**COVID-19 Evidence Accelerator Collaborative**

**Lab Meeting 48**

*Thursday, January 20th, 2022, 3:00 - 4:00 pm ET*

Call Summary

## Overview of Lab Meeting 48

Lab Meeting 48 focused on the importance of capturing sexual orientation and gender identity (SOGI) in real-world data and how it can help inform understanding of sex and gender-related health disparities. First, Dr. Chloe E. Bird of the RAND Corporation discussed how doubling investment in women-focused clinical research would positively impact health outcomes and result in large societal savings. Next, Dr. Jeff Brown of TriNetX, Dr. Sean Cahill of the Fenway Institute, Dr. Ulka Campbell of Aetion, and Dr. Mark Schmidt of Kaiser Permanente had a discussion on what changes can be made in capturing SOGI data to improve our understanding of the impact of these differences on health outcomes.

## The Return on Investing in Women's Health Research

*Dr. Chloe E. Bird, PhD, RAND Corporation*

**Representation of Women in Clinical Research**

- Clinical research tends to focus more on men than on women – historically, women have been excluded from investigational trials to avoid complications with pregnancy and potential for hormonal differences to impact results.
- Even when women are included in clinical research there is not always an analysis dedicated to examining sex differences.
- This lack of representation has real world implications (e.g., we know heart attack symptoms differ for women, and women also have higher one-year mortality after a heart attack). Need to study these differences to understand and address varying outcomes.

**Impact of Alzheimer's Disease (AD) & Alzheimer's Related Dementia (ARD) on Women**

- AD/ARD has a significant impact on women and society as a whole:
    - Women are twice as likely to get dementia than men
    - By 2050, 12.7 million people will be living with AD
    - In 2021 the societal cost of AD/ARD was estimated to be $355 billion
    - Additional costs for unpaid caregivers (60% of whom are women) who lose wages when they quit work to be a caregiver
- Some existing policies require reporting of sex/gender in clinical research, some requiring analyses by sex – still many studies do not include an analysis based on sex leaving questions unanswered

**Investing in Women-Focused AD/ARD Research**

- Examined the extent to which increased investment in women's health research in four disease areas has an impact on individual and societal outcomes.

- Estimate the impact of a one-time doubling of investment in women-focuses research on outcomes 10-30 years later: **Health improvements from research** – decreased AD/ARD, slowed disease progression, improved health-related quality of life
- **Impact of health improvements** – more life years, fewer years living with AD, more quality-adjusted life years, fewer years of lost productivity for informal unpaid caregivers
- **Impact on costs** – fewer nursing home years, other health care costs
  - Key assumptions
    - Assumed every $1 invested in women's health research would benefit both sexes
    - Based calculation of informal caregivers' lost wages on earnings for non-Hispanic white men – leaves open a future where there is pay equity
    - NIH budget for AD/ARD – $2.4 Billion, $288 Million on projects focused on women (12%)

**Results**
- Even based on the most conservative scenario calculated, doubling the one-time investment in women-focused AD/ARD research results in 224% return on investment:
  - **Healthier lives** – ~4,000 more years of life, ~6000 fewer years of disease
  - **Improved health-related quality of life** – ~3600 fewer years in nursing homes, ~16k more quality-adjusted life years
  - **Substantial societal savings** – $369 million savings in nursing home costs, lower health care spending
- Doubling the one-time investment in women-focused research in other disease areas showed even greater ROI: 9500% ROI for coronary artery disease, 174000% ROI for rheumatoid arthritis

**Conclusions**
- **Large returns on investment** – even with the smallest of health improvement assumptions
  - These results can aid decision making by funders to support efficient resource allocation
- **Societal impacts** – lowering prevalence of AD/ARD adds years of life and years without disease, leading to reduced health care spending
- **Sex and gender data reporting and analysis is needed** – need to understand these differences interact with other demographic differences (race, ethnicity, etc.)

**Panel Discussion on Sex/ Gender Identity/ Sexual Orientation Data – Exploring what, why, and how**
*Dr. Jeff Brown, TriNetX; Dr. Sean Cahill, Fenway Institute; Dr. Ulka Campbell, Aetion; & Dr. Mark Schmidt, Kaiser Permanente*

**Sexual Orientation and Gender Identity (SOGI) Data Critically Needed for Health Equity**
*Dr. Sean Cahill*
- LGBTQIA+ people experience higher rates of cardiovascular disease (CVD) risk factors (mental distress, lifetime depression diagnosis, smoking), myocardial infarction (MI), diabetes, obesity, and substance use
- These risk factors often intersect/interact with racial/ethnic and other health disparities
  - Black and Hispanic gay and bisexual men and transgender women at higher risk for HIV

- o Lesbian and bi women may have higher rates of ovarian, breast, and cervical cancer, but are less likely to receive a mammogram or Pap test; this is also true of mostly heterosexual Black and Latina women, so the intersections of these populations are a priority for prevention and screening
  - o Rural LGBT people seldom or never disclose their SOGI
- SOGI data are needed to be able to document the full extent of health disparities
  - o Important for population health management, clinical decision support, to inform preventive screening
  - o Included in Meaningful Use (now called Promoting Interoperability) and Interoperability Standards Advisory since 2015/2016, US Core Data for Interoperability v2 in 2021
  - o There are acceptable ways of asking SOGI questions, and 90% of patients understand why these data are needed and are not offended by being asked about their SOGI
- COVID laid bare racial/ethnic health disparities, systemic problems in nursing homes and long-term care, and exposed surveillance gaps including the collection of SOGI data.
  - o Data show LGBT+ people are probably more likely to become infected (for example twice as likely to work in front line jobs like retail and food services, more likely to have risk factors like obesity, diabetes, or risk factors like smoking and vaping, that can cause people to develop complications from COVID-19, require hospitalization).
  - o Still no federal guidance on collecting SOGI data, five states & DC do some collection but no reporting
  - o Federal and state level surveillance/data reporting systems should integrate the collection/analysis of SOGI in COVID-19 testing, care and vaccination, and more generally make SOGI data collection standard in health care and disease surveillance

**Discussion**

**What progress has been made on improving collection of SOGI data?**

**Mark** – Collection of SOGI data has improved more in community healthcare settings, less progress in integrated health systems. Early on SOGI data were very poorly collected and could not be used for broad population-based assessments. Even with efforts such as the healthcare systems research network working to incorporate SOGI data collection of is still widely variable. We need a better understanding of how these data are captured – at one point in time or multiple instances? Is it intended to capture changes over time or just capturing it in different ways?

**How does the progress in capturing these data translate to data analytics?**

**Ulka** – The way "sex" is captured in EHR data is less "conscious" than other questions. How was the question asked? Was the question intending to ask about gender or sex – these terms are often used interchangeably when they are distinct. There is a need to be more conscious about how SOGI questions are being asked – data scientists need to be able to look at a SOGI data point and know exactly what was being asked rather than assuming whether the question asked about gender or sex.

**Jeff** – Frequently a data model will include the term "gender" when it is intended to mean sex. Language is important when thinking about the collection of SOGI data and incorporating changes in big data models. Several health systems have a module for SOGI data, but not all sites are populating them with these data. If there is nowhere to put SOGI data in these models then data just sits in health systems,

but if it is not being captured consistently by health systems it cannot be modeled. The time variation in captures of SOGI is also challenging. If gender is being captured and there is a time-element, it must be modeled differently than sex. Important to do the work to understand how these data are being captured.

**What is the business case for capturing SOGI data?**

**Sean** – When you ask these questions in an affirming way and explain to patients why you are asking them, it creates an environment of tolerance and inclusion for all community members. Important to collect the data and use it, but also important to send a message of tolerance and inclusion. Benefit goes far beyond the data point.