

## Design and Development of an Electronic Health Record According to Argentine Gender Identity Law

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### Abstract

*Health information systems face the challenge of collecting data on patients' gender identity. The absence of this information may lead the patients to situations of vulnerability and discrimination. The objective of this study is to describe the process of designing and developing an Electronic Health Record according to the Argentine Gender Identity Law. This health record allows clinics to record legal names and surnames, other social names, gender identity, sex at birth, and legal sex.*

### Keywords:

Transgender persons, Electronic Health Records, Latin America

### Introduction

Currently, healthcare institutions are facing new challenges in relation to Information Systems, including how to appropriately collect and document information on the patient's gender identity in the electronic health records (EHR).

These information needs reflect a moment of cultural change related to social representations of gender, towards a perspective that includes diversity [5]. In 2012, Argentina enacted the Law 26,743 on "Gender Identity" [9], which defines that every person has the right to be recognized by their gender identity; to be treated according to their gender identity and, in particular, to be identified in that way in the documents proving their identity in terms of the name, image and sex registered therein [6]. Likewise, the Ministry of Health of the Republic of Argentina issued "Guidelines for healthcare providers" on comprehensive healthcare for transgender people. These guidelines state that the health system should respect people's name and gender identity both in their physical environment where they provide care or hospitalization, as well as in their patient registration documents (health records, appointment system, certificates, electronic prescriptions, patient index, among others) regardless of whether or not the person has changed this information in their ID.

There is relevant literature on the importance of including sex, gender and social name - e.g., the person's chosen name - in the EHR [1,3]. However, this information is rarely included in the information systems, whether electronic or not, which can place patients in situations of vulnerability and discrimination [7,10]. The fact that the vast majority of patients are not transgender has led to the implementation of a male and female-oriented binary system across multiple platforms, such as EHR, billing, coding, and laboratory systems. However, this structure prevents the collection of accurate medical information, and therefore such systems have to be reconsidered and modified.

Given the aforementioned need, an interdisciplinary team addressed this issue at Fundación Huésped. Considering the importance of visualizing the information related to gender identity, it was thought to incorporate this information in the design of the organization's EHR (RedClin), thus allowing the provision of comprehensive and quality care.

The objective of this study is to describe the process of designing and developing RedClin compliant with the Gender Identity Law and the needs of the diverse population care.

### Methods

Fundación Huésped is an Argentine organization with regional scope that works to guarantee access to health and disease control and prevention, focusing on HIV/AIDS, viral hepatitis, vaccine-preventable diseases and other transmissible diseases, as well as sexual and reproductive health. Fundación Huésped is the clinical site in Argentina for the Caribbean Central and South American network for HIV epidemiology (CCASAnet), representing the region in HIV cohort studies.

A mixed-design research was conducted in three phases:

#### Design Phase 1: Situational diagnosis.

We conducted a review of the literature. The papers were reviewed manually and a selection was made of those related to the determination of the different identities in EHR. Then, the legislation in force in our country was evaluated in order to include the regulatory framework. At the same time, a Participatory Workshop was held with professionals from both Fundación Huésped and Centro Médico Huésped (a neighboring clinic), with the aim of understanding the registry process for medical assistance for transgender patients.

#### Design Phase 2: Analysis

The collected data were analyzed, establishing a comparison between the current collection of gender information and the needs of the new EHR that meets gender identity requirements. Requirements of information to be included in the EHR were prioritized and organized in two main categories - general/common data and gender-specific data - in order to determine how to display these data in the RedClin EHR.

#### Phase 3: Prototype design

Given the literature reviewed, the local law regarding Gender Identity, and the identified requirements, we convened a multidisciplinary group of specialists in medical informatics, IT analysts, primary and healthcare providers and RedClin provider. Different prototypes were designed to cover the different uses of the system. Within this third phase, the focus was on visualizing information that identifies individuals in

different applications (EHR and appointment system), according to the resulting needs of the community, the users, and local regulatory requirements. It comprises social name, legal name and surnames -names as recorded on the ID, sex at birth, gender identity (self-perceived gender), and legal sex.

## Results

The resulting RedClin EHR includes modules and sections with structured text that allows recording of social names, gender identity, sex at birth, legal sex, and other data fields. Once a section is selected, users have the possibility of recording information in drop-down menus, radio buttons, and eventually free text boxes. These entries become part of the display in RedClin and electronic prescriptions of drugs and vaccines. This information is available during all clinic visits.

The same design was implemented for the appointments system, according to the guidelines on gender identity. That system allows clinic staff to record social names, legal names, gender identity, sex at birth, and legal sex of patients. A patient search can be performed by social name and legal surname.

## Discussion

The design of an EHR according to the requirements of the Argentine Gender Identity Law aimed to respond to the needs of the trans community, healthcare professionals, and regulatory bodies.

Our revised ERH will help reduce missteps in data collection and inadequate health service delivery for transgender people that is known to have a negative impact on their health [4]. In 2010, the Institute of Medicine (IOM) refers "data on gender identity must be collected in the EHR and this objective has to be incorporated into meaningful-use objectives" [2]. In line with international recommendations [4,10], having these data will allow comparison of the epidemiology of health problems of LGBTQ patients with heterosexual and cis patients, giving us a measure of the quality of the attention for this population.

The experience presented in this article represents a compromise between the identified needs of the trans community and the usability of the system. For example, the RedClin revisions did not include all possible gender identities (e.g., non-binary) and there are fields that could be eliminated due to regulatory requirements (e.g., legal sex). The changes incorporated to RedClin allow us not only to improve data collection but also the display of that information on the screen. This clear presentation of information helps prevent mistakes during the clinical visit and respects gender identity in the way people are named and represented in screens and documents (prescriptions, EHR summary).

## Conclusions

Medical informatics has to address the needs of the transgender population by designing and developing information systems that allow for the collection of precise and accurate data and align with social and legal changes. With clear communication of gender identity in its user interface, RedClin is expected to improve healthcare delivery for transgender people in this context.

## Acknowledgements

This work was supported by the NIH-funded Caribbean, Central and South America network for HIV epidemiology (CCASAnet), a member cohort of the International

Epidemiologic Databases to Evaluate AIDS (IeDEA) (U01AI069923). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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