Sexual Orientation and Gender Identity in the Electronic Health Record

Edward J. Callahan, Ph.D.
Associate Dean for Academic Personnel
University of California, Davis
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Objectives of Talk

I. Share story of UCDHS launch of gender identity and sexual orientation in our EHR
II. Identify goal, obstacles
III. Share business case for rollout
IV. Share compelling data why it is critical
V. Identify our next steps
VI. Recommend federal requirement for capacity to gather these data in all EHRs
UCDHS Commitments

• Building an Electronic Health Record which:
  – enhances quality of care with diverse individuals, families
  – reduces health disparities

• Initial EHR Task Force instituted REAL data collection in 2009

• That Task Force felt it could not add Sexual Orientation/Gender Identity
Dean Pomeroy Appoints New Task Force on Inclusion of SO/GI in EHR

- Decision elicited pushback from some administrators
  - "Clinicians not comfortable discussing SO/GI"
  - "Clinicians not knowledgeable about SO/GI issues"
  - "Why must sensitive topics be discussed?"

- Negative reactions to LGBT topics
  - Both homophobia and unconscious bias leave clinicians uncomfortable
  - Religious and political bias against LGBT people
Pushback = Opportunity

Pushback reveals that education is needed:

1. Significant LGBTI IQ health disparities exist
2. Health disparities are related to social treatment
3. Desensitization to SO/GI can improve care
4. LGBTI IQ people are us, not “other”!
   - GLEE spinoff and atmosphere
   - Develop 4 yr curriculum for SOM
   - Demographics of faculty, residents
5. That UCDHS welcomes LGBTI IQ patients, trainees, staff and faculty
LGBT Health Disparities: IOM 2011

Disparities apparent even in LGBT children:
- Bullying, physical and verbal, higher for LGBT
- Increased levels of anxiety, depression
- Lead to maladaptive coping
  - Higher rates of cigarette smoking, alcohol, drug use
  - Changes in eating patterns
  - Increased self-harm, including SI, suicide attempts
  - Targets for sexual abuse, and sometimes seek early experiences

Maladaptive coping sows seeds for disparities identified across the life cycle in IOM (2011) report
- Respiratory problems, alcoholism, addiction
- Eating disorders, obesity
- Depression and anxiety disorders, SI, suicide attempts
- Relationship disorders
Does Medicine Have an Unwritten Don’t Ask, Don’t Tell (DA/DT) Policy?

• Pushback to proposal suggests DA/DT remains strong

• Literature:
  – Fewer than 13% of primary care physicians ask sexual history
  – Fewer than 50% of lesbians and gays are out to their providers
  – Anecdotes of transgender people who “pass” having difficulty getting PSA tests (MTF) or treatment for breakthrough bleeding (FTM)
LGBT Providers Also Hide SO/GI

- Out as providers only rarely; often not out to pcp
- Gallup Poll: 40% of US public would not see an LGBT provider
- Harvey Makadon describes coming out in NEJM (2006)
- I also came out to my pcp after 9 years (20 years ago)
  - “I have never had a gay or lesbian patient”
  - Lost a physician I had valued
  - Needed to find a new pcp during a key period of change
  - Need to contribute to educating other pcps
  - Leading this Task Force is a huge privilege

- As a provider, I rarely share my SO
- As a patient, it is critical that I do so
Should Medicine Repeal DA/DT?

– People learn to hide SO/GI as **bias avoidance**
  • common way people reduce stress in their lives
  • works to reduce stress short term
  • but can produce negative effects long term

– Not knowing SO/GI status:
  • Prevents needed counseling about health risks
  • To get past it in medicine, need to change doctors, patients and systems
  • Newer data emphasize harm avoidance for families given early counseling
Family Acceptance Project: Caitlin Ryan, Ph.D.

- Built on data from 2009 Peds study
- Compared self report of LGBT young adults on their family experience coming out
- Youth reported family support behaviors and family rejection behaviors
- Also reported current health behaviors
Youth Reporting Low Support v. High Support From Family

- **Variable Compared** (self report of:)
  - Suicidal ideation
  - Suicide attempts
  - Serious depression
  - Illegal drug use
  - Unprotected sex

- **Odds Ratios: Low/High Support**
  - 8 X increase
  - 8.4 X attempts
  - 5.9 X depression
  - 3.4 X use
  - 3.4 X reports
Why Is Ryan Work Important?

- LGBT children are usually born into heterosexual families
- Gender variant and sissy kids are spotted early
- LGBT children usually come out to parents early (younger by decade since 60s, as young as 8-10)
- Ryan et al.: educating families to maintain support for LGBT children as they come out can reduce, if not eliminate, health disparities
- Role for pcps working with children, parents
Ryan Work and Task Force

• Caitlin Ryan will present the final plenary for AAMC Group for Diversity and Inclusion on November 6 in San Francisco.

• The work presents primary care providers with a role in educating families and youth.

• The data are compelling for parents, grandparents, primary care providers.

• Gathering data for EHR also desensitizes providers for having these discussions.
Big Picture of EHR:

To help providers see and value everyone in all their diversity.

“You might as well just be yourself; all the other options are already taken.”

-Oscar Wilde
Recent and Current Steps

- Continuing Grand Rounds, workshops
- Rolling out education to all providers
- Developing electronic list of LGBTIQ-friendly providers
- Using MyChart questionnaire to allow patients to self-identify as LGBTIQ
- Training patient complaint personnel to handle concerns about questionnaire
How Did We Develop Questions?

- Endless debate
- Talking with LGBTIQ patients, colleagues
- Building off work of Fenway
- Modifying it to meet our culture
- Recognize these are not in stone
Question on Sexual Orientation

1. Sexual orientation: Do you think of yourself as:

   - [ ] Straight or Heterosexual
   - [ ] Lesbian
   - [ ] Gay or Homosexual
   - [ ] Bisexual
   - [ ] Self-identify

   ____________________________ (Please Describe)

   - [ ] Don’t know
Question on Gender Identity

2. Gender identity: Do you think of yourself as:

- _____ Male
- _____ Female
- _____ Trans: Male to Female (MtF)
- _____ Trans: Female to Male (FtM)
- _____ Other self-identification
  _____________________________(Please Describe)
Next Steps

• Questionnaire to identify LGBT-friendly providers
• E-mail information
• Videotape Grand Rounds and workshops
• Work with Epic to systematize where and how to locate these demographics
• Systematize prompts for physicians caring for trans patients
• Advocate for SO/GI as meaningful use
EHR companies may overlook need for these demographics without incentive

• Seek federal requirement that all EHRs include this information

• Recognize that atmosphere of health systems needs to change, not just ability to ask

• Encourage gay/straight alliances in health systems to address this critical issue