Representation of the Transgender Population in Electronic Health Records: Implementation Strategy in the Public Health Care System of Buenos Aires City

Denise Levi[a], María Victoria Vazquez[a], María Victoria Giussi[a], S. Esteban[a], Analía Baum[a]

[a] Health Information Systems Office, Ministry of Health, Buenos Aires City, Argentina

Abstract

Electronic Health Records (EHR) face the challenge of collecting data about patient's gender identity in order to provide standardized and quality data to manage public policies in order to improve health disparities of the Trans population. Innovation in Health Information Technologies (HIT) develops in the midst of a cultural change process related to social representations of gender in favor of a diversity perspective. Understanding the health field as a complex adaptive system, the changes in the systems must consider multiple factors in every stage of the process. It is relevant to consider the people involved in it and the culture in which they are embedded. This article describes the implementation strategies of functionality that represents the transgender population in the EHR of the Public Health Care System of the Buenos Aires City.

Keywords:

Electronic Health Records; Transgender Persons; Cultural Evolution

Introduction

Transgender people are individuals whose gender identity differs from their sex assigned at birth, and may involve the modification of their appearance or body function through pharmacological, surgical or other means. In recent years, the Electronic Health Record (EHR) faced the challenge of representing the transgender population. Correctly identifying this population allows longitudinal health records that facilitate continuity of health care. On the other hand, it is indispensable to have standardized data in order to obtain quality metrics and create research opportunities that contribute to the management of public health policies for this vulnerable population.

On the legal level, in different countries transgender people can change their name and gender in their identity documents. However, the laws vary in different countries and localities. Since the process of opening a patient's chart in the EHR depends on the patient's identification, changing the name or gender of any individual represents a challenge when it comes to ensuring the longitudinality of the clinical record.

Articles from different countries mention how the systematic legal, economic, and social exclusion of trans people negatively affects every area of their lives: family, health, education, work, housing, and security. Their living conditions often face poverty, precarious housing or homelessness, and inequality in education, work and health.

Experiences of stigma and discrimination have been described in various areas, highlighting health in particular, protagonized by both administrative staff and health care professionals. The most feared situation that trans people describe is to be called by the name that appears in the person's legal documentation instead of the chosen one. This produces discomfort and ridicule that can lead to absenteeism of future healthcare appointments [1-3]. These experiences have a negative impact on patient satisfaction, the patient-professional relationship, and can also lead to a risk of verbal and physical assault by other patients in the waiting rooms.

In Argentina in 2012, National Law 26.743 "Gender Identity" was passed. This law granted people the right to be identified according to their self-perceived gender in the instruments that accredit their identity, among other rights [4].

In the United States in 2016, The Centers for Medicare & Medicaid Services (CMS) and The Office of the National Coordinator for Health Information Technology (ONC) announced that every entity certified under the Meaningful Use incentive program, will be requested to create structured fields allowing users to register, change, and access data on their gender identity [5]. Since then, several recommendations and guidelines have been developed in order to ensure efficient documentation of these data. It has been detailed how to request, store and display the data in the user's interface [6-8]. Furthermore, the incorporation of structured fields for the recollection of the chosen name, gender identity, sex assigned at birth and pronoun preference as demographic variables have been described [9-11]. Other research inquired about the perspectives of Trans people and healthcare professionals in relation to providing or having gender identity data [12-15]. Even controlled vocabularies for statistical and epidemiological analyzes such as the International Classification of Diseases 11th Edition (ICD-11) of the World Health Organization (WHO), proposed a new chapter related to sexual health conditions. The proposal was to include "Gender Inconsistency" as diagnostic category, instead of as a mental disorder as described in ICD-10 [16, 17]. The same happened with the Diagnostic and Statistical Manual of Mental Disorders (DSM) on its 5th edition [18]. Since 2009, people and organizations from different countries have set up an International Network for the Depathologization of Trans Identities. The goal has been to raise awareness and expose the psychiatrization of gender diversity and request the withdrawal of the aforementioned diagnostic categories from the ICD and DSM, previously classified as mental disorders [19].

A process of cultural change is currently gestating in favor of the recognition of the diversity of gender. It implies a modification of structures and social representations. It is important to take into consideration the cultural aspect, since it constitutes a system of shared meanings from which people interpret reality, define their way of acting and how to proceed. Otherwise, the mere IT tool that allows the recording of data in question would be insufficient. The goal of this paper is to describe the strategy that was used in the Public Health System of the Autonomous City of Buenos Aires for the implementation of functionality that represents the transgender population in the EHR.

Methods

Setting

The City of Buenos Aires has an area of 204 km² inhabited by 3,059,122 people. The health care system has 3 main sectors: The public sector, social security, and the private sector. These 3 can often coexist. The public health care system strives to offer medical access to all its inhabitants.

According to 2016 statistical data, 20% of Buenos Aires' population can only access healthcare through the public system. This percentage rises to 50% within the most unprivileged who live in the south of the city [20]. And it scales up to 78% among the transgender population [1].

Software

Since June 2016 an EHR has been gradually implemented within the outpatient setting [21]. In 2017, the "Self-perceived Name" functionality was incorporated, which allowed the user to to register a patient's preferred name in relation to their gender identity, when this names differs from their identity document.

Subsequently, in all the places where the person's name displayed in the EHR, the self-perceived name is displayed, with the initial letter of the identity document in parentheses next to the self-perceived name. All data related to the patient can be found within the personal data sheet. From this sheet, the name registered in the person's documentation can be extracted in order to be used in billing processes, prescription of medication or other legal operations.

Study Design

This is a descriptive study about the implementation strategies of a functionality that represents the transgender population in the EHR of the Public Health System of Buenos Aires City.

Results

The implementation strategy of this functionality included the following aspects:

1. Intersectoral approach

We convened the General Directorate of Coexistence in Diversity of the Undersecretariat of Human Rights and Cultural Pluralism, with dependence on the Vice-Government Office. Its responsibilities are to work on public policies and spaces for promotion, prevention and protection to reduce acts of discrimination and violence towards the people of the various groups that cohabit in the Autonomous City of Buenos Aires.

2. Profile stratification

The diversity of actors was stratified in different profiles to personalize the content. The stratification was decided according to the fulfilled function;

- Implementers: train end-users of the healthcare information system.
- Help Desk Operators: provide technical and functional support to the system users' queries.
- Administrative Staff: the patient's first point of contact when interacting with the healthcare system and are in charge of collecting the identification data.
- Healthcare professionals: professionals from different disciplines that provide healthcare.

3. Preparation of materials

Specific materials were developed for each profile, including: instructions explaining how to operate the new functionality,

specific conceptual content of this topic (Table 1) and its legal framework. This was also made available on the Primary Health Care Web Portal, an intranet service that provides a communication space among healthcare workers.

4. Institutional stratification

The institutions that had the largest Trans population were identified in order to intensify the training.

5. Training

Two types of training were planned for all profiles:

- Face-to-face group training: a 3-hour workshop format was implemented. The aim was to raise awareness about gender issues. To accomplish this, different triggers were used to get in touch with the actors' perceptions which allowed to explain the concepts of gender binarism and heteronormativity. Then the concept of gender identity was introduced and it was differentiated from the concept of sexual orientation. Living conditions and health indicators for the Trans population were shared and the legal framework was deepened.
- Individual virtual training: several courses taken by administrative personnel and healthcare professionals were modified. The courses that were modified related to the use of applications for identifying people, granting and managing shifts, and the EHR application.

6. Communication

The communication strategy had 2 main recipients:

- Users of the information system: a pop-up was introduced in the login interface to the system notifying about the new functionality with a link to materials and instructions. In addition, a message to all users was posted on the Web Portal, emphasizing not only the opertation part, but also conceptual issues and regulatory framework.
- Users of the healthcare system: the Trans population was informed that they can register with their self-perceived name in the public healthcare system.

As of November 2018, there are a total of 170 Self-perceived Name records (Table 2).

Table 1 - Illustrative content about gender issues

Concept	Definition
Gender identity	The internal and individual experience and feeling of each person's gender which may or may not correspond to the sex assigned at the time of birth.
Biological Sex	The set of chromosomal, anatomical and physiological information that differentiates men and women. It is used to assign gender at birth.
Intersex	People whose anatomy does not fit the standards of female or male biological sex. It makes reference to the corporal diversity.
Gender expression	It involves everything that is communicated from our gender to others: clothing, hairstyles, body language, our interactions and social roles.
Gender binarism	It is a social construct that classifies people, limiting themselves to fulfilling feminine or masculine roles based on their anatomy.
Cisgender	People whose gender identity matches the sex assigned at birth.

Transgender	People whose gender identity differs from the sex assigned at birth.
Sexual Orientation	The ability of a person to feel emotionally, sexually and affectively attracted by a person of the same gender (homosexual), of the opposite gender (heterosexual), of more than one gender (bisexual).
Queer	Sociocultural movement that considers gender and sexual orientations as a social construct and seeks the disappearance of this categorization.
Heteronormativity	The social rule that assumes the alignment of biological sex, gender identity and heterosexuality as desirable and normal.

Table 2– Self-perceived Name records in EHR

Year	Month	Records
2017	July-August	8
	September-October	13
2018	November-December	15
	January-February	12
	March-April	21
	May-June	36
	July-August	36
	September-October	29
	Total	**170**

Discussion

As seen from the diagnostic categories of ICD-10 and DSM-5, historically the transgender population has been considered in terms of abnormality, anomaly or disorder [19]. In recent years, questioning of gender binarism and heteronormativity have given rise to a broader perspective of diversity, thus beginning a process of cultural change. Even so, these changes are incipient. The lack of legal frameworks in many countries and the persistence of stigma and discrimination affect the quality of life of this population in various areas of their lives.

This paper describes the implementation strategies for functionality that allows the identification of transgender people according to their self-perceived gender identity. Multiple strategies were contemplated with an emphasis on raising awareness on this matter, going beyond the use of the system. The intersectoral approach made it possible to have the resources and means necessary for communication and training. It was also key to have specialists involved in the subject matter for the preparation of contents and materials in order to provide training that encouraged active participation. This helped to address people's concerns, questions, and understand their emotions given the complexity of the subject.

Initially, when face-to-face group trainings were conducted, the perceptions and previous knowledge about being a woman or a man were explored. The goal was to visualize the representations of social models of the binary gender system and understand them as a social construct were people are classified into two unique categories – feminine and masculine – based on biological differences, and also linked to social roles, behavioral expectations, sexual orientation, etc, which helps to maintain control and establish social order. After this collaborative work, the gender diversity perspective was introduced. This way of presenting the content was planned as a strategy to minimize resistance, using a deconstructive current. This current established that only by revealing the

apparently hidden, and previous pragmatic elucidation of the success of an ideological system, there is a chance to actually glimpse the questioning or disarticulation of a socio-cultural structure and dynamics in view of its transformation or construction of a new meaning [22].

On the other hand, the strategy of stratifying profiles had its foundation in understanding health organizations as complex adaptive systems, shaped by dynamic networks of actors interconnected with different roles, functions, conflicts and interests [23]. Therefore, the contents were customized with a focus on the fact that implementers' and help desk operators' profiles should have tools to train all user profiles. The administrative profile is the patient's first contact with the healthcare system and they are in charge of collecting identification data. It was also taken into consideration that within the medical profile, the biologicist conception usually predominates. At the same time, these institutions are characterized by the concentration of power at their bases and not only in the hierarchical areas that are laid out on the formal organization chart. The governance in relation to both administrative and professional workers has a particular complexity. A great deal of emphasis was placed on the legal framework – the National Gender Identity Law No. 26,743 and the National Law No. 23592 Antidiscrimination – and how the system allows respecting the provisions of the law [9].

The stratification of institutions with the greatest Trans population was carried out with the aim of reinforcing training. Surprisingly, we found that they were the users with the highest awareness and had the best manners when it came to Trans patients. However, since they were familiar with the patients, many users indicated that they did not register Trans patients' data in the system since they were well known by every worker in the healthcare institution. In these cases, the training was directed to the importance of the registry of data, explaining that other institutions of the public healthcare system network can also access to this information.

Conclusions

Incorporating structured fields to the EHR to represent Trans people with standardized data that allow a correct identification of this population is essential to ensure the continuity of care. However, even though systems accompany the cultural changes, the computer tool alone do not transform people's practices. Therefore, it is important to consider the human factor and the culture in which people are embedded as a part of the strategy to implement functionality that meets the neds of the Trans population.

Limitations and Future Direction

Future research is needed to evaluate the implementation and perceptions of patients in relation to the quality of care in healthcare institutions, as well as the development of indicators to monitor the quality of the registry. In addition, other lines of work should aim to relieve specific information needs that are required at the EHR level for this population's healthcare.

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Address for correspondence

Levi Denise Paula

Ministry of Health, Autonomic City of Buenos Aires, Argentina.

E-mail: dlevi@buenosaires.gob.ar

Phone Number: +54 9 11 54987439