 18. Narducci F, Lops P, Semeraro G. Power to the patients: The HealthNetsocial network. Inf Syst. 2017;71: 111–122.
- 19. Oliva-Felipe L, Barrué C, Cortés A, Wolverson E, Antomarini M, Landrin I, et al. Health Recommender System design in the context of CAREGIVERSPRO-MMD Project. Proceedings of the 11th PErvasive Technologies Related to Assistive Environments Conference. New York, NY, USA: Association for Computing Machinery; 2018. pp. 462–469.

20. Wayman E, Madhvanath S. Nudging Grocery Shoppers to Make Healthier Choices. Proceedings of the 9th ACM Conference on Recommender Systems. New York, NY, USA: Association for Computing Machinery; 2015. pp. 289–292.

- 21. Schaffer R. "Harnessing the supermarket": Grocery store-led intervention improved diet quality. In: Healio [Internet]. 3 Apr 2022 [cited 4 Nov 2023]. Available: https://www.healio.com/news/cardiology/20220403/harnessing-the-supermarket-grocery-storeled-intervention-improved-diet-quality
- 22. Fry A, Littlejohns TJ, Sudlow C, Doherty N, Adamska L, Sprosen T, et al. Comparison of Sociodemographic and Health-Related Characteristics of UK Biobank Participants With Those of the General Population. Am J Epidemiol. 2017;186: 1026–1034.
- 23. Ibrahim H, Liu X, Zariffa N, Morris AD, Denniston AK. Health data poverty: an assailable barrier to equitable digital health care. Lancet Digit Health. 2021;3: e260–e265.
- 24. Smith GS, Anjum E, Francis C, Deanes L, Acey C. Climate Change, Environmental Disasters, and Health Inequities: The Underlying Role of Structural Inequalities. Curr Environ Health Rep. 2022;9: 80–89.
- 25. Aschemann-Witzel J, De Hooge I, Amani P, Bech-Larsen T, Oostindjer M. Consumer-Related Food Waste: Causes and Potential for Action. Sustain Sci Pract Policy. 2015;7: 6457–6477.
- 26. Ricci F, Rokach L, Shapira B. Introduction to Recommender Systems Handbook. In: Ricci F, Rokach L, Shapira B, Kantor PB, editors. Recommender Systems Handbook. Boston, MA: Springer US; 2011. pp. 1–35.
- 27. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. Public Health Rep. 2014;129 Suppl 2: 19–31.
- 28. Bhattacharjee A, Sultana S, Amin MR, Iqbal Y, Ahmed SI. "What's the Point of Having this Conversation?": From a Telephone Crisis Helpline in Bangladesh to the Decolonization of Mental Health Services. ACM J Comput Sustain Soc. 2023. doi:10.1145/3616381
- 29. Pendse SR, Nkemelu D, Bidwell NJ, Jadhav S, Pathare S, De Choudhury M, et al. From Treatment to Healing:Envisioning a Decolonial Digital Mental Health. Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems. New York, NY, USA: Association for Computing Machinery; 2022. pp. 1–23.
- 30. Levin J, Hein JF. A faith-based prescription for the Surgeon General: challenges and recommendations. J Relig Health. 2012;51: 57–71.
- 31. Figueroa CA, Luo T, Aguilera A, Lyles CR. The need for feminist intersectionality in digital health. Lancet Digit Health. 2021;3: e526–e533.
- 32. Ovalle A, Subramonian A, Gautam V, Gee G, Chang K-W. Factoring the Matrix of Domination: A Critical Review and Reimagination of Intersectionality in AI Fairness. arXiv [cs.CY]. 2023. Available: http://arxiv.org/abs/2303.17555
- 33. Latulippe K, Hamel C, Giroux D. Social Health Inequalities and eHealth: A Literature Review With Qualitative Synthesis of Theoretical and Empirical Studies. J Med Internet Res. 2017;19: e136.
- 34. Gallegos-Rejas VM, Thomas EE, Kelly JT, Smith AC. A multi-stakeholder approach is needed to reduce the digital divide and encourage equitable access to telehealth. J Telemed Telecare. 2023;29: 73–78.
- 35. Roski J, Bo-Linn GW, Andrews TA. Creating value in health care through big data: opportunities and

policy implications. Health Aff . 2014;33: 1115–1122.