Identification of LGBT Patients & Health Disparities Using Electronic Health Records

Jesse M. Ehrenfeld, MD, MPH

Assistant Professor of Anesthesiology & Biomedical Informatics
Co-Director, Vanderbilt Program for LGBTI Health
Director, Perioperative Data Systems Research
Director, Center for Evidence-Based Anesthesia
Medical Director, Perioperative Quality
Vanderbilt University School of Medicine
Overview

• Vanderbilt Program for LGBTI Health
  – Programmatic Overview

• Vanderbilt Research Efforts
  – Identification of Barriers to Disclosure
  – Natural Language Processing for Identification of LGBTI Patients & Evaluation of Disparities

• Revising Our Clinic Intake Forms & Planned EHR Rollout
  – Three stage implementation plan
  – Next steps
Who Serves the LGBT Population?

97% of LGBT patients in the U.S. receive care at non-LGBT affiliated medical facilities\(^1\)

Vanderbilt University Medical Center

- 200 Vanderbilt LGBTI employees registered for domestic partner benefits
- 1,000 LGBTI students attend Vanderbilt University
- 1,794,513 patient visits; 65,685 admissions / year
- Approximately 4.7% of our patients are LGBTI

\(^1\)Ng, H., Sudano, J. “Health Centers in the United States” American Public Health Association Meeting 2012.
Vanderbilt’s LGBTI Evolution

2000
- Employee nondiscrimination includes SO
- Ad campaign to LGBT community

2005
- Employee domestic partner benefits

2006

2007

2008
- GSA hosts first annual LGBT Health Week
- Patient nondiscrimination includes SO

2009
- Initiation of curriculum reform
- Policy inclusion of gender identity
- First participation in HEI

2010

2011

2012
- Inclusive visitation policy
- LGBTI Program Launched
Vanderbilt’s LGBTI Evolution

1. Establish the Need for Change
2. Assemble the Team
3. Design the Innovation
4. Implement the Proposals
5. Evaluate the Outcomes

Vanderbilt’s LGBTI Evolution: Curriculum

Establishing the Need for Change:
• Fenway and IOM Reports
• AAMC Recommendations
• Medical Student Data

<table>
<thead>
<tr>
<th>Self-Reported Issues Associated with LGBT Patient Care</th>
<th>Percent (n=109)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students that reported feeling adequately trained to care for the LGBT population</td>
<td>35.8%</td>
</tr>
<tr>
<td>Students that reported knowing how to direct LGBT patients to LGBT friendly healthcare providers and services</td>
<td>9.3%</td>
</tr>
</tbody>
</table>

Wilburn CR, Johnson KB, Moore DC. 2010. Analysis of Lesbian, Gay, Bisexual, and Transgender Cultural Competency among Third Year Medical Students. *Vanderbilt Emphasis Presentation*
LGBTI Program Leadership

Kristen Eckstrand
MD, PhD Candidate, Class of 2016

Andre Churchwell, MD
Associate Dean for Diversity

Traci Nordberg, JD
Associate Vice Chancellor and
Chief Human Resource Officer

Deborah Grant, JD
Executive Director of Human Resources

Arie Nettles, PhD
Director, Office of Inclusion and Health Equity

Tristan Van, RN
Nurse Practitioner, Children’s Hospital

Lashonda Moore
LGBTI Program Assistant

Jesse Ehrenfeld, MD MPH
Assistant Professor of Anesthesiology

Julie Morath, BSN MS
Chief Quality and Patient Safety Officer

Titus Daniels, MD
Vice Chair for Clinical Affairs
Department of Medicine

Terrell Smith, MSN RN
Director of Patient and Family Centered Care

Nora Spencer
Director, Office of LGBTQI Life

Laura Kelley, MSN RN
Director, Nursing Diversity

Barry Noland
Staff, Office of Diversity
Opportunity to Lead

Working Vision

Promote national leadership in providing excellent patient care, education, research, and advocacy for the LGBTI community
Model for LGBTI Health

Patient Care

Health Education

Policies

Visibility

Community Outreach

Institutional Climate

Promoting national leadership in providing excellent patient care, education, research, and advocacy for the LGBTI community.
Vanderbilt HEI Testimonial
Diversity: It’s Who We Are

Vanderbilt’s mission is to bring the full measure of knowledge, skill, respect, and compassion to patient care, education, and research. Central to our mission is inclusivity and service to the diversity of our patients, students, faculty, and staff. Participation in the Healthcare Equality Index is a reflection of our culture.

LGBTQI inclusiveness requires our attention at all organizational levels, and must permeate the depth and breadth of our community in all that we do.

We are dedicated to providing personalized health care and we respect and honor patients’ rights to define their families and support persons. We are committed to protecting patient and visitation rights; providing cultural fluency training for our faculty and staff; reflecting inclusivity in electronic and printed materials; upgrading our intake processes to gather critical patient information regarding sexual orientation and gender expression; and appropriately modifying our facilities.

Our educational mission is supported by LGBTQI-inclusive employment and benefits policies, dedicated to providing our students, faculty, and staff with the knowledge, skills, attitudes, and behaviors to reflect and enhance our diversity. We understand the value of LGBTQI inclusiveness and education across our medical center throughout all levels, from senior leadership to the frontlines of patient care delivery. We support LGBTQI inclusion in our community through health events and LGBTQI-friendly provider access.

We are on the leading edge of research into LGBTQI health issues through the lenses of education and patient care. Our education research centers around enhancing student knowledge and attitudes to better prepare future providers to care for LGBTQI patients. Our patient care research addresses LGBTQI health disparities in both health access and health outcomes.

Being included among the Leaders in LGBT Healthcare Equality is a tremendous honor representative of our commitment and an affirmation of our efforts. We look forward to the journey ahead as we advance this important mission.

C. Wright Pinson, MD, MBA, Deputy Vice Chancellor for Health Affairs and CEO of the Vanderbilt Health System
Marilyn Dubree, MSN, RN, NE-BC, Executive Chief Nursing Officer, Vanderbilt University Medical Center
Introduction

The Vanderbilt University Medical Center Program for LGBTI Health is an innovative effort to improve healthcare for lesbian, gay, bisexual, transgender, and intersex (LGBTI) patients that is housed within the Office for Diversity in Medical Education.

LGBTI patients experience disparities in access to and quality of care, leading to preventable, adverse health outcomes including elevated risk for specific chronic diseases and increased rates of suicide and depression. The Vanderbilt Program for LGBTI Health works to address these disparities, improve the health of LGBTI patients, support education around LGBTI Health, and foster research on the optimal ways to care for LGBTI patients and families.

Vision Statement

Promote national leadership in providing excellent patient care, education, research, and advocacy for the LGBTI community.
Model for LGBTI Health

Promoting national leadership in providing excellent patient care, education, research, and advocacy for the LGBTI community

Patient Care: medical centers should provide quality personalized medicine to LGBTI patients

- Provider and staff training
- Clinic intake forms
- Electronic health records
Identification of Barriers to Disclosure
Natural Language Processing for Identification of LGBTI Patients & Evaluation of Disparities

PART II – OUR RESEARCH
Identifying Facilitators and Barriers to Disclosure of Sexual Identity to Health Care Providers

• Participants recruited from two gay and lesbian community centers

• Subjects asked questions about their willingness to disclosure their sexual orientation to a provider using “think aloud” interviews

• Race/Ethnicity
  – African Americans – 23%
  – American Indian/Caucasian – 7%
  – Asian – 7%
  – Caucasians – 31%
  – Hispanic/Latina/o – 23%
  – Mexican American – 7%

• Educational level
  – 12 (high school graduate) to 20 years (doctorate, mean = 16.54, SD = 2.64)

• Age
  – 24 to 61 years (mean = 39.23, SD = 11.57)

• Length of time out to others ranged from 5 to 22 years

• 84% of participants had disclosed their sexual identity to at least one health care provider

Fogel, S.C., Identifying facilitators and barriers to disclosure of sexual identity to health care providers. The Kansas Nurse, 2005. 80(9).
<table>
<thead>
<tr>
<th>Facilitators to Disclosure</th>
<th>Barriers to Disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being treated like everyone else</td>
<td>HCP is same ethnicity as client</td>
</tr>
<tr>
<td>HCP is sensitive to LGBT issues</td>
<td>HCP does not seem to listen to client</td>
</tr>
<tr>
<td>HCP is same gender as patient</td>
<td>HCP has an abrupt or abrasive manner</td>
</tr>
<tr>
<td>HCP is lesbian or gay</td>
<td>Frequent changes in health insurance</td>
</tr>
<tr>
<td><strong>Sexual identity was asked by HCP</strong></td>
<td>Sexual identity not known to many people</td>
</tr>
<tr>
<td>Interest in client and client’s care</td>
<td><strong>Sexual identity written in medical record</strong></td>
</tr>
<tr>
<td>HCP has experience treating LGBT clients</td>
<td>Assumption of heterosexuality on forms</td>
</tr>
<tr>
<td>HCP is known to be gay friendly</td>
<td>Poor relationship with HCP</td>
</tr>
<tr>
<td>Familiarity - Have seen HCP many times</td>
<td>Previous bad experience with disclosure to HCP</td>
</tr>
<tr>
<td>Trust in HCP</td>
<td>Only religious-based reading material in waiting area</td>
</tr>
<tr>
<td><strong>Perception that HCP needs to know</strong></td>
<td><strong>Other people (office staff) having access to private information</strong></td>
</tr>
<tr>
<td>Client identified risk of HIV or other STD</td>
<td>HCP/staff overheard making negative comments about gay people</td>
</tr>
<tr>
<td>Partner involvement in healthcare decisions</td>
<td></td>
</tr>
<tr>
<td>Needing medical test that is invasive</td>
<td></td>
</tr>
<tr>
<td>Needing serious medical care</td>
<td></td>
</tr>
<tr>
<td>A recognized symbol of acceptance (red ribbon or rainbow flag)</td>
<td></td>
</tr>
<tr>
<td>HCP recommended by a friend</td>
<td></td>
</tr>
<tr>
<td>Social familiarity with HCP</td>
<td></td>
</tr>
</tbody>
</table>

Perioperative Data Systems Research Group

Undergraduate Students
- Molly Cowan
- Lindsay Lee
- Shane Selig
- Jacob Schifftan
- Emily Wang

Project Manager
  Angelo del Puerto

Director
  Jesse Ehrenfeld, MD

Graduate Students
- Amlan Bhattacharjee
- Sean Chester
- Kristen Eckstrand
- Aneesh Goel
- Paul Hannam
- Monika Jering
- Mary Marschner
- Ilana Stohl

Data Warehouse Architect
  Michaelene Johnson

Health Systems Database Analyst
  Chris Eldridge

Data Intelligence Analyst
  Jason Denton

Health Systems Database Analyst
  Dylan Snyder

Research Analyst
  Khensani Marolen

Data Management Specialist
  Lily Zhu

Research Analyst
  Catherine Bulka

Last updated 10.1.2012
Natural Language Processing for Identification of LGBTI Patients & Evaluation of Disparities

• Specific Aim 1: Identify LGBTI patients using existing electronic records

• Specific Aim 2: Determine how LGBTI status affects diagnosis, treatment, and health outcomes by comparing an LGBTI cohort with a matched cohort of patients not identifying as LGBTI
Approach

• Develop a series of natural language processing (NLP) tools to identify LGBTI patients in existing records

• Determine sensitivity/specificity and positive/negative predictive values

• Determine how status affects diagnosis, treatment, and health outcomes
What Is NLP?

• Process that uses computers to analyze free-text data

• Uses algorithms to process natural language

• Trial/error and algorithms to apply rules of the English language to the data
Initial Search Strategy

• Search records for key terms alone and in combination
  - Lesbian
  - Transgender
  - Queer
  - Bisexual
  - Homosexual
  - Gay

• More intricate searches:
  – Patients listing a same-gender emergency contact or primary insurance guarantor with a different last name
# Preliminary Data

<table>
<thead>
<tr>
<th></th>
<th>Clinical Notes</th>
<th>Problem Lists</th>
<th>Discharge Summaries</th>
<th>Clinical Communications</th>
<th>Family History</th>
<th>Reports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gay</td>
<td>1327 (636F, 691M)</td>
<td>177 (89F, 88M)</td>
<td>329 (139F, 190M)</td>
<td>382 (199F, 183M)</td>
<td>16 (11F, 5M)</td>
<td>194 (89F, 105M)</td>
</tr>
<tr>
<td>Homosexual</td>
<td>1466 (197F, 1268M)</td>
<td>119 (21F, 98M)</td>
<td>257 (25F, 230M)</td>
<td>7 (2F, 5M)</td>
<td>20 (4F, 16M)</td>
<td>1 (M)</td>
</tr>
<tr>
<td>Lesbian</td>
<td>191 (175F, 16M)</td>
<td>42 (39F, 3M)</td>
<td>30 (27F, 3M)</td>
<td>12 (9F, 3M)</td>
<td>8 (5F, 3M)</td>
<td>0</td>
</tr>
<tr>
<td>LGBT</td>
<td>3 (M)</td>
<td>0</td>
<td>0</td>
<td>1 (M)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Transgender</td>
<td>199 (39F, 160F)</td>
<td>12 (5F, 7M)</td>
<td>7 (4F, 3M)</td>
<td>6 (3F, 3M)</td>
<td>1 (F)</td>
<td>0</td>
</tr>
<tr>
<td>MTF</td>
<td>1122 (522F, 600M)</td>
<td>8 (5F, 3M)</td>
<td>241 (115F, 126M)</td>
<td>21 (12F, 9M)</td>
<td>0</td>
<td>164 (67F, 97M)</td>
</tr>
<tr>
<td>FTM</td>
<td>15 (10F, 4M)</td>
<td>2 (1F, 1M)</td>
<td>0</td>
<td>2 (F)</td>
<td>0</td>
<td>79 (35F, 44M)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>185 (61F, 124M)</td>
<td>18 (4F, 14M)</td>
<td>31 (11F, 20M)</td>
<td>3 (1F, 2M)</td>
<td>4 (3F, 1M)</td>
<td>0</td>
</tr>
<tr>
<td>Queer</td>
<td>11 (4F, 7M)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Intersex</td>
<td>47 (32F, 15M)</td>
<td>2 (F)</td>
<td>3 (2F, 1M)</td>
<td>2 (F)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Receptive Partner</td>
<td>2 (M)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Anal Sex</td>
<td>174 (59F, 115M)</td>
<td>2 (M)</td>
<td>5 (3F, 2M)</td>
<td>9 (7F, 2M)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Anal Intercourse</td>
<td>369 (138F, 230M)</td>
<td>1 (M)</td>
<td>8 (3F, 5M)</td>
<td>3 (1F, 2M)</td>
<td>6 (3F, 3M)</td>
<td>0</td>
</tr>
</tbody>
</table>

|                      |                 |               |                     |                        |               |         |
|                      | Anal Intercourse + Gay |                 | 13 (M)             |                       |               |         |
|                      | Anal Intercourse + Homosexual |             | 68 (3F, 65M)     |                       |               |         |
|                      | Roommate + Age>30 | Clinical Notes + Discharge Summaries: 3230 (1725F, 1505M) |             |                       |               |         |
Chart Review

• In process of refining search algorithm & reviewing 3,000 patient records
  – Initial False Positive Rate $\rightarrow$ 22%
  – Revised False Positive Rate after Adjustment $\rightarrow$ 3%
  • Negation words such as “Ben” before “Gay”
  • Still having difficulty with phrases like “without vaginal or anal intercourse”

• Specific Goals:
  – Understand where documentation is occurring
  – Learn about frequency of documentation
Chart Review - Results

- Chief Complaint: 3%
- Problem List: 7%
- Impression/Plan: 7%
- Other: 8%
- Clinical Communications: 10%
- Past Medical History: 14%
- History of Present Illness: 14%
- Physical Exam: 1%
- Review of Systems: 1%
- Social History: 35%
Chart Review - Results

• 30 months after 1st visit = average time before LGBT status documented in medical record (std 24.6, min=0, max=81)

• 17 = average # of clinical encounters where LGBT status documented (std =16, min=1, max=28)

Patients in this sample had been seen at Vanderbilt for an average of 5 years
“XX year-old transgender with a recent history of self-mutilation of the scrotum”
“A/P: recommended gay AA meetings”
“Patient is bisexual since age 17”
“Problems - Transgender- male to female since age 18”
“HPI: Apparently he is bisexual”
“lesbian, monogamous relationship”
“Prefers ‘Chris’---trans female to male”
“Pt denies current sexual activity; states he uses condoms and practices receptive anal intercourse”
“Sexually active: yes, lifetime number of partners: she is lesbian”
“SOCIAL HISTORY: She is a smoker. She is homosexual.”
“Social History: single, homosexual”
PART III – REVISED CLINIC INTAKE FORMS & EHR ROLLOUT

Three stage proposal

Next steps
Consensus Building

• Approach to generating support
  – Executive Leadership Team (C-Suite)
  – Executive Faculty (Chairs & Chiefs)
  – Enterprise Leadership Assembly
  – Medical Group Leadership Team
  – Cultural and Linguistics Committee
  – Patient & Family Council
  – Department Level Meetings
  – Target Specific Clinics
Clinic Intake Forms

“Gathering data on LGBT individuals will help researchers, policy makers, health care providers, and advocates identify and address health disparities affecting LGBT patients” ~Secretary Kathleen Sebalius

Recommendations for Improvement

• Patients should have the opportunity to self-identify their sexual orientation and gender identity

• Patients should have the opportunity to define their relationship status

• Patients should have the opportunity to identify their family

• Patients should be asked about power of attorney / healthcare proxy and advanced health directives
Clinic Intake Forms

Phase 1
- Review available clinic and intake forms
- Pilot collection of sexual orientation and gender identity at one adult clinic
- Address weaknesses/concerns

Phase 2
- Pilot collection of sexual orientation and gender identity at one adolescent clinic
- Add additional recommendations to forms serving adults and expand pilot collection to multiple clinics
- Address weaknesses/concerns

Phase 3
- Complete intake form revision for all 95 physician practices / clinics
Clinic and Intake Forms

Recommendation 1: Gender Identification
Legal Name: ____________________________________________________________
Preferred Name (if different): ___________________________________________
Sex at Birth: □ male □ female
Gender Identity if Different: □ male □ female □ transgender □ prefer not to answer

Recommendation 2: Sexual Orientation
Sexual Orientation: □ Heterosexual/Straight
□ Lesbian
□ Gay
□ Bisexual
□ Queer
□ Something else
□ Prefer not to answer
Key Issues

• Who is asking?
  – Front desk? Provider?

• Where is it recorded in the EHR?
  – Demographics? Social history? Medical history?

• How often to ask?
  – Every visit? Every 6 months?

• What to ask?
  – Identity vs. Behavior – both confer risk
Summary of Recommendations

• Self-identified orientation, gender-identity, and sexual behavior should be collected during routine clinical encounters in order to improve health outcomes
  – *Substance abuse is predicted by both self-identified orientation and sexual behavior*

• When collecting sexual orientation & gender identity data on health care intake forms, patients should have the right to opt out
  – *Suggest using phrase “prefer not to answer”*
  – *Facilitates ability to use patient preferred terminology during subsequent encounters*

• Prior to collecting sexual orientation & gender identity data, health care institutions should develop and make available educational materials for both patients and staff which explain why collecting this information is important and that this information remains confidential
  – *Sample forms available at [www.medschool.vanderbilt.edu/lgbti](http://www.medschool.vanderbilt.edu/lgbti)*
Acknowledgements

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lgbti.health@vanderbilt.edu
http://www.medschool.vanderbilt.edu/lgbti