



Seeking SOGI: A Large Healthcare Organization's Journey to Ask Every Patient About Sexual Orientation and Gender Identity

2018 Opportunity Conference Workshop

March 27, 2018

Speakers

- **John M. Knudsen, MD** – Medical Director, Mayo Clinic Office of Health Equity and Inclusion (OHEI)
- **Brenda J. Morrison** – Program Manager, OHEI
- **Elizabeth (Liz) L. Canan** – Operations Administrator, OHEI

No Financial Disclosures



What's happening?

#LGBTQopportunity

#OppCon2018

#LGBTQhealth

@JMKnudsenMD

Overview

1. Background
2. Development of data standards
3. Collaboration with new EMR vendor
4. Pre-implementation research
5. Implementation strategy
6. Initial experience

Background

LGBT Practice Task Force 2011-2012

Practice leadership endorsement 2012

New EMR announced early 2013

OHEI established 2013

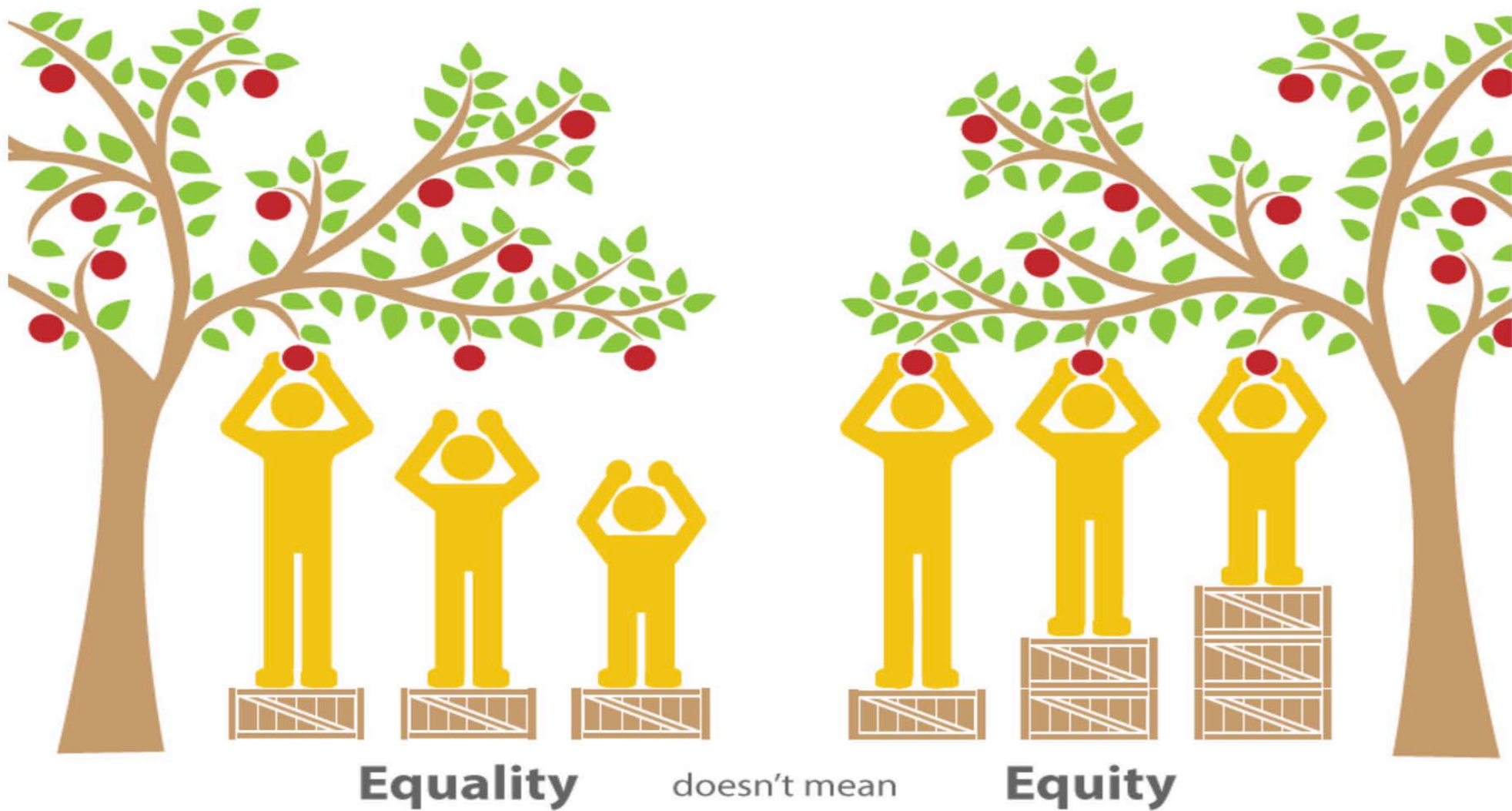
Socializing LGBT Health Awareness

Making the Case

LGBT people are largely **invisible** to health care providers

Why?

Meeting patient **needs**



https://www.communityview.ca/images/2014_health_equity_SHR_health_equity.png

Why?

Identifying gaps in **quality** (health care **inequities**)



All Recommend Collection of SOGI

- Joint Commission
- HHS through Healthy People 2020
- National Academies of Medicine
- Meaningful Use 3



Researching SOGI Data Standards

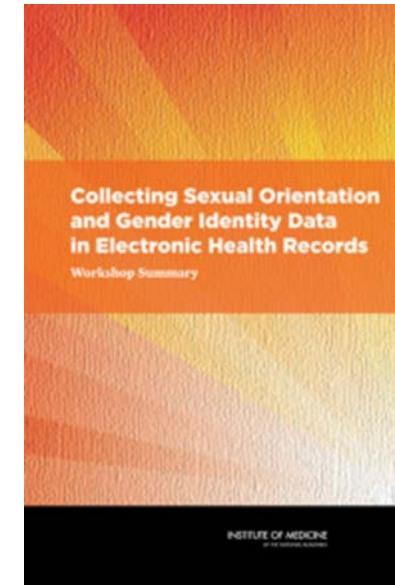
Identifying a national standard
or
Converging on best practices

No National Standards Best Practices



Consulted with National LGBT Education Center at Fenway Institute to gain insight from their work with their LGBT population

No National Standards Best Practices



Institute of Medicine workshop - October 2012

Recommendation: Best practice every healthcare organization should ask SOGI questions

No National Standards

Best Practices

- Sexual orientation question
- Gender identity question
- Sex assigned at birth question.
- Voluntary - Choose not to disclose or blank
- *Every* patient is asked
- Confidentiality assured
- Privacy optimized – on-line portals, tablets, or apps

Sexual Orientation Question with Responses

Patient's **sexual orientation** (SO) value set (choices):

Do you think of yourself as:

- *Bisexual*
- *Lesbian, gay or homosexual*
- *Straight or heterosexual (not lesbian or gay)*
- *Something else*
- *Don't know*
- *Choose not to disclose*

Gender Identity Question with Responses

Patient's **gender identity** (GI) value set (choices):

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

- *Female*
- *Male*
- *Transgender Female/Male-to-Female*
- *Transgender Male/ Female-to-Male*
- *Genderqueer, neither exclusively male nor female*
- *Additional gender category/(or other), please specify)*
- *Choose not to Disclose*

Sex Assigned at Birth

- Patient sex assigned at birth:
 - Female
 - Male
 - Unknown
 - Not recorded on birth certificate
 - Uncertain
 - Choose not to Disclose

Development of Data Standards

- In 2004, Mayo recognized a need to get a handle on all our data
 - Where was all our data coming from?
 - What systems was the data coming from?
 - What were the definitions of that data?
 - Who was using the data and for what purpose?
 - What systems were considered “gold standard?”

Mayo Clinic Data Governance

- New Data Governance Section established in 2005
 - Data modeling started and asked these questions:
 - Who
 - What
 - Where
 - Why
 - How
 - Inception of standardization efforts started in earnest

MC Data Governance Committee

- Established Data Governance Committee
 - Rigorous processes put in place to review any proposed data standard
 - SOGI question set went through process which included:
 - Again looking at national or international standards
 - Research into coding structures
 - Reviewed by appropriate clinical, research and administrative stakeholders

Final Steps

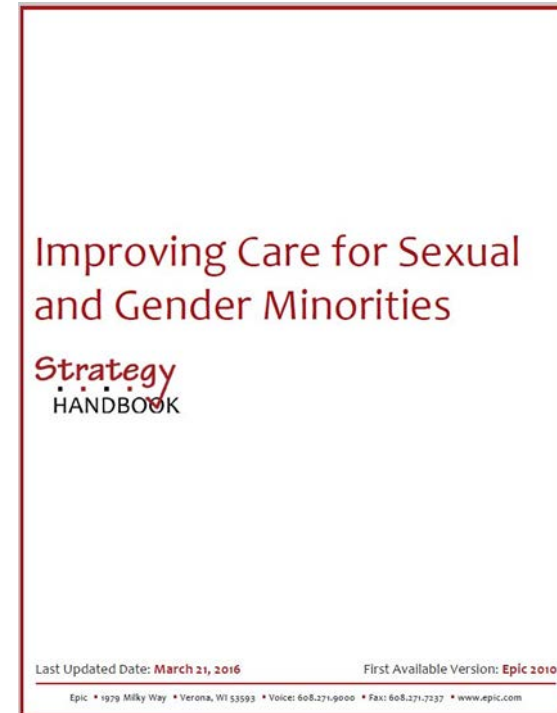
- SOGI question set reviewed by newly formed Patient Clinical Questionnaire Workgroup (standardizing patient questions/answers) for endorsement
- Final approval by Mayo Clinic Data Governance Committee
- New standard (SOGI question set) was born!!

EMR Issues

- 2013
 - 3 different versions of Cerner
 - Mayo Clinic Health System, Mayo Clinic Arizona and Mayo Clinic Florida
 - Mayo Clinic Rochester – GE Lastword
 - Planning underway to converge EMRs
- 2014 – Commit to converge to Epic
 - Nothing happens until go live starting in 2017
 - Epic commits to supporting our goals to collect SOGI

EMR Vendor

- Administrative sex
- Gender Identity
- Sex assigned at birth
- Preferred name
- Sexual orientation
- Smart Forms – anatomic inventory and transition information



“Are we going to ask *every* patient this question?”

“How will our patients react?”

Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers

- 301 patients at 4 health centers (Chicago, Boston, Baltimore, and Beaufort, SC)
 - 51% heterosexual
 - 15% transgender
- SOGI questions and then surveyed
- Wide acceptance (2% failed to answer SAB or 1% GI)
- Understood importance
- Age related differences (some)

Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, et al. (2014) Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers. PLoS ONE 9(9): e107104. <https://doi.org/10.1371/journal.pone.0107104>

Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience

**The UC Davis experience
Education and preparation
Overcoming initial resistance**

Callahan, Edward J., et al. "Introducing sexual orientation and gender identity into the electronic health record: one academic health center's experience." *Academic Medicine* 90.2 (2015): 154-160.

Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial

- 491 patients randomize + / - SOGI questions (218 control v 273 SOGI)
- 3 clinics in Rochester, MN area
- All patients received short survey following completion of questionnaire
- Further follow up including phone call interviews
- Average age 53
- 99.2% heterosexual
- No transgender patients

Rullo, J. E., Foxen, J. L., Griffin, J. M., Geske, J. R., Gonzalez, C. A., Faubion, S. S. and Ryn, M. (2018), Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial. Health Serv Res. . doi:[10.1111/1475-6773.12843](https://doi.org/10.1111/1475-6773.12843)

Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial

[Rullo JE](#), [Foxen JL](#), [Griffin JM](#), [Geske JR](#), [Gonzalez CA](#), [Faubion SS](#), [van Ryn M](#)

- 3% reported being distressed, upset, or offended by SOGI questions
- No significant differences in patient attitudes between experimental and control groups ($P > 0.05$).
- 7% didn't answer SAB
- 6.6% didn't answer GI
- 13.6% didn't answer preferred pronoun
- 11.4% didn't answer sexual orientation (more likely to respond as being distressed, upset or offended)
- More questions about questionnaire from controls than SOGI respondents

Rullo, J. E., Foxen, J. L., Griffin, J. M., Geske, J. R., Gonzalez, C. A., Faubion, S. S. and Ryn, M. (2018), Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial. *Health Serv Res.* . doi:[10.1111/1475-6773.12843](https://doi.org/10.1111/1475-6773.12843)

Implementation Strategy

- Developed internal training module
 - SOGI questions
 - SOGI definitions to ensure greater understanding among both staff and patients
 - Reasons why we are asking for this information
 - Scripted responses for staff to use if questions or concerns arise from patients
 - Researched external content and consulted internal experts (Mayo Employee Resource Groups)
- Module imbedded into central learning hub for Epic training and now mandatory
- Augmented module with in-person presentations to further increase staff awareness of new data elements

Initial Experience

Patients Completing SOGI Questions

- Timeframe - July 2017 thru February 2018
- MN & WI Mayo Clinic Health System sites
- Optional questionnaire available to patients in MyChart
 - Three questions: SO, GI, and Sex Assigned at Birth (SAB)
 - Won't be presented with questionnaire again if at least one valid response provided
 - Can voluntarily go in and update information at any time

Initial Experience

Early Findings

- Total unique patients assigned SOGI = 189,987
 - Fewer than 5 complaints brought forward to Office of Patient Experience
- Total number SOGI completed = 75,741
 - GI – <0.18% (120 patients) responded other than M or F; 10% no response
 - SO – 14% no response; of patients responding something other than Straight, 2.7% chose not to disclose
 - SAB – 24% no response; highest of all three questions – Why?
 - Many may not have been asked this question before
 - Future enhancement – hover box with definition and why we are collecting it

Challenges

- Awareness in midst of significant organizational disruptive change
- Inability to easily ask patients these questions
- Low initial use of Patient Online Services (MyChart)
- Tablet availability for patients
- Insufficient time in lobby for Welcome completion



QUESTIONS ??

OFFICE OF HEALTH EQUITY AND INCLUSION