

Housekeeping Items □ Webex Overview □ Notice: Today's webinar will be recorded □ Webinar materials will be shared following the program □ Audience Questions: Chat to 'All Panelists' □ 1.0 Nurse CE available – complete evaluation by September 25



Assistant Vice President, Health Equity & Policy Illinois Health & Hospital Association (IHA)

> **ASK:** Introduce yourself to the group with your name, pronouns, title and organization



Illinois Health and Hospital Association

"Legal X" and Illinois Law

HB3534 "SOS Docs-Gender Designations"

- In 2019, the General Assembly amended the IL Identification Card Act and Vehicle Code
- · The Secretary shall permit applicants to choose between "male," "female," or "non-binary" when designating the applicant's sex... [on identification cards/ driver's licenses]
- Change to take effect in the coming months under the new administration.

Illinois officials say tech contract holding up availability of nonbinary IDs

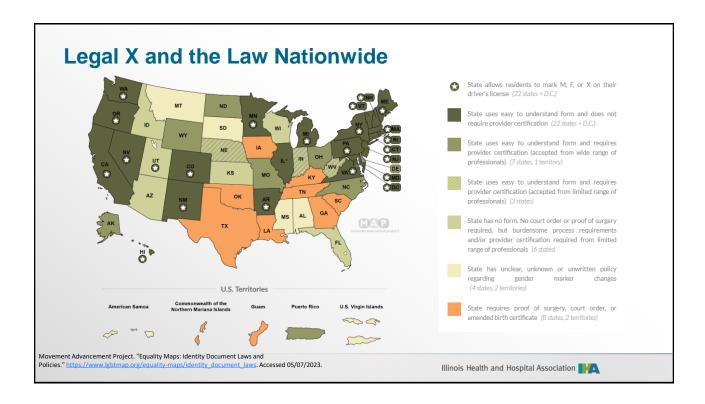
A contract that doesn't expire until 2024 is holding up implementation of a 2019 law that would allow residents to identify as nonbinary on driver's licenses.



https://www.ilga.gov/legislation/publicacts/101/101-0513.htm

Illinois Health and Hospital Association





Speaker Introduction

Lauren B. Beach, JD/PhD (they/them)

Assistant Professor, Dept. of Medical Social Sciences

Assistant Professor, Dept. of Preventive Medicine

Director, ReACH SGM Laboratory

Northwestern Feinberg School of Medicine

Director, ADVOCATE SGM Health Program

Institute for Sexual and Gender Minority Health and Wellbeing





Illinois Health and Hospital Association

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Sexual Orientation and Gender Identity Data Collection & Legal X

September 11, 2023
Illinois Health & Hospital Association

Lauren B. Beach, JD, PhD (they/them)
Director, ADVOCATE SGM Health Program
Institute for Sexual and Gender Minority Health and Wellbeing (ISGMH)
Assistant Professor, Medical Social Sciences
Northwestern University Feinberg School of Medicine





Learning Objectives

After this session, participants will be able to:

- Create an inclusive environment to facilitate capture of patient pronouns, preferred name, legal sex, sex assigned at birth, gender identity, and sexual orientation
- Accurately and appropriately document pronouns, preferred name, legal sex, sex assigned at birth, gender identity, and sexual orientation information
- Develop and implement a new workflow to collect a legal sex of "X" from patient identification documents
- Address common patient concerns about SOGI questions
- Use SOGI data to identify disparities and improve care

Tell Us Who You Are: Patient Demographics Are Part of Patient Centered Care



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Vector template of sample driver license plastic card for USA Illinois By AlexOakenman

CMS Framework for Health Equity 2022-2032

- CMS recently released a report on the path forward for improving data to advance health equity solutions.
- CMS acknowledges evidence that consistent health disparities exist among LGBTQ+ individuals and across different sexual and gender identities
- New look at both sex and SOGI collection standards and processes will be required.

CMS Framework for Health Equity Priorities



Priority 1: Expand the Collection, Reporting, and Analysis of Standardized Data



Priority 2: Assess Causes of Disparities Within CMS Programs, and Address Inequities in Policies and Operations to Close Gaps



Priority 3: Build Capacity of Health Care Organizations and the Workforce to Reduce Health and Health Care Disparities



Priority 4: Advance Language Access, Health Literacy, and the Provision of Culturally Tailored Services

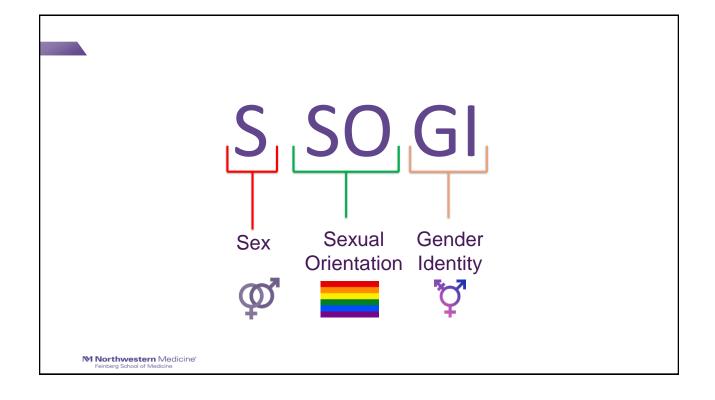


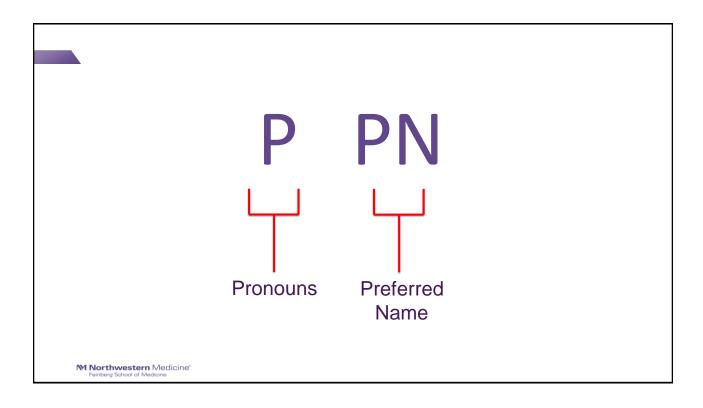
Priority 5: Increase All Forms of Accessibility to Health Care Services and Coverage

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https://www.cms.gov/About-CMS/Agency-Information/OMH/health-equity-programs/cms-framework-for-health-equity







Dimensions of Sex

Sex assigned at birth

☐Legal sex

What is "Sex assigned at birth"?



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https://www.usbirthcertificates.com/illinois

Dimensions of Sex

- There are multiple dimensions of sex
 - Genitals
 - Chromosomes
 - Secondary sexual characteristics (hair, breast development, etc.)
 - Hormones
 - Identity
- Sex assigned at birth is often based (only) on genital appearance
 - "X" marker now available on adult birth certificates in Illinois July 1, 2023 based on self-attestation!

Sex is not binary: Intersex People and Variations in Sex Characteristics

- O Intersex Pride Flag
- Intersex people have sex characteristics that do not fit "typical" definitions of male or female
 - Example: Congenital adrenal hyperplasia (CAH)
- A note on terminology...
 - Variations in sex characteristics (VSCs)
 - Differences in sex development
 - Many people with VSCs do not identify as intersex

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What is "Legal Sex"?



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In October 2023, IL Driver's Licenses Will Include "X" Legal Sex Option Based on Self Attestation

Male Female X

What is "Legal Sex"?



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In Illinois, Sex on Birth Certificates Can Be Amended to "X"



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https://www.usbirthcertificates.com/illinois

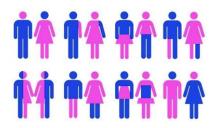
Dimensions of Gender

Gender identity

- A person's internal sense of their gender (do I consider myself a man, woman, non-binary, agender?)
- All people have a gender identity (though maybe not a label)

Gender expression

- How one presents themselves through their behavior, mannerisms, speech patterns, dress, and hairstyles
- May be on a variable spectrum



Gender identity vs. Gender expression

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Illinois identity documents do not document gender



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Because there is no "gender" field, nonbinary people may select "X" for the "sex" field



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Intersex people may also select "X" for legal sex



Lambda Legal Client Dana Zzyym Receives First 'X' U.S. Passport

By Lambda Legal OCTOBER 27, 2021



Today, Lambda Legal client Dana Zzyym, an intersex and nonbinary U.S. Navy veteran, became the first U.S. citizen to receive an official U.S. passport with an "X" sex/gender marker, the culmination of their six-year legal battle to get an accurate passport that did not force them to identify as male or female.

"I almost burst into tears when I opened the envelope, pulled out my new passport, and saw the 'X' stamped boldly under 'sex," Zzyym said. "I'm also ecstatic that other intersex and nonbinary U.S. citizens will soon be able to apply for passports with the correct gender marker. It took six years, but to have an accurate passport, one that doesn't force me to identify as male or female but recognizes I am neither, is liberating."

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https://legacy.lambdalegal.org/blog/co. 20211027_dapa-zayym-receives-first-us-nassport-with-y-gender-marke

Preferred Name and Pronouns

- What name would you like our staff to use for you?
- What are your pronouns?



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Identity

Do you consider yourself gay, lesbian, bisexual, straight, asexual, another label?

Behavior

Do you have sex and/or relationships with men, women, nonbinary people, people of multiple genders, no one?

Attraction/Desire

What gender(s) are you attracted to sexually and/or romantically? Do you experience these attractions at all? Behavior does NOT define identity!

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LGBT by the Numbers

LGBT By The Numbers

- 7.2% of US adults identify as lesbian, gay, bisexual, or transgender
- 58.2% of LGBT adults identify as bisexual
- 19.7% of Gen Z individuals identify as LGBT

heterosexual; Lesbian; Gay; Bisexual; Tran	ourself to be? You can select as many as ap asgender	pply. Straight of	
	U.S. adults	LGBT adults	
	%	%	
Lesbian	1.0	13.4	
Gay	1.4	20.2	
Bisexual	4.2	58.2	
Transgender	0.6	8.8	
Pansexual	0.1	1.7	
Asexual	0.1	1.3	
Queer	0.1	1.2	
Other LGBT	0.1	1.8	
Sum of categories may exceed 100% or the total becar Pansexual, Asexual, Queer and other LGBT identities an Based on aggregated data from 2022 Gallup telephone	e volunteered responses.		

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https://news.gallup.com/poll/470708/lgbt-identification-steady.aspx

LGBT By The Numbers: Illinois

Quick Facts About Illinois

Percent of Adults (18+) Who are LGBTQ **4.3%**

Gallup/Williams 2019

Total LGBTQ Population (13+) **506,000**

Williams 2020

Percent of Workforce That is LGBTQ 5%

Census 2018; Williams 2020

Total LGBTQ Workers 326,000

Williams 2020

Percent of LGBTQ
Adults (25+) Raising Children
28%

Gallup/Williams 2019

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https://www.lgbtmap.org/equality_maps/profile_state/IL

LGBT By The Numbers: Sex

- 1/2000 people are intersex
- This is the same percentage of people who have red hair

Recommendation

Given that intersex people only come to the attention of data collectors through chance or an apparent medical reason, the actual numbers of people with intersex variations are likely to be as much as 1.7%. Despite the limitations of the data, 1.7% seems more justifiable as an upper limit figure than alternatives, to date.

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https://ihra.org.au/16601/intersex-numbers/

LGBT By The Numbers: Transgender Adults

1.3M

adults identify as transgender

300,000

youth identify as transgender

18%

of people who identify as transgender are ages 13_17

8%

of people in the U.S. population are ages 13-17

39%

are transgender women

36%

are transgender men

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LGBT By The Numbers: Nonbinary Adults

1.2M

LGBTQ people in the US identify as nonbinary

11%

of LGBTQ adults

76%

of nonbinary LGBTQ adults are between the ages of 18-29

89%

live in urban areas

68%

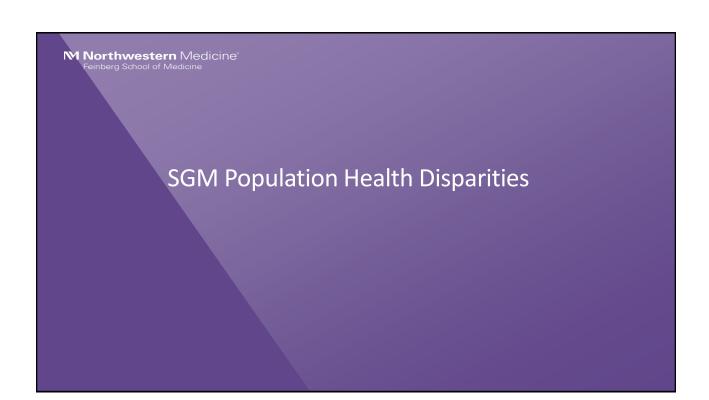
of nonbinary adults do not have enough money to make ends meet

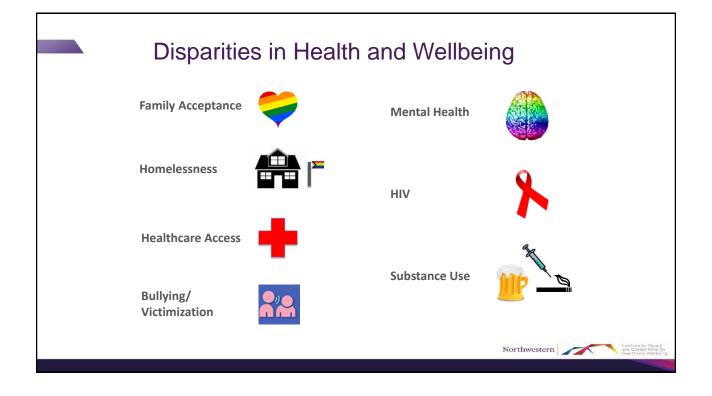
57%

live below 200% of FPL

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Source: https://williamsinstitute.law.ucla.edu/publications/nonbinary-lgbtq-adults-us/







SSOGI, Name, Pronouns and the Quality Perspective

Why Collect SSOGI and Pronouns and Preferred Name Information?

Proper collection of SSOGI and PPN is critical at a variety of levels

Patient

• sensitive care, proper history, clinical

Patient care

improving clinical decision support

Health System:

• identifying population health gaps in screening, prognosis, treatment

Surveillance:

 Health system SSOGI data as a source of public health surveillance/registry data



SSOGI: sex, sexual orientation,

gender identity

PPN: pronoun, preferred name

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https://www.cms.gov/About-CMS/Agency-Information/OMH/health-equity-programs/cms-framework-for-health-equity

The Joint Commission: Use Data to Identify Disparities Across Patient Groups

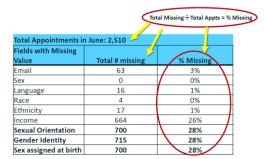
- Sociodemographic characteristics can be used to <u>stratify</u> quality data to identify disparities
- Organizations can <u>align measures with existing quality work</u> or required reporting measures
 - IHA Racial Equity in Healthcare Progress Report includes SOGI

M Northwestern Medicine Feinberg School of Medicine Joint Commission Strategie AHE Report

Best Practices: Data Reporting and Quality Checks

- Develop Summary Reports
 - Missing Patient Demographics Report
- Develop Dashboards
- Incorporate SSOGI into existing quality reports
 - Social Determinants of Health
 - Intimate Partner Violence
 - Diabetes/Hypertension
 - Cardiovascular disease
 - Oncology
 - HIV testing
 - UDS Measures
- · Compare data proportionally and within categories to identify problem areas
 - e.g., compare Gender Identity by: Country of Birth, Age Group, New Medical Patients, Social Determinants of Health
- · Use Sex Assigned at Birth and Gender Identity—and organ inventory—to identify transgender and nonbinary patients

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Sexual Orientation	Cervical Cancer Screen Completed?		n
	Yes (%)	No (%)	Total (%)
Lesbian/Gay			
Bisexual			
Straight/Heterosexual			
Something Else			
Don't Know			
Missing			
Total			

Future Directions: Laying Groundwork for a Learning Health System Design and Measure Enhanced collection of SDoH and patient demographics, including SSOGI and PPN data Analyze Identify disparities in screening, treatment, and prognosis experienced by sexual and gender minority (SGM) patients Use evidence to inform continual quality improvement Implement Targeted interventions to improve intersectional SGM outcomes and experiences

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Registration Workflow: Name, Pronoun, and Legal Sex Data Collection Best Practices

Preferred Name, Pronoun, and Legal Sex Proposed Ambulatory Collection Workflow

New Patient or Annual Prompt

- Receive My Chart notification to complete demographic fields
- Definitions/informational prompts included

Pre-encounter reminder

- Text message
- Pre-visit questionnaire packet
 - Personal information form

Reception Desk/Check In

- In person check includes collection of identification and insurance information
- Legal sex documented in legal sex field
- Recommend to also ask patients preferred name (which may differ from id) and pronouns

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Patient Portal Preamble

Details About Me



Why do we invite you to share this information? You may choose to share information that will help your clinical providers to know more about you. Northwestern Medicine uses this information in our quality improvement efforts to help ensure we are delivering consistently excellent care to all patients.

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Front Desk Collection: Preferred Name and Pronouns

- What name would you like our staff to use for you?
- What are your pronouns?



Collecting Preferred Name

- "What name do you go by"
- "What name do you use?"
- "By what name do you prefer to be addressed?"
- "What name would you like our staff to use?"

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Collecting Pronouns

- "May I ask..."
- "Which pronouns do you use?"
- "What are your pronouns?"
- "How would you like me to refer to you?"
- "How would you like to be addressed?"

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What to do if you make a mistake

- Quickly apologize and correct yourself
 - "I'm sorry, I meant to say [they] instead of [he]"
 - "Hello, John, oh, I'm sorry, Jane"
- Move on

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> Clinical Workflow: Sex assigned at birth, gender identity, sexual orientation, anatomy

SSOGI Proposed Ambulatory Collection Workflow

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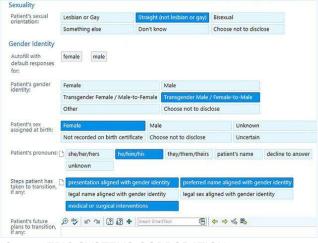
Private Encounter with Clinician

- If SSOGI fields still not completed, trained clinician inquires
- If patient has X for legal sex or is TGNB, prompt organ inventory
- · Clinical decision support

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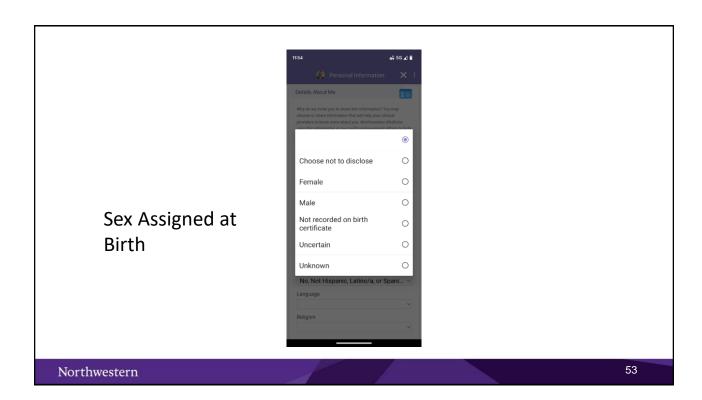
Epic SOGI Smart Form

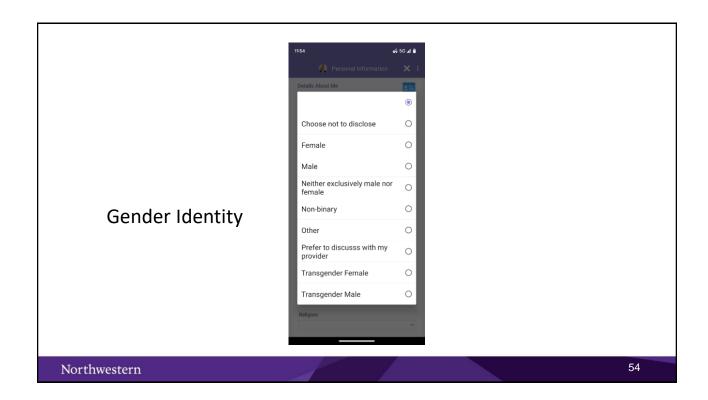


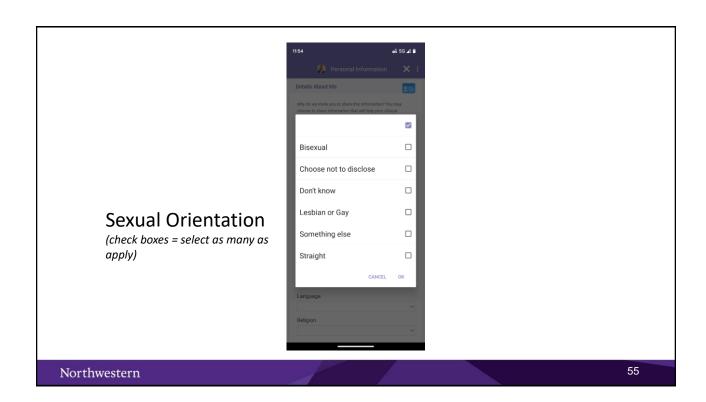
© 2017 EPIC SYSTEMS CORPORATION

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Do Ask, Do Tell Existing research shows high patient acceptability of SSOGI questionnaires **High Patient Acceptance Increased Patient Comfort Low Refusal Rates** Assessment of SOGI has been added SGM patients to emergency rooms All patients (across age, race, to multiple national studies and report greater comfort and ethnicity) in multiple-outpatient missing/refused to answer improved communication when settings report high levels of responses to SOGI questions in SOGI was collected via nonverbal acceptance and satisfaction with these datasets are typically less self-report. Non-SGM have no collection of personal SOGI data. than 5% (lower than missing/refused preference. to answer income) Northwestern

Practice Point: Modeling Inclusive Language

- Hi, my name is (care provider role title) + (name), I use they and she pronouns. How are you doing today?
- What name and pronouns would you like me to use to refer to you?
- I'm going to ask you a few standard questions we are asking all our patients to improve the care that we offer.
 - Instead of, "Do you identify as LGBT?", use "How do you identify?"
 - Instead of, "Do you have sex with men, women, or both?", use "What are the genders of your partners?"



Do Ask, Do Tell: Addressing Common Concerns

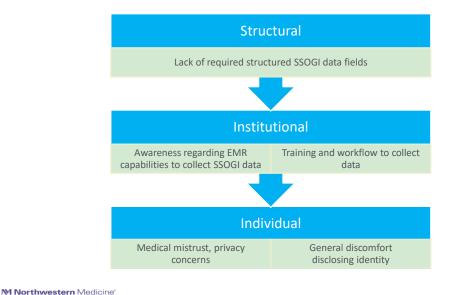
- Concern: I don't want to offend people
- Concern: This private information doesn't seem necessary or relevant to collect
- Concern: I need more training

Best Practices: Responding to Patient Concerns

- Why are you collecting this information?
 - "We want to make sure that we identify and address all of our patients' needs, ensuring that all of our patients receive the highest quality of care."
- Who will see this information?
 - "This information is confidential and the only people to see this information will be members of your care team and those who are authorized to see your medical record."
- Why are you asking for my pronouns and preferred name?
 - "We want to be sure we correctly address all of our patients. Asking this information of everyone helps us get it right."
- I'm obviously a [man/woman], why are you even asking me this?
 - "These are questions we ask everyone to make sure our records are correct. Let's move on to make sure the other information we have on file for you is right."

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Multilevel Barriers to SSOGI Data Collection



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Multilevel Training Opportunities to Enhance SSOGI Data Collection

- Short visual LGBTQ+ 101 on demand training for full workforce
- FAQ page with scripts
- Tip sheets including EMR documentation instructions
- PowerPoint training slide decks for new employees
- Written training manuals
- LGBTQIA in person workshop for champion/trainer certification
- Incorporation of evaluation metrics in training

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Beyond Data Capture: Implications of X and SSOGI for Patient Care and Billing

Workflow Synthesis

Pre-Visit

 Patient receives/completes intake forms that ask preferred name, pronouns, legal sex, sex assigned at birth, sexual orientation, gender identity, and other demographics, e.g., race, ethnicity, ability, language

Registration

- · Patient service representative
 - Requests identification
 - Records legal sex
 - Asks/confirms preferred name
 - Asks/confirms pronouns
 - Gives patients pre-visit forms in office if not completed pre-visit

Encounter

 Clinician asks sexual orientation, sexual behavior, gender identity, anatomy

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Case Study: Legal X Implementation at NM

Legal Sex of X Implementation Overview

 $\begin{tabular}{ll} OPPORTUNITY: on 1/1/24, Illinois is implementing the ability to have X designated as the legal sex on a driver's license \end{tabular}$

SCOPE: To ensure that all EPIC logic with any sex module flows correctly through internal and external downstream systems and workflow

MEASUREMENT OF SUCCESS: GO LIVE date of 12/15/23 with all downstream logic in each workflow, interface and third-party system operating correctly.

Creation of 2 Workstreams

- 1. Operational: Better Patient Care:
- Develop new/revised clinical care guidelines and processes for patients with X in Legal Sex
 - Implement Epic tools such as organ inventory, education, resources, and other changes as needed to implement revised care pathways
 - 2. Technical: Foundation: Allow "X" in the Legal Sex in Epic
 - ensure all downstream systems and applications handle this information appropriately
 Update patient facing technologies

• Epic has a check list to follow.

X (over 22 and growing)

Illinois is not the first state to implement a legal sex of

What we already know

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X and SSOGI have clinically essential implications for patient care

- To prepare for X implementation, Northwestern found hundreds of labs, best practice announcements, and procedures that differed by sex in Epic
- To ensure patients get the best possible patient care, it is important to use all sex, gender, and anatomy information available on file in Epic
- Epic has "reliable sex logic" that can help with getting started
- Legal sex of "X" means patients would benefit in particular from more SSOGI and anatomy documentation on file to direct clinical decision support

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Circulation



ASO Author Reflections | Published: 27 October 2021

ASO Author Reflections: Constructing a Transgender and Nonbinary Cohort to Analyze Breast Cancer Screening

Mona Ascha MD, Dylan Felt BA, Lauren B. Beach JD, PhD, Swati A. Kulkarni MD & Sumanas W. Jordan MD, PhD ™

Annals of Surgical Oncology 29, 1718–1719 (2022) Cite this article

Future

Guidelines for breast cancer screening among TGNB patients should be updated, including the development of consensus guidelines for screening following gender-affirming mastectomy. A unique barrier to healthcare access for TGNB patients is the gendering of anatomy. Terms such as "breasts" may be discomforting for some patients. We provide two recommendations:

(1) Providers should mirror the language their patients use to provide culturally competent care, and (2) providers, researchers, patients, and society should strive to uncouple organs from gender, to reduce patient distress and promote preventative healthcare. Finally, we

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 $https://www.ahajournals.org/doi/10.1161/CIRCULATIONAHA.122.063156?url_ver=Z39.88-2003\&rfr_id=ori:rid:crossref.org\&rfr_dat=cr_pub\%20\%200pubmed$

X, Billing and Third-Party Vendors

- Not all third-party vendors have the ability to accept legal sex of "X"
- Not all billing systems accept legal sex of "X," including CMS
- Opportunity to write patient-facing letters to indicate your health system's commitment to providing inclusive care to all patients while asking for patient preferences for sex documentation to insurance, other third parties

Learning Objectives

After this session, participants will be able to:

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