

BEYOND THE BINARY: A PROPOSAL FOR UNIFORM STANDARDS FOR GENDER  
IDENTITY AND MORE DESCRIPTIVE SEX CLASSIFICATIONS IN ELECTRONIC  
MEDICAL RECORDS

by

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**CERTIFICATE OF APPROVAL**

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This is to certify that the Master's Capstone Project of

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*Beyond the binary: A proposal for uniform standards for gender identity and more descriptive sex classifications in electronic medical records*

Has been approved

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## **Abstract**

Sex and gender are commonly thought to be synonymous, and both are generally classified using the binary categories of male and female. Existing standards applying to electronic health records (EHRs) all use, or until very recently have used, only these two categories plus “unknown” or “not-specified” with the latter options existing more for irretrievable or absent information than for purposes of documenting a diverse set of possible expected answers. Evidence is mounting that the binary options may not be adequate for many populations, including but not limited to intersex and transgendered patients. Insufficient granularity may result in insurance denials, documentation irregularities, or even medical misadventure. For example, a patient documented as male and appearing unremarkably in a masculine manner may present with pelvic pain and experience unnecessary delays and expense, possibly even harm, when the presence of an abnormally-behaving uterus is not discovered until a computerized tomography (CT) scan is performed.

The realization that more options might be needed crystallized in the recommendation by the Institute of Medicine (IoM) in March 2011 that more diverse categories for sex and/or gender classification be considered in developing Meaningful Use recommendations for EHRs. In March 2012, as part of Meaningful Use Stage 2 rule making, the Department of Health and Human Services (DHHS) solicited feedback regarding the need for, and appearance of, a new gender classification model. In Oct 2012, DHHS chose to defer a decision pending clearer guidance from stakeholders. This paper examines the supporting basis for more inclusive and clear gender and sex classifications in EHRs, provides an argument that Meaningful Use Stage 3 should include a requirement for such a classification scheme, and proposes a framework for such requirements that would meet the needs of the affected population, providers, and vendors taking into account the experiences gathered by trailblazing providers and vendors since the IoM report of 2011.

## **Introduction**

The electronic health record (EHR) is a person-centered application. The focus of the information contained therein is the individual patient, and the key identifier for each entry in the application database is unique to one human being. Other common examples of person-centered applications are those that track students in a school, employees in a workplace, or citizens of a nation. Like other applications that catalog or track individuals, the foundation of the EHR is demographics. According to the Random House Unabridged Dictionary, demographics are “the statistical data of a population, especially those showing age, income, education, etc.”<sup>1</sup> The demographic categories used by any particular electronic application vary widely, but some are essentially ubiquitous. Nearly universal categories include a person’s name, date of birth, and sex or gender.

Certain demographic categories, even those that are fundamental to identifying an individual, are expected to change over time. The archetypical example of this is “name.” A common practice in many cultures is for a woman to assume the family name of her husband upon marriage. Person-centered applications must be configured to handle this change, and to maintain the integrity of previously collected data regardless of changes made to any such demographic field.

Other demographic categories are commonly seen as static. The best example of this might be date of birth. Short of a clerical error, there is no reason to expect that a person’s date of birth would change. Other essentially ubiquitous demographic fields commonly treated as being static are race or ethnicity, and sex or gender. But are these determinations truly static and unchanging? For example, what metric should be used to determine the latter, especially early in life before personal preferences can be expressed? As has been witnessed and well documented

with the United States Census since 1960, race and ethnicity are not static concepts and their classification by individuals and across populations will change over time.<sup>2</sup> Since 2000, a similar epiphany has been manifesting regarding sex and gender.<sup>3,4</sup>

Sex or gender demographic references in the United States currently reflect the historically prevailing perception that there are two and only two immutable sexes or genders (male and female), and that sex and gender are synonymous. We reviewed the Department of Motor Vehicle websites for each state in May 2013 and found that in each jurisdiction the driver's license, the most ubiquitous form of government-issued ID in the United States, allows only M or F. This review also noted the terms 'sex' and 'gender' being used synonymously, changing from state to state and even being used interchangeably on the same website. Most other records encountered in everyday life, including such documents as birth certificates and military ID cards, follow this same standard. It is no surprise that American EHRs and their related features reflect this perception.

However, sex and gender are not synonymous, they are not necessarily static, and they are certainly not universally binary. The World Health Organization (WHO) recognizes this, citing the fa'afafine of Samoa and the kathoey of Thailand as just two examples of 'third' genders in some cultures. Based on examples like these, the WHO acknowledges that sex and gender are not the same, they can change from that assigned at birth, and they are not perfectly binary.<sup>5</sup> Elaboration on what exactly this means for a discussion about EHR demographics will be a focus of this paper.

The distinction between sex and gender is of importance in the United States because there are at least three well-distributed populations for whom adherence to a strict and interchangeable sex/gender binary is at best a disservice, and at worst potentially life threatening.

These populations are the intersexed, the transgendered, and those who have had sex organs removed or modified for medical reasons, such as abnormal bleeding or the presence or risk of cancer, despite otherwise conforming unremarkably to the traditional sex and gender binaries. Although the sensibilities and needs of each of these populations vary widely, each requires a perspective on sex and gender that transcends the established connotations assumed from simple “male” or “female.”

This paper will review existing published or posted documentation referencing sex or gender as a demographic field in EHRs, report the increasing recognition that this topic is of importance to the development of EHR applications in the United States, and then finally build a case for separate and more granular options for sex and gender in American EHRs.

## **Background**

### **Prevalence of affected populations**

When first introduced to the idea that sex or gender options exist beyond male and female, or that a differentiation between sex and gender is advisable, many Americans wonder if the size of the affected populations warrants the investment necessary to include them in demographics such as those underlying EHRs. This view is often buttressed by the fact that gender or sexual incongruities are often not apparent and not openly discussed, so people do not recognize in their everyday lives those around them who so affected.

Further supporting the misperception of triviality is a finding from 1968 suggesting the rate of transsexualism in the United States to be 1:100,000 for those classified as male at birth and 1:400,000 for those classified as female at birth.<sup>6</sup> In retrospect, these numbers were minimized by the focus on transsexual surgery, which at the time was very difficult to obtain, and the societal prejudice against transsexualism which prevented many from obtaining the care necessary to transition their sex from their birth classification to their identified one, or if they did pursue transition did so outside the normal medical framework or abroad and afterwards did their best to blend back into society in their chosen presentation without calling attention to themselves by contributing to statistics.

Data collected since that time has suggested a much higher prevalence of those affected by gender dissonance, or the sense that the gender assigned to them at birth, as either a sex or gender marker, does not apply effectively to them. In a 2003 study performed in Belgium, a sex-combined ratio of 1:18,975 was noted.<sup>7</sup> In this study, the trigger was again those who had undergone surgical procedures – a rather high bar that artificially reduces the nominator by excluding, among many others, those with limited financial means.



Most recently, surveys of populations in the northeastern United States have been performed through the Behavioral Risk Factor Surveillance System. The results of these surveys suggest the prevalence of transgenderism, which involves gender dissonance whether or not surgery is desired but where hormone alteration may be pursued with the resulting medical impacts, is on the order of 0.5% in Massachusetts as a whole, to 0.6% in Boston, to 0.9% in neighboring Vermont.<sup>8</sup> Based on the United States Census of the population of Massachusetts in 2010 being 6,547,629 persons, this would calculate out to over 32,000 transgendered individuals in just one average-sized US state.<sup>9</sup>

Another population challenged by sex classification are the intersexed, or those whose genotypic (genetic) and/or natural phenotypic (anatomical) presentation does not match the male or female norm. Prevalence numbers vary depending on inclusion criteria used, but range between 0.018% and 1.7%.<sup>10</sup> Those with external genital ambiguity are often surgically ‘corrected’ in infancy, and many of those later renounce their assigned sex and seek medical care that parallels the transgendered.

Finally, although most certainly in a very different category than the transgendered or intersexed, approximately 20 million American women in 1999 had at some point in their lives undergone hysterectomy. Approximately 55% of those had experienced bilateral oophorectomy, or the removal of both their ovaries.<sup>11</sup> As will be noted later in this paper, assumptions made about the status of sex organs as a result of a documented sex or gender designator can impact the quality and cost of care in any patient for whom the organs do not match the expected norm. A mechanism for indicating variation in sex organ status would benefit these patients as well.

## Sex versus Gender

As has been recognized earlier in this paper, sex and gender are often used interchangeably, but they are not the same. The online edition of the Merriam-Webster dictionary defines *gender* as, “the behavioral, cultural, or psychological traits typically associated with one sex ,”<sup>12</sup> and *sex* as, “either of the two major forms of individuals that occur in many species and that are distinguished respectively as female or male especially on the basis of their reproductive organs and structures .”<sup>13</sup> Most demographic models in use today have only one measure and tend to conflate both sex and gender into this measure using the two terms interchangeably. EHRs are no exception to this.

As defined, sex denotes the anatomy and/or biology of an individual. While that may seem simple, it isn't. Intersex individuals can present with the naturally occurring external phenotype of one sex while carrying the genotype of the other, such as women with complete androgen insensitivity syndrome (AIS) who generally present unremarkably as female and often are recognized as having AIS only when they fail to experience menarche or attempt, unsuccessfully due to their absence of a uterus, to get pregnant. Those with Klinefelter's Syndrome (XXY) have two X chromosomes on allele 46 along with one Y, yet present with male features and generally are able to father children. Postoperatively and with cross-sex hormones, a transsexual female (male assigned at birth) may be indiscernible from a cisgendered (sex and gender matched) female on external examination including genitalia. Such women can even lactate and breastfeed infants.

Gender reflects the perception of an individual's sex. Gender identity is internal to every individual: how they perceive themselves. Gender expression is the perception of an individual by others. While the concept of gender as separate from sex may not seem intuitive,

consideration of the importance of gender conformity in American society can help clarify the fact that gender and sex are very different constructs. The use of terms like ‘sissy’ by children on a playground is evidence that one can be seen as diverging from gender norms related to one’s sex, even unintentionally.

### Current State of Sex/Gender Standards in Electronic Systems and EHRs

The notation of sex or gender in four common standards of information exchange between EHRs are International Standards Organization (ISO) component 5218,<sup>14</sup> Health Level Seven (HL-7) field PID-8,<sup>15</sup> Digital Imaging and Communications in Medicine (DICOM) CID 7455,<sup>16</sup> and X12-837 element ‘patient sex’.<sup>17</sup>

The oldest electronic standard still in use for sex or gender is the ISO 5218 code, first instituted in 1976. ISO 5218 is labeled ‘Codes for the representation of human sexes’ and has four possible class options: (0) not known, (1) male, (2) female, and (9) not applicable or specified.<sup>18</sup> The ISO standard is proprietary, but publically available references to it describe that the standard states it isn’t for medical purposes. That said the standard for the DICOM specifically references ISO 5218, as do many EHRs as they explain their sex or gender category options. It should also be noted that, while the term sex is used in some portions of the standard, sex and gender are used interchangeably in others. There is no effort made to differentiate between the two.

The most ubiquitous information exchange standard in American health care is the HL-7 interface standard. The defined sex class options in HL-7 are (F) Female, (M) Male, and (UN) Undifferentiated. Unlike other standards, HL-7 allows user-defined classes, but there is no guarantee that they will function. Each sending and receiving system must agree on any user-

defined standard which requires a level of coordination generally infeasible except between applications developed and maintained by the same vendor.

There are several fields in HL-7 that carry sex or gender information, all of which follow the same format as the PID-8 (Administrative Sex) field, which covers administrative purposes like bed assignments.<sup>19</sup> All HL-7 sex codes carry the caveat that they are not to be used for clinical purposes. That said, the absence of an HL-7 clinical sex or gender standard has necessitated the use of the PID-8 and mirrored fields as the sex or gender fields for all EHR purposes, including clinical needs. The standard for PID-8 uses the terms gender and sex interchangeably.<sup>20</sup> A splendid discussion of problems presented by HL-7's lack of an effective clinical standard can be found in a December 1, 2010 blog post by Dr. William Hogan where he notes that in the standard documentation only one example of the use of the PID-8 field is specifically identified: "the appropriate allocation of an inpatient bed assignment."<sup>21</sup>

"So our state-of-the-art EHRs cannot even represent sex vs. gender, let alone reason appropriately with the data or exchange sex and gender data in an interoperable way. And HL7 and related terminology standards offer us no assistance, and even hinder us, in this regard.

With the net effect that our entire healthcare information system is really using an attribute—intended only for gender-specific bed assignment, an increasingly irrelevant task—for patient care, setting health care policy, and numerous other secondary uses of 'administrative-but-forced-on-physicians-and-patients-as-clinical-at-least-in-part-because-IT-vendors-and-IT-departments-and-standards-organizations-cannot-figure-out-sex-vs-gender' data."

So in their own documentation, HL-7, for the most part *the* standard for information exchange between EHRs in the US and many other countries, states there is no field in HL-7 to handle the clinical and billing functions for which sex/gender information will have the most patient impact.

The DICOM standard, used primarily with imaging applications, was updated in 2005 to include the most elaborate gender or sex class options in any major standard in use by EHRs to date. Please refer to table 2 for the sex class options offered by DICOM CID 7455, version PS 3.16-2004.<sup>22</sup>

Table 2

<b>Code Value</b>	<b>Code Meaning</b>	<b>Code Value</b>	<b>Code Meaning</b>
M	Male sex	MC	Male sex changed to Female sex
F	Female sex	FC	Female sex changed to Male sex
U	Unknown sex	121032	Subject Sex (clinical purposes)
MP	Male Pseudohermaphrodite	121104	Ambiguous sex
FP	Female Pseudohermaphrodite	121102	Other sex
H	Hermaphrodite	121103	Sex of subject undetermined at time of reporting

The final major data exchange standard involving EHRs is the X12-837 standard that governs insurance messages. Like HL-7, this standard closely aligns with ISO 5218. As will be discussed later, the impact of this alignment is far-reaching for insurance coverage; even those systems which are designed to allow a broader range of sex and/or gender classes cannot convey this broader terminology to the insurer.

Similar problems are found with documentation standards that touch on gender or sex, such as LOINC<sup>23</sup> and SNOMED.<sup>24</sup> Both utilize only the term “gender,” even when sex is clearly the intent (i.e. determination of fetal status during ultrasound).<sup>21</sup>

Based in part on these standards, the practice for most EHRs tracks the ISO 5218 classes. In some cases, such as the Allscripts<sup>25</sup> EHR application, the individual site can configure options beyond binary sex or gender, but even in that case there is only one field designed to be used for the purpose.<sup>26</sup> Also, regardless of what the Allscripts user sees on the screen, integration with other systems, both internal to the organization and external, is limited by the interface standards described above. See the Discussion section for further analysis of the limitations of “site

configurable” systems versus systems that benefit from programming changes and interface possibilities made possible by standards.

### Meaningful Use:

In March of 2011, the Institute of Medicine’s (IoM) Board on the Health of Select Populations released their review of the health needs of lesbian, gay, bisexual, and transgender persons in the United States.<sup>3</sup> Among the many recommendations contained therein, the IoM encouraged the US Department of Health and Human Services (DHHS) to consider inclusion of more extensive sex and/or gender markers in EHRs as part of the “Meaningful Use” requirements mandated by the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009.<sup>3</sup>

Pursuant to this guidance, in March 2012, as part of Meaningful Use Stage 2 rule making, the DHHS solicited feedback regarding the need for, and appearance of, a new EHR gender classification model in their Notice of Proposed Rule Making (NPRM) dated March 7, 2012. In that document, the DHHS requested “comment on whether we should also include the recording of gender identity and/or sexual orientation. We encourage commenters to identify the benefits of inclusion and the applicability across providers.”<sup>27</sup>

Feedback was extensive and varied.<sup>28,29,30,31,32,33</sup> While much of it was supportive of or open to the idea, no single model found consensus, and industry was understandably nervous about a lack of clear standards. There was also the concern expressed that poor execution could impair patient-provider trust. As such, in Oct 2012, DHHS determined to defer the decision pending clearer guidance from stakeholders.<sup>34</sup> Since that time, stakeholders have made strides to develop a consensus model in anticipation of Stage 3 rule making. Key among these efforts was

a one-day workshop held in Washington, DC by the IoM to define the framework for the effort.<sup>4</sup> Recognition of the need was clearly evident at those proceedings, but no universal agreement was found during the event.<sup>4,26,35,36,37</sup>

It is expected that the NPRM for Meaningful Use, Stage 3 will be released late in 2014.<sup>38,39</sup>

### The Veteran's Administration takes a stand

The Department of Veterans Affairs Veteran's Health Administration (VHA) is the largest single health care entity in the US, potentially serving nearly 22 million former service-members and influencing a significant proportion of American physicians. The VA developed and maintains its own EHR, VistA, which is public domain and available free (although unsupported except through third parties) to organizations outside the US Government. On Feb 8, 2013 the VA issues directive 2013-003 which stated, among other things, that "the documented sex in the Computerized Patient Record System (CPRS) needs to be consistent with the patient's self-identified gender."<sup>40</sup> While this was quite a milestone, complications arose and continue given VistA limits gender choices to the binary model (male, female, unknown/other). In practice, various VA's have developed different work-arounds using comments to expand upon the limitation of the sex/gender documentation field.

In an interesting correlation to the HL-7 discussion earlier, much of the directive explains how this document is to be applied in bed assignments. There is no discussion of non-binary presentations and all terminology is in terms of male, female, male-to-female, or female-to-male.

## The “Organ-Based” Model

In May 2013 a peer-reviewed report was released in the Journal of the American Medical Informatics Association which described the results of an “EMR Working Group” convened by the World Professional Association for Transgender Health (WPATH) to “make recommendations for developers, vendors, and users of EHR systems with respect to transgender patients.” This report summarized the findings of sixteen professionals in the fields of transgender medicine ranging from physicians to social workers to pharmacists.<sup>26</sup>

The result of this group’s work were five recommendations for EHRs:<sup>26</sup>

1. The current systems designed for a binary model inhibit the flow of accurate medical information and should be modified.
2. Preferred name, gender identity, and pronoun preference should be available demographic variables. A table was provided which suggested a two-question model for gathering gender and sex data. It was recommended that the field be flexible and permit individuals to categorize themselves.
3. A means should be available to maintain an inventory of a patient’s medical transition history and current anatomy. Specifically, it was suggested that EHRs have a mechanism to document current organs present instead of documenting a current sex that would imply this inventory. This was the most radical suggestion of the group and will be explored in more detail.
4. The system should permit a smooth transition when a field changes, with no loss of data integrity or continuity.
5. Staff should be clearly and obviously notified by the system of a person’s preferred name and/or pronoun, especially if either differs from legally documented name or sex.

As noted, it was recommended that EHR’s provide the means to inventory the current organ status of a patient. The recommendation went further to provide ‘non-exhaustive’ tables outlining such a suggestion with organs such as prostate, cervix, ovaries and penis listed. In concert with such an inventory, it was recommended that procedures historically associated with sex be ‘uncoupled’ and instead based on this organ inventory. The specific example was provided of a male with a cervix requiring a pap-smear. Beyond anatomy, treatments and procedures themselves could be used to affect values in the EHR. For example, a hemoglobin



lab value that is high in a woman would not flag as excessive if the patient had a prescription for high-dose testosterone and a status of trans-female (transitioning from male to female) or genderqueer (identifying as somewhere between or outside the two traditional genders).

### The “Two-Question” Model

Also published in 2013 was a peer-reviewed quantitative study which finally provided some evidence-based science behind a specific expanded data collection schema for sex/gender markers.<sup>41</sup> This work built on previous research in the area of ethnic studies using two-question methods, the most commonly recognized might be the question of whether an American is of Hispanic descent being asked in tandem with their identified ethnic group. It also followed the adoption of a similar collection format by the US Centers for Disease Control and Prevention for adult case reporting as well as electronic HIV/AIDS surveillance.<sup>42</sup>

In their study cited above, Tate et. al. conducted three sub-studies across seven samples. The first sub-study asked one question, “What is your gender?” It offered only four choices: Male, Female, Transgender, and Other. The wording of this question was taken from the at-the-time current standard questions used by researchers.

The second sub-study used two questions. The first question asked “What is your current gender identity?” with options for Female, Male, Transgender, Genderqueer, and Intersex. The second question asked “What gender were you assigned at birth?” with options for Female, Male, and Intersex. The third sub-study took the same two-question model and examined whether it could be applied effectively to community samples.

The authors of this study found that the two-question model provided a much more effective method for identifying transgender and intersex individuals, with some caveats

regarding the understanding of those answering the questions in regards to often generally unfamiliar terms such as ‘transgender’ and ‘intersex’. Although the study was not done specifically in medical clinic populations, the authors did make a strong case for the results being applicable to the medical setting. This seems supported in light of previous suggestions for the use of this model for gender purposes by the Fenway Institute and others.

### 2015 EHR Certification Criteria

In February of 2014 the Office of the National Coordinator for Health Information Technology (ONC) released a NPRM describing plans for “Voluntary 2015 Edition Electronic Health Record Certification Criteria” and soliciting feedback.<sup>43</sup> These criteria, although voluntary in 2015, would become mandatory in 2017 for certified EHRs (CEHRT). As part of the proposal, ONC outlined their plans to explore including sexual orientation and gender identity in the criteria. In the 2015 NPRM the ONC noted that some responses to the 2014 Edition NPRM had contained unsolicited requests for these criteria to be added.

At the time the ONC declined to move in that direction since their mandate in 2014 was very specific to accommodating Meaningful Use Stage 2, which as noted previous did not contain requirements for data collection related to sexual orientation or gender identity. Since that time, the NPRM went on to explain, the report from the IoM workshop from October 2012 on the topic of collecting sexual orientation and gender identity data in EHRs had been published.<sup>4</sup> As had been intended by the workshop organizers and participants, this publication caused the ONC to desire to “seek comment on whether certification should require that EHR technology be capable of enabling a user to electronically record, change, and access data on a patient's sexual orientation and gender identity.” The NPRM went on to ask the following:<sup>43</sup>

“To facilitate the standard capturing of this data, we request comment on whether the following code sets could be used to capture this information in a structured format:

SNOMED CT® for sexual orientation.  
SNOMED CT® for gender identity.”

As was the case with the responses to the Meaningful Use Stage 2 NPRM, the responses were extensive and varied, and often from the same sources although generally now as co-signatories to two group responses (The Fenway Institute and The Consumer Partnership for eHealth).<sup>44,45,46</sup>

In their April 28, 2014 responses in which sexual orientation and gender identity was just a small subset of the text that went on to cover other topics in the NPRM such as military service and implanted devices, both the Consumers Union and the Consumer Partnership for eHealth (an umbrella containing organizations such as American Association for Retired Persons and the American Heart Association) referred to the Fenway Institute’s response for details on a model to address collecting such data. Their main concern was to support the collection of more inclusive and expansive data, both letters recognizing the need and the benefits to consumers. Neither group was enthusiastic about the use of SNOMED CT codes to collect this information, in part because of their one-question nature.<sup>45,46</sup>

The Fenway Institute’s April 28, 2014 response, cosigned by 155 institutional signers and over 60 individual luminaries, contained a specific model which closely followed their previous proposal discussed at the Oct 2012 IoM sexual orientation/gender identity data collection workshop.<sup>44</sup> Reflecting the growing acceptance of the “two question” model for sex/gender data collection, they split gender/sex into two fields with two additional fields for preferred pronoun

and preferred name. The former pair of questions closely followed the format used by Tate et.al, likely in an effort to benefit from the prestige of an academically-supported foundation.<sup>41</sup> A version of this protocol is also now promulgated by the University of California San Francisco's Center of Excellence for Transgender Health.<sup>47</sup>

What is your current gender identity? (check all that apply)

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MtF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male or female
- Additional Gender Category/(or Other), please specify \_\_\_\_\_
- Decline to answer

What sex were you assigned at birth on your original birth certificate? (check one)

- Male
- Female
- Decline to answer

Preferred gender pronoun:

- He/Him
- She/Her
- Something else (Specify:\_\_\_\_\_)

Preferred name: (Specify:\_\_\_\_\_)

In their letter, the Fenway authors explained that “by asking about sex assigned at birth as well as current gender identity, we will get better, more clinically relevant data, and have a clearer picture of the patient’s identity and clinical needs.” In explaining the latter two fields, the authors suggested “adding two additional questions to prevent misunderstandings that may occur for transgender people who do not have identification documents that accurately reflect their current name and gender identity.”

In addition to their proposed data collection model, the letter went on to directly address the most commonly mentioned reservations about collecting this data, specifically that of privacy and invitation to discrimination. To the privacy concern, the letter explained that technology has reached a level which should ensure integrity of sensitive data and that regulations such as the 2012 updates to HIPAA should ensure patient confidentiality. On the topic of self-exposure to discrimination, the authors specifically reference Section 1557 of the Affordable Care Act as well as recent CMS regulations in maintaining that the risk of such discrimination is manageable and does not exceed the benefits that would be obtained by the data collection. The authors closed by emphasizing that providing the data is voluntary on the part of patients, as is the case with all demographic data.

As noted before, the Fenway letter represented the views of a wide swath of American stakeholders including a multitude of LGBT and social justice organizations, several Planned Parenthood sections, university organizations, and health care foundations. It was also positively referenced in the responses of many other organizations.

### Current End-User Practices

The same author who in 2013 was the lead author for the report of the WPATH expert group on EHR gender classifications in 2014 published a survey of end-user practices.<sup>48</sup> Sixty seven respondents from convenience sample covering both medical and non-medical disciplines responded to a host of questions regarding collection of gender data in their settings. Solicitation for the survey was done through the WPATH list-serve as well as at a transgender health summit in Oakland, CA.<sup>48</sup> As such, the population surveyed was almost certainly providers specialized in the field of transgender medicine which limits the generalizability of the results.

Of interest from this study, more than half of respondents reported being required to use a single field to record both sexual orientation and gender identity. Approximately 27% reported recording preferred pronoun while 55% recorded preferred name. Surprisingly, no mention was made of the rate of two-question usages, but given so many respondents were finding it necessary to conflate sexual orientation with gender identity in their systems, it seems likely such sites were rare if existing at all.

In the discussion, the authors noted many sites were using free-text fields to document information rather than discrete data fields. Some sites used problem lists or adapted social history fields. None of these options generally permitted data entered in these locations to be linked for clinical purposes such as decision support.

### An Epic Solution

Verona, WI based Epic<sup>49</sup> is the largest provider of both hospital and clinic EHRs in the United States. In March, 2014 the EHR trending firm Software Advice, using Meaningful Use attestation data from CMS, estimated the market penetration for Epic to be about 20% for both ambulatory and inpatient practices.<sup>50</sup> Given Epic's marketing focus on large integrated systems and big hospitals, the impact of Epic on the patient population in the US cannot be understated. A Forbes article in 2012 estimated that in 2013 40% of Americans would have their medical information in an Epic system.<sup>51</sup> Although its size might suggest the inability to be nimble or take risks, this is not the case. In 2010, at the request of its largest client, Epic released to its clients what in 2014 apparently remains a unique document - "Improving Care for Sexual and Gender Minorities."<sup>52</sup>

Although to date Epic has not changed its programming code to better accommodate the stated populations (they still state coding changes are ‘planned’), this 28 page strategy guide details all the ‘tips and tricks’ Epic staff and customers have devised to accommodate sexual and gender minorities. The document is not just a technical guide – it is also a workflow guide and provides extensive suggestions regarding training and education. In the executive overview it explains how important it is to inservice all ‘patient-facing’ staff regarding sexual and gender minorities to ensure they are able to make effective use of the design functionalities. To quote the guide, “In combination, workflow changes and staff education have the potential to substantially improve health care for LGBT patients at your organization.”

This document represents the greatest single advance in LGBT recognition and accommodation within the EHR in the history of the industry. Even without programming changes, Epic clearly explains how any Epic organization can do the following:<sup>52</sup>

- Present preferred name in the patient header so that properly-trained staff use the correct name when referring to the patient
- Prompt questions about sexual orientation, gender identity, and sex assigned at birth when intake information is collected. Nurses or other staff can routinely record this information so that it is available for the benefit of other clinicians.
- Make appropriate data collection forms appear to gather information regarding transgender patient transition history or plans.
- Provide more specific sex values and clinical decision support prompts to help providers be aware of relevant clinical information such as gender identity, sex assigned at birth, and transition history and plans.
- Advisories can appear to remind clinicians of care requirements for LGBT patients at the appropriate points in their workflows. For example, an advisory might remind clinicians to perform cervical exams on patients whose sex assigned at birth is listed as female, regardless of what sex value is recorded in their chart.

The guide goes on to describe a workflow scenario where a patient presents to a clinic and is asked their preferred name, something that need not be a transgender-charged question given many people prefer nicknames that may not even have an obvious relation to their legal

name. The staff would then enter the preferred name in the name field and the legal name in a ‘confidential name’ field. The preferred name would then appear in the patient header but the legal name would appear for billing.

Even more granularity would be possible during history-taking. A field called “Partners” could document that a patient has both female and male sexual partners. “Gender identity” could document a patient as being a gender that varies from their sex, for example a male who is genderqueer. As noted, sex assigned at birth would permit clinicians to identify the patient’s ‘starting point’ which could still denote organs present and other physiologic realities.

On the other hand, there are limitations placed on what Epic could accomplish without programming changes and in the absence of standards changes that would impact systems to which or from which Epic might send or receive data. Limitations listed by Epic themselves include:<sup>52</sup>

- Clear standards do not always exist for what value to record in the sex field for transgender patients, so this information alone cannot consistently be relied upon for clinical decision making.
- Lab reference ranges may be inaccurate for transgender patients who have taken steps to physically transition.
- Medication alerts, such as lactation warnings and sex-drug interactions, might be inaccurate for transgender patients who have taken steps to physically transition due to limitations of third-party data.
- Room assignments for admitted patients are usually based on the value in the sex field, which might be inappropriate for transgender patients. For example, only patients whose sex is recorded as female can be admitted to labor and delivery units, although transgender men might be pregnant.
- Some clinical decision support rules are based on the value in the sex field. For transgender patients, this might mean that clinically necessary features do not appear or are difficult to access.
- Some clinical decision support features are based on the value in the sex field. For transgender patients, this might mean that inapplicable content appears while other relevant content does not.
- Health Maintenance plans are restricted by sex, so some transgender patients might be inappropriately excluded from these plans.
- Staff in different contexts might interpret the value in the sex field in different ways. For example, clinical users and billing users might need different values for this field.



- Transgender patients might not have the same sex value recorded in all contexts, or at all third-party organizations, which might cause confusion.
- Reporting that relies on the value in the sex field to group patients might not accurately represent transgender patients.
- Billing for transgender patients can be heavily affected by the value recorded in the sex field within Epic. Examples include the following:
  - Claims for transgender patients might be rejected because of a mismatch between the sex value stored in Epic and the sex value on file at the insurance company or at a third-party claims review organization.
  - Claims for some procedures or medications might be rejected for transgender patients because some insurance companies consider those procedures or medications inappropriate for patients with certain sex values. For example, a prostate exam might not be covered for a patient whose sex value is recorded as female, regardless of whether or not the patient has a prostate and needs a prostate exam.
  - If a claim is rejected for either of the previous reasons, any other charges listed on the same claim will also be rejected.
- Pronouns on post-discharge reports are determined by the value recorded in the sex field and might be inappropriate for transgender patients.
- Some features may not be able to maintain privacy in regards to minors.

Still, even with the limitations, the detailed guidance given by Epic in this single document gives users of the Epic EHR unprecedented tools, if they choose to use them, to make their system serve the needs to non-gender-conforming patients. The next section will discuss the real-world experience of one such Epic customer.

### The University of California at Davis Experience

The University of California at Davis Health System<sup>53</sup> (UC Davis) serves much of northern California with physician clinics, inpatient beds, and other services. In 2012 they reported 61,000 ED visits, 31,000 inpatient admissions, and 888,000 office visits.<sup>54</sup> In June, 2013 the system publicly announced their intention to invite clinic patients to share their sexual orientation and gender identity information for use in their medical record. UC Davis' decision

was driven by the IOM report of 2011 as well as later publications by Fenway Health and the Department of Health and Human Services.<sup>54,55</sup>

UC Davis took a very careful approach to considering how they were going to meet the needs of these patients. From the very beginning, UC Davis leadership engaged clinical leaders, identifying early on LGBT welcoming providers. They ran focus groups of patients in general as well as targeted interviews with identified transgendered patients. During late 2012 and early 2013 they ran surveys of adults in their service area asking how they would react to being asked about sexual orientation and gender identity information. The survey suggested patients in their area would be positively inclined to the information being collected. 48% of self-identified LGBT patients and 42% of heterosexual patients expressed that it would be a good idea. 21% of self-identified LGBT and 15% of heterosexual patients thought it would be a bad idea. Going into more detailed questions, they identified that patients would be more inclined to provide personal information during a physician visit rather than over the phone or through an online form.<sup>54</sup>

In configuring their functionality UC Davis pulled from the Epic guide described previously and followed the two-question format. Patients at UC Davis are now voluntarily asked their assigned sex at birth, their current gender identity, and their current sexual orientation. Although in the survey many patients expressed less enthusiasm about providing this information electronically outside the clinic, UC Davis also has provided a portal for answering this demographic information through their Epic MyChart<sup>56</sup> patient portal. Participation in the new initiative was slow to start with 230 self-reports documented in the first 10 weeks. Media coverage in the Sacramento area during the summer of 2013 was generally positive and officials

expected participation to increase over time as more patients visit clinics after the summer season.<sup>54,55</sup>

### Facebook dives in

Although not specifically a health care industry event, it is worth noting that in February 2014 the social media giant Facebook<sup>57</sup> announced that they would be providing an expanded list of options to select rather than simply choosing ‘other’ when opting out of the standard responses of male or female.<sup>58</sup> To much media fanfare, the social media site moved to offer over 50 different choices for users in the US and Canada to describe themselves. The choices were selected in consultation with LGBT advocacy groups, and it has been Facebook’s policy to solicit input from such groups in each country before rolling out terms for users in those countries. Of direct interest in the EHR discussion, Facebook did not permit users to free-text self-identify. Users must select one of the proffered choices which ensure that the data is discrete and can be used for business purposes such as marketing and information pooling. The move by Facebook, and the format for their new field, has met with widespread acceptance and approval.

## Methods

A review of available literature was performed using a three-pronged strategy. An initial search was performed through both Google<sup>59</sup> and Google Scholar<sup>60</sup> using the terms ‘transgender’, ‘transsexual’, ‘transsexualism’, ‘transgenderism’, ‘gender identity’, ‘gender’, ‘intersex’, and ‘disorders of sex development’ on one side linked with “and” statements to the terms ‘medical records’, ‘demographics’, ‘electronic medical records’, ‘electronic health records’, and ‘gender markers’.

The above search was then replicated for the medical literature in Medline Ovid<sup>61</sup> using appropriate MeSH terms and the search strategy detailed in Table 1.

Table 1.

<ol style="list-style-type: none"><li>1. exp Sex/</li><li>2. exp Transsexualism/</li><li>3. exp Gender Identity/</li><li>4. exp Transgendered Persons/</li><li>5. exp data collection/</li><li>6. 1 or 2 or 3 or 4</li><li>7. 5 and 6</li><li>8. exp "Delivery of Health Care"/</li><li>9. exp "Quality of Health Care"/</li><li>10. 8 or 9</li><li>11. 7 and 10</li><li>12. exp Attitude to Health/</li><li>13. 11 and 12</li><li>14. (((medical\$ or health or patient) adj3 record\$) or ehr or emr) adj10 (intersex\$ or transsex\$ or transgend\$ or hermaphro\$ or ((sex\$ or gender\$) adj3 (indent\$ or ambigu\$))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]</li><li>15. (((collect\$ adj5 (data or inform\$)) or questionair\$ or survey\$ or interview\$) adj10 (intersex\$ or transsex\$ or transgend\$ or hermaphro\$ or ((sex\$ or gender\$) adj3 (indent\$ or ambigu\$))).mp.</li></ol>
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Likely documents identified in the initial two searches through titles and abstracts which indicated relevance to gender and/or sex documentation in medical settings were then obtained and their content reviewed for relevance to the use of EMRs in a practical setting. The references cited in those materials found to be applicable were then examined using the same

criteria and additional materials were identified and obtained in a 'snowball' manner where such relevant references were retrieved and their references cited were examined.

This search strategy was performed first in the autumn of 2012 and again replicated in the spring of 2013 and in September 2014 to gather materials that had been released or published since the first exhaustive search.

In addition to the aforementioned literature search, the author attempted to reach out to EHR vendors in an effort to gather unpublished materials or verbal descriptions of their experiences, policies, or plans regarding expanded gender markers in their products. Institutional Review Board approval for inquiries directed at vendors related to their products and services was obtained in spring 2014 and communications with vendors were then attempted via email and personal communication.

## **Discussion**

### **The Need**

Populations varying from the strict binary sex or gender classifications are numerous enough to warrant attention, sex and gender really are separate categories warranting distinct consideration, and the standards supporting EHRs, and the applications themselves, do not generally permit classes beyond the binary or allow for more than a single combined sex/gender field.<sup>26</sup> The entities regulating health care in the United States have recognized this as an issue to address and many stakeholders are engaged in the process of considering options.<sup>3,4</sup>

Despite this, a clear and universally-accepted model for classifying sex and gender in electronic systems including EHRs has not yet emerged.<sup>34</sup> Even the topics to be addressed by such a model have yet to be definitively characterized.<sup>4</sup> Save for two articles published as recently as 2013, only one of which has a grounding in evidence-based principles, there is nothing in the peer-reviewed medical or informatics literature establishing a specific desired endpoint.<sup>26,41</sup> Policy is in advance of the science, which is understandable given the lack of attention this topic received until recently due to societal unease, misunderstanding, and prejudice.<sup>3</sup> As is often the case with socially-contentious issues, human beings lead the charge and it is up to regulations and even science to play catch-up.

At least one major commenter to the Stage 2 proposed rule, the American College of Physicians, expressed reticence regarding the collection of sexual orientation data, and, by implication, gender identity data as well, due to concerns over the impact asking these questions would have on the provider-patient relationship.<sup>33</sup> This concern is best countered by ensuring that the question is asked in a respectful manner and by explaining to patients the benefits that justify what could be seen as an invasion of privacy.<sup>41,45</sup>

It should also be noted that the Meaningful Use guidelines specifically state that patients may decline to provide requested information, and that such declination will not be seen as an omission to gather the information by the attesting provider.<sup>34</sup> This was the philosophy pursued with success by UC Davis during their implementation of sexual orientation and gender identity information in summer 2013.<sup>54</sup> Permitting patients to decline will protect the approximately 15% of the LGBT population, as quantified by the UC Davis surveys, that react negatively to the prospect of this data being collected. While this may detrimentally impact the quality of care for those patients, it protects their privacy without preventing other more willing patients to benefit from the workflows made possible by the data collected.

There are many reasons why patients would benefit from documenting sex and gender in a clear and complete manner. Beyond the simple respect of calling patients, and not just transgender patients, by their preferred name and pronouns, perhaps the overriding medical reason why inclusive and clear sex classification should be documented in EHRs is computerized electronic decision support. As EHRs become more complete and ubiquitous, more clinical activity is guided by the software we use. For examples, fields may be automatically filled in based upon previously entered values, specific care maps may be employed targeting their diagnosis and demographics, and drug doses and diagnostic reference ranges may be tailored to a particular patient based on the contents of their medical record. This is generally a good thing. Evidence based medicine, for all its faults, improves overall care. Standardized practices with electronic double-checks prevent errors. Both, however, are only as good as the assumptions made by the software. If the demographic data for a patient does not reflect the reality of the patient, misadventure very likely may result. This is the classic garbage-in, garbage-out scenario.

An archetypical example of this, a presentation which is discussed regularly by providers treating the transgendered community, involves a male, unremarkable in his physical appearance, presenting with pelvic pain. Due to concerns about prejudice characterized by the IoM, he declines to share his gender history.<sup>3</sup> Such a patient can experience unnecessary delays and expense, possibly even harm, when the presence of a uterus is not discovered until a computerized tomography (CT) scan is performed. A similar scenario, and one even harder to detect, is the presence of a prostate in a physically unremarkable woman – a prostate which, like any other prostate which developed in the presence of testosterone, needs to be monitored for cancer in the same manner as a cis-gendered male. Many transgendered patients will not freely offer their gender history for fear of prejudice, although when asked in a respectful manner they will generally explain their organ status. Most electronic systems are currently rigged to fail for populations who fall outside the rigid sexual norm.<sup>4,26</sup> More accurate sex and gender classification, as well as the training and education which should come with it, would help alleviate this problem.

Other decision support examples include sex-specific lab values (i.e. hormone levels or hematocrit) and their interpretations, medication dosing for drugs with low therapeutic indices, therapeutics-directing tools such as workflows that map care, epidemiology (women and men have different risk factors for many conditions), and diagnostics assistance and documentation (i.e. differing presentations of men and women for myocardial infarction). In all these cases, the intersex and transgendered, and possibly even post-hysterectomy cisgendered women, may have very different needs, certainly from their birth sex, and perhaps even from their identified sex. Clinical decision support tools may ill serve these groups due to lack of sex classification granularity.



Placing non-binary people into binary categories confounds binary data. The reverse is even more important, because we know so little about the unique health needs of transgendered and intersex patients. Using binary classes to categorize non-binary populations prevents data collection of these populations, making it impossible to target treatments accurately for these patients. Without accurate categorization, we can't learn.<sup>4,26,41</sup>

Next it must be noted that more accurate sex and gender classification would facilitate data transmission and, hopefully, insurance. With the acceptance of unified terminology, critical standards like HL-7 and SNOMED could better accommodate these patients. Customized EHRs like the Allscripts and Epic examples mentioned previously would then be able to communicate their data to other systems and Health Information Exchanges. X12-837 could allow data to pass to insurers for patients who don't fit the sexual norm. For example, a woman who needed a prostate biopsy or a man requiring a pelvic exam wouldn't necessarily 'throw a flag' and be rejected for treatment coverage, as commonly happens now.<sup>3,4</sup>

Finally, there is the simple argument of respect. In the Oct 2010 National Transgender Discrimination Survey Report on Health and Health Care, 6450 respondents from all 50 US states and the territories reported their experiences with the US health care system. 28% of respondents reported being verbally harassed in a provider setting, 19% reported being refused care outright, and 2% reported physical threats or harm. 28% of respondents reported deferring health care for fear or anxiety of mistreatment.<sup>62</sup> As providers, we cannot provide care to patients afraid to come see us. By adjusting the systems we use to accommodate the realities of these populations, and with the training and education which should accompany these improvements, we enhance not only the care received by those who do come in, but also improve

the chances patients will seek out preventative care and treatment appropriate for conditions detected.

### Our Proposal

There has been much discussion in the LGBT community, as well as clinical and scientific circles as witnessed by the activities of the IoM and the few publications on the topic in the literature, regarding how best to approach a more diversified accounting for gender in EHRs. That said, very few words have been written about what vendors think on the topic. It is a simple fact that the vast majority of Americans are not directly touched by variance from the typical male and female presentation of gender. Given the demand for improvements to EHRs that impact far larger populations than the transgender and intersex community, it isn't surprising that vendors are generally silent publically and reluctant privately.

No EHR vendor was willing to speak with the author on the record despite efforts to solicit information, and with the exception of Epic's strategy guide available only to Epic customers, were extremely limited in what they would share privately. The general sense is vendors don't consider this topic anything except a public relations nightmare waiting to happen if they misstep, hence their reluctance to even discuss it. With the exception of Epic, no one expresses interest in moving until there are standards, and they universally (even Epic) don't see this as a priority for their very limited and expensive programming resources. Given the economic realities of the industry, this appears very reasonable to someone trained in the informatics field.

Looking at the proposals that have been publically discussed, by far the most involved and resource-demanding would be the organ-based model. While this model might be the most

complete one, and it would accurately accommodate the broadest populations with the best decision-support potential, it would require extensive changes both to standards and the core programming of all systems. The very demographic and clinical documentation framework based on markers as proxy for organs and clinical values would need to be changed. Once software changes were made, these changes would need to be implemented at sites with the requisite extensive workflow redesigns and education.

Given the stretched resources of medical providers and the reluctance to take on new mandates, as witnessed by the continued lobbying of the American Medical Association to delay ICD-10 as an ‘unfunded mandate’, it doesn’t seem likely such a fundamental change in methods for the benefit of such a small sub-population would be well-received.<sup>63</sup> It seems more likely that changes within the current framework would be seen as more practical, and therefore find wider acceptance. There is also no data to support the organ-based model save for a ‘working group’ within a transgender professional association, even if the author participated in it.<sup>26</sup> This is the reality for vendors. With this understanding, the organ-based model seems a laudable goal in the distant future, but a non-starter for Meaningful Use 3 and the next five years.

The two-question model, on the other hand, works generally within the current demographic framework, simply adding a question to differentiate sex at birth vs current gender identity.<sup>41</sup> By extension it logically also adds a preferred name to the existing legal name field. Some would add preferred pronouns to the list.<sup>44,45</sup> Of these, only sex at birth seem to require interfacing to have the desired impact since preferred name and pronouns would not reason to have clear downstream effects beyond the system in question. While this method would require programming changes to do right, the resource requirements would appear to be less onerous in

light of the current use of internal variations of the two-question model in existing EHRs including Epic and All-Scripts.<sup>26,48,54,55</sup>

The two-question model has also been tested in the real population. Tate et al. has published the only quantitative, peer-reviewed study on the topic of gender markers with promising results supporting the two-question model.<sup>41</sup> Shortly after Tate's work, UC David performed their surveys of northern California adults which also non-scientifically validated the utility of the two-question model.<sup>54</sup> The experience with UC Davis since implementation suggests it can be well-received by the public and media.<sup>46</sup> Finally, while not a two-question model per se, Facebook's successful experience demonstrates the American public, albeit perhaps a younger cross-section who uses computers and therefore may not perfectly reflect the population frequently using medical care, seems ready to accept being asked sex/gender questions with answers beyond simply male and female.<sup>58</sup>

Based on the peer-reviewed work of Tate et. al. as well as published non-scientific research by Fenway Health and UC Davis, when added to the stated plans of Epic and the implemented workflow of UC Davis, experience seems to point strongly toward the two-question model being acceptable for near-term use.<sup>41,44,52,54</sup> It has been tried and tested. The next step would be to build upon and extend the work of UC Davis and Epic to other vendors and health systems. Using their success as a proof of concept, the two-question model should be made part of Meaningful Use Stage 3 and therefore the standard in the US for documentation of sex/gender. With incorporation in Meaningful Use Stage 3, private standardization bodies such as HL-7 and X12-837 would be obliged and empowered to create and enforce a standard of information exchange which would permit clinical and billing data to flow between systems in ways not possible now. Properly implemented, such data exchange would resolve such vexing

issues as insurance-denied treatments based on sex marker and irrational reference ranges reported by interfacing lab systems.

With Meaningful Use Stage 3 and interfacing standards, vendors would finally know what to design to rather than facing the prospect of chasing uncertain solutions, the infamous ‘moving target.’ Practical established standards would make vendors much more amenable to investing scarce programming resources. Uncertainty regarding final standards is likely part of even Epic’s reticence to move forward with ‘hard-programing’ changes to their software they have established as a goal in their strategy document since 2010. With Meaningful Use Stage 3 standards in place, vendors would feel safe to develop complete and lasting solutions which would address the limitations of ad-hoc solutions detailed by Epic in their strategy document.

## **Conclusion**

The current binary model used in most EHRs, with a single, combined gender/sex field, is not sufficiently serving all patient populations seeking care in the United States. Work is underway to develop a new model, most likely separating sex and gender into separate fields and providing more descriptive options than simply “male” and “female.” This work with standards should be continued and a model defined in time for inclusion in the Stage 3 Meaningful Use rules pursuant to the HITECH Act. Based on the results of efforts by the Institutes of Medicine, Fenway Health, and UC Davis, as well as published literature, the best solution for near-term implementation would be the two-question model where patients would be asked their assigned sex at birth in addition to their current gender identity as well as their preferred name and pronouns in addition to their legal name. These should be included in the Meaningful Use Stage 3 standards.

With standards and a model developed and the mandate set, developers of EHR software and bodies establishing standards for information exchange will have the foundation for coding toward a single, defined target. This would greatly improve care of gender minorities while also respecting the needs of vendors and providers to have a workable framework given their current resource and workflow realities. Nothing in setting these standards should prevent an EHR developer from creating more extensive features, even an organ-based model for a site that specialized in LGBT populations for example, if they so choose as long as it worked within the two-question standard.

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