

Desiderata for a New Generation of EHRs for Inclusive Healthcare

Contribution from the IMIA Health Information Systems Working Group

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Summary

Objectives: This research addresses several factors relevant to inequity in healthcare that may be susceptible to being addressed in a new generation of electronic health records (EHRs).

Methods: Through a scoping review of the literature, inequities related to ethnicity, gender, and socioeconomic aspects in healthcare in general and, more specifically in EHRs, have been considered. Papers have been identified between 2011 and 2022 in three categories: EHR, gender inequalities, and ethnicity inequalities.

Results: Twenty-two recommendations have been identified within the scope of the three categories indicated above. These exposed requirements focus on two spheres: (1) technical sphere, mainly focused on the characteristics and tools that the EHR should develop from taking into account the studied inequalities; and (2) clinical sphere, which mainly affects patients, health professionals, and health providers.

Conclusions: Ethnic and gender inequalities are essential factors to take into account when diagnosing, monitoring, preventing, and treating a patient. These factors give us the keys to discovering recommendations for a new generation of EHRs to help mitigate these needs.

Keywords

Electronic Health Records, healthcare, gender, ethnic, socioeconomic factors

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1 Introduction

1.1 Ethnic Inequalities

In recent years, interest in understanding how different forms of racism affect health has been growing. This interest has been triggered by the significant health inequalities of people of different ethnicities at the frontline of the same health system [1].

Racism is defined as an organized social system where a dominant racial group classifies people into different social groups called “races” and differentially allocates resources and social opportunities to each inferior group [2, 3]. Racism is a significant cause of racial inequalities in health because, as a structured system, it interacts with other social institutions such as political, economic, and legal institutions [4, 5]

Del Pino *et al.* [6] propose some strategies to eliminate ethnic health inequalities such as: (1) making integrated efforts to prevent racism from blocking the chances of success, allowing everyone to access resources with equity, and (2) health systems to shift their focus from treating diseases to preventing them, providing quality care, adapted to each patient’s culture and needs.

It is also known that for sustainable development to exist, inequalities must be reduced by collecting vital information on each social group, such as gender, ethnicity, and age, among others [7].

Despite advances in research and reducing inequalities, African Americans, Native Americans, Native Hawaiians, and other Pacific Islanders have poorer health than the white population [8]. Launer *et al.* [9] conclude that, according to statistics, in the United States and the United Kingdom, people with black or brown skin have poorer health than people with white skin and receive poorer quality health care. In Germany, patterns of ethnic inequality in health care use are related to inequalities related to education, income, and work [10].

Ethnicity often acts as an independent variable in terms of inequality but can also intersect with other determinants such as social and educational deprivation [9]. Ethnicity is a determining factor in using health systems [10]. Migrant populations often have different health care needs, preferences, and expectations or face barriers in the use of health services, and this needs to be addressed.

1.2 Gender Inequalities

One of the structural determinants of health inequalities is gender. It determines health behavior, care practices, and health outcomes [11, 12].

The World Health Organization (WHO) defines the concept of health inequalities as the different opportunities and resources related to people’s health, depending on their

social class, gender, territory, or ethnicity, relating a worse state of health to the most disadvantaged groups. It also states that these differences are unnecessary, avoidable, and unfair [13]. Rohlfs *et al.* [14] consider that women and men get sick differently and have different lifestyles.

Hay *et al.* [15] propose a set of objectives to make health systems more gender-equitable. They focus on “(1) reflecting and reinforcing a gender-equitable society; (2) addressing gender norms and the root causes of inequalities across the life course; (3) providing equal opportunities for health professionals of all genders to enter, thrive, and progress within health systems; (4) ensure equal access to and use of high-quality health services by people of all genders, without financial, social and geographic barriers; and (5) commit to accountability for addressing gender inequalities at all levels.”

However, despite the efforts made, gender inequity in health persists today [16], and health systems remain a fundamental source of these inequalities [17].

Studies such as Kennedy *et al.* [18] propose analyzing gender inequalities from adolescence onwards since, from that stage, gender inequalities related mainly to contraception and reproduction are recognized.

Sen *et al.* [19] differentiate between two types of perspectives in the health and gender approach, which are related to each other: (1) biological perspective and (2) social perspective. The latter can be modified through health and social policies.

Most studies agree that health systems need to ensure equity in health care for patients of different genders. Some propose changes in health policies, in the training of health professionals, or in patient education, but there is still no consensus.

1.3 Electronic Health Records

The implementation of electronic health records (EHRs) in the US healthcare system [20] and worldwide [21] is leading to the rapid growth of data in digital format. This growth offers enormous potential for the use of clinical data beyond patient care. *Secondary use* of clinical data is defined as “the non-healthcare use of personal health information, including,

but not limited to, analytics, research, quality/safety measurement, public health, payment, provider certification or credentialing, and marketing and other activities, including strictly commercial activities” [22].

The information contained in the EHR is of great value to: (1) furthering research in clinical informatics, (2) improving clinical practice, and (3) improving healthcare [23]. However, EHRs have essential data that cannot be reused, as they do not store the information entirely or store it in a complex format. Studies show that EHRs omit important patient data [24] or provide other information in a format that is not machine-processable, complicating data analysis.

This also undermines the analysis and storage of data related to gender and ethnic inequalities, which results in the loss of information on the behavior of these inequalities concerning affected patients and their diseases. Moreover, these data are necessary to combat these inequalities and eradicate them from health systems.

With this situation in mind, we undertook a scoping review of the literature to identify several factors relevant to inequity that are likely to be addressed by implementing a new generation of EHRs to respond to these needs.

2 Materials and Methods

A scoping review method defined below has been designed to identify and extract the relevant information to develop these desiderata.

2.1 Identifying the Information Sources

A search for literature related to the topic of study was conducted in the PubMed database. The search was carried out between 2011 and 2022 for English and Spanish articles to obtain the most recent information on this research. The reason for searching in two languages was to get broader and more diverse information on territorial issues.

A pattern of searching the information was established with different terms, from more general to more specific. The general

terms included: (1) Electronic Health Records, (2) EHR, (3) Electronic records, (4) Medical Records, and (5) Patient Records. Subsequently, a search was conducted for more specific terms such as (1) Gender, (2) Ethnicity, (3) Gender inequality, (4) Gender inequalities, (5) Ethnicity inequality, (6) Ethnicity inequalities, (7) Inequalities in HER, (8) Socioeconomic inequality, and (9) Socioeconomic inequalities.

Considering the search keywords, a total of 741 articles were detected.

To select the papers, inclusion, and exclusion criteria were defined, detailed in the following section, and the information in each article was further analyzed. Firstly, the titles were analyzed, the abstract was read, and finally, the introduction, discussion, and conclusions. Three iterations were carried out to identify the articles that met the inclusion criteria and classify them into three categories: (1) EHR, (2) Gender inequalities, and (3) Ethnicity inequalities.

2.2 Inclusion and Exclusion Criteria

In order to limit the search for information and the scope of the review to meet the objectives proposed in this research, inclusion and exclusion criteria have been established.

Inclusion criteria:

1. Papers that identify factors in EHRs related to gender or ethnic inequalities and that generate health impact;
2. The importance of good data storage in the EHR to improve clinical care and research is explored;
3. Not all studies presented in each article must have been conducted in the same country;
4. The selected article must be in English or Spanish.

Exclusion criteria:

1. The EHR information discussed in the article does not focus on improving EHR;
2. The article focuses on gender or ethnic inequalities contained in EHRs, but not on their impact on health;
3. Other types of situations that have an impact on health conditioned by EHRs are discussed.

2.3 Extracting the Information

Once the papers that met the inclusion criteria had been identified, the relevant information related to the present research was extracted and classified into the three categories defined in the section “Identifying the information.” A total of 51 references were finally identified.

First, the titles were read, and a first classification was made. Each article was assigned a number within its category within this classification, and its reference was included. As the information contained in each paper was explored in more depth, the information relevant to the present research was extracted. This information was linked to the numbered paper and its reference within the category it had been assigned. If the paper was considered to be classified in another category due to the content, the change was made if there was consensus among the authors.

Based on the results, discussions, and conclusions of the articles identified, a classification was made, and recommendations were drawn.

3 Desiderata

The recommendations proposed by this research are listed below.

3.1 Ethnicity

Several relevant needs have been identified in addressing ethnic inequalities that are addressable from the point of view of EHR design and use. These are represented schematically in Table 1:

1. Improving the health of a country's ethnic minorities should not only focus on the needs caused by deficits [25] as many are, compared to a region's population, healthier concerning non-communicable diseases such as cancer [26]. Moreover, the doctor-patient relationship is often paternalistic for this population, which differs from the type of relationship promoted today that is more consensual between doctor and patient;
2. A reasonable health rate in a particular age group of an ethnic group is not a

Table 1 Desiderata for ethnicity inequalities.

Desiderata		References
1	Improving health by going beyond deficits	[26,26]
2	Updating the doctor-patient relationship	[27]
3	Studying the health rate by age group does not provide insight into future behavior	[28]
4	Adapting clinical information and communication to patients whose native language is not the same	[29-31]
5	Provide access to health care for all ethnic groups	[29, 32]
6	Encouraging contact with social support services	[6]
7	Promoting racial diversity among health professionals	[33,34]

- predictor of good health in the future, i.e., if within a particular ethnic group there is an age range in which there is generally good health, it does not mean that when they change age range, they will continue to be in good health [27];
3. Even if ethnic groups established in a region speak the language of that region, healthcare professionals need to adapt information and communication with these patients. This is especially true for those of non-Western ethnic origin [28]. Furthermore, it is necessary to provide health education, especially to young adults of diverse ethnic backgrounds;
 4. Individualized health care is also necessary for ethnic minorities, and health professionals should consider the risk factors and social needs of ethnic minorities to place greater emphasis on disease prevention [29]. In particular,

strengthening patient-centered primary care would reduce health inequalities [30, 31];

5. Providing access to healthcare for different ethnic groups reduces overall healthcare costs and improves the health of this population [29]. In 2017 [32], the United States introduced the “Medicare for All Act” initiative to provide a universal right to decent healthcare. Total healthcare costs were reduced by 9.6%;
6. To improve the health of these ethnic minorities is essential for health care providers to encourage contact between these patients and social support services [6];
7. Research suggests that racial diversity among health professionals generates a benefit in healthcare [33] as health professionals from underrepresented minorities are more likely to work with underserved populations [34].

Table 2 Desiderata for gender inequalities.

Desiderata		References
1	Focusing on the prevention of inequalities from adolescence onwards	[35,36]
2	Improving the quality system in health care to reduce inequalities	[37-39]
3	Providing training for health professionals	[39-41]
4	To know the behaviour of infectious diseases according to gender	[41]
5	Knowing what works, for whom in particular and in what context	[38,39,42]
6	Knowing the financial, human and infrastructure needs	[38,39]
7	Promote data stratification	[38]
8	Encourage the use of support tools	[38]

3.2 Gender

1. There is a need to prevent gender inequalities in early adolescence [35] by establishing strategies at individual, societal and structural levels [36];
2. Quality health care systems must be improved to reduce gender differences by strengthening national legislation and programs [37-39];
3. Provide continuing education courses for health professionals on the relationship between gender differences and health problems to improve healthcare quality. In addition, it would also be good to introduce a subject in medical studies on the relationship between gender and disease [39-41];
4. In the field of infectious diseases, knowing the infectious burden and symptoms present in each gender would be positive for optimal diagnosis, monitoring, and treatment of the disease [41];
5. In order to address the problem of inequalities, it is necessary to know: (1) what works, (2) for whom in particular it works, and (3) in what context it works. The more specific the knowledge, the fewer inequalities [38, 39, 42];
6. There is a need to know what financial, human, and infrastructural resources are needed to address gender inequality [38, 39];
7. Promote the use of data disaggregated by stratifies such as gender in order to address different pathologies [38] specifically;
8. The use of different tools EHR-based should be promoted to find out the current needs concerning gender inequalities for health professionals and patients [38]. In addition, these tools can provide information on monitoring the results of addressing inequalities.

3.3 EHR

In terms of the needs found to improve the EHR, they are schematically represented in Table 3:

1. Standardization and structuring of the information contained in the EHR would improve the use of information for research and disease management [23, 43];

Table 3 Desiderata for EHR.

Desiderata		References
1	Standardizing and structuring information	[23,43]
2	Use of Natural Language Processing	[23,43-45]
3	Computational and readable data	[43]
4	Implement set operations and relational algebra	[43]
5	Representing information with structured rules	[43]
6	Patient portals should consider several levels of literacy	[46,47]
7	Integrating digital therapeutics into the EHR	[48-50]

2. The use of NLP allows for decision support by considering variables such as gender and ethnic inequalities, which are often overlooked and highly relevant [23, 43]. Furthermore, the application of NLP has proven to help take into account social determinants in clinical decision-making and reduce inequity [44, 45];
3. The data contained in the EHR must be human-readable and computational so that they are coupled, and one can be automatically generated from the other [43];
4. Implementing set operations and relational algebra will provide crucial information on the influence and relationship of the different inequalities to the diseases suffered by this type of patient [43].
5. Representing inequality criteria with structured rules makes it possible to compare information on inequalities and diseases and to support complex workflows that take into account and relate a more significant number of variables [43];
6. Portals to EHRs (called patient portals) should be designed to address various levels of digital literacy and health literacy of the patients, thus minimizing the risk of excluding certain groups of the benefits of patient portals. In their Cochrane review, Ammenwerth *et al.* [46] cite the following “In contrast, as a possible adverse eDect, EHR access may increase feelings of confusion and anxiety when patients read clinical information that is unclear to them. In addition, HER access, like many other eHealth solutions, is created for “people like me.” These eHealth solutions, therefore, may only

address the needs of “well-educated and well-to-do [wealthy] users rather than the needs of the most disadvantaged in society (the disempowered, disengaged, and disconnected)” [46]. For example, a study on the patient portal of Kaiser Permanente Georgia showed that portal users were significantly more likely to be white and to have a higher level of education [47].

7. To have digital therapeutics integrated into the EHR to make it more inclusive. Digital Therapeutics Alliance has declared digital therapeutics as “evidence-based therapeutic interventions driven by high-quality software programs to prevent, manage, or treat a medical disorder or disease” [48]. Digital therapeutics appears to be well-suited for the delivery of clinical therapies digitally that would usually be delivered in face-to-face encounters with live therapists, such as cognitive-behavioral therapy (CBT), clinical hypnotherapy, or clinical physiotherapy [49]. Digital therapeutics facilitates access to the therapies in a more independent environment without being limited to time and other restrictions of a meet-up with the clinician physically. The patients who are suffering from mental health disorders may experience less stigma when treated with digital therapeutics. Digital therapeutics allow more significant levels of granularity when personalizing the treatment. Since it has a history of data, it facilitates the clinicians involved in physical encounters to assess the progress and the outcomes. Digital delivery of therapy

ensures consistency of quality throughout the treatment independent of the environmental factors. Digital therapeutics may provide advantages such as ease of access, the convenience of usage, fewer side effects, and cost-effectiveness [50]. Hence, the above factors make digital therapeutics a more inclusive method of delivering health care when integrated into EHRs.

4 Discussion

This manuscript aims to expose the unmet needs that exist today concerning gender and ethnic inequalities. It has been shown that ethnic inequalities are closely related to socio-economic inequalities.

These exposed needs focus on two spheres: (1) Technical sphere, mainly focused on the characteristics and tools that the EHR should develop from taking into account the studied inequalities when making a diagnosis, treatment, and follow-up of disease and implement preventive measures for each group, and (2) Clinical sphere, which mainly affects patients, health professionals, and health providers. Several communications and relationship needs are identified about patients, training needs for health professionals, and policy development needs for health providers and health systems.

The study has a series of limitations:

- Restricted search: the search for information has only been carried out on PubMed when other sources of information can provide relevant data;
- More specific review methodology: the review method could be improved and, above all, extended. This study could be expanded with a more in-depth analysis comparing countries or regions of the world;
- Obtaining recommendations has not been developed based on a more systematic methodology (such as a Delphi panel). Instead, it identifies needs to facilitate discussion that will serve to advance the discovery of recommendations for a new generation of EHRs.

5 Conclusions

Gender, ethnic and socio-economic differences are determinants that significantly affect patients' health who suffer from them. Some of the problems related to these differences include:

- Limited access to health services due to lack of financial resources. This leads to delays in diagnosis, lack of preventive measures, and lack of follow-up;
- Mistrust of health professionals with whom they do not communicate well due to language differences;
- Lack of health education for patients in this type of situation;
- Lack of knowledge about the health implications of a patient's gender or ethnicity concerning the disease;
- Patients generally do not have access to their health information and, if they do, lack of literacy can be an impediment.

The main objective of this research is to highlight the importance of taking into account the gender and ethnicity status of patients when diagnosing, treating, preventing, and monitoring disease. There is a critical need to explore this issue further and to treat these characteristics as a condition for achieving one of the main goals of medicine in recent times (personalized medicine). As is becoming increasingly clear, patients must be studied individually, considering all the factors that affect their health. Ethnic and gender inequalities are essential factors to take into account when diagnosing, monitoring, preventing, and treating a patient.

These factors give us the keys to discovering recommendations for a new generation of EHRs to help mitigate these needs.

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