Using Data Effectively to Advance Health Equity

Sara Rainer
Project Director
Kimberly Philips, PhD
Project Director
NH Disability & Public Health Project

Trinidad Tellez, MD
Director
Amy Parece-Grogan, MEd
Cultural & Linguistic Competence Coordinator
NH Office of Health Equity

Team Up, Take Action: Partnering for Health Equity
November 15, 2017
Objectives

Following this session, participants will be able to do the following:

• Define key terms related to health equity
• Describe barriers to effective use of data
• Discuss strategies and best practices in using data to promote health equity
Public health is...

“...what we, as a society, do collectively to assure the conditions in which people can be healthy”

(IOM, 1988)

• Whether in the health, healthcare, human, social service, or other domain
Public health is...

“...what we, as a society, do collectively to assure the conditions in which people can be healthy”

(IOM, 1988)

income, education, payer type, geography, race/ethnicity, language, country of origin, body type, physical or cognitive ability, religion, sexual orientation, gender identity, etc.
NH is Healthy!

NH is Healthy!

Opportunity measures poverty, housing affordability and equality for women, minorities and people with disabilities.

Does this resonate with our experience?
Does this resonate with our experience?

http://www.countyhealthrankings.org/app/new-hampshire/2017/overview
<table>
<thead>
<tr>
<th>Disparities</th>
<th>Inequities</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions” (NIH, 1999)</td>
<td>“Differences in health that are unnecessary, avoidable, unfair and unjust” (Whitehead, 1992)</td>
</tr>
<tr>
<td></td>
<td>“systematic, socially produced (and therefore modifiable) and unfair” (Whitehead &amp; Dahlgren, 2006)</td>
</tr>
</tbody>
</table>
Health Equity is…

The “attainment of the highest level of health for all people”

Healthy People 2020

The “assurance of the conditions of optimal health for all people”

Dr. Camara Jones, CDC, APHA
Health Equity is…

The “attainment of the highest level of health for all people”

Healthy People 2020

The “assurance of the conditions of optimal health for all people”

Dr. Camara Jones, CDC, APHA

“Health equity is not an outcome, but a process – and one that requires vigilance to sustain”

Dr. Camara Jones, CDC, APHA
Role of Data in Advancing (Health) Equity

Start with identifying and addressing disparities
Consider…

• How many people with disabilities do you serve?

• What proportion of your clients/patients need American Sign Language or other communication access when using your services? How many of them get that regularly?

• Do people with mobility limitations use the tobacco quitline as successfully as people without disabilities?

• How do colorectal cancer screening rates in your patient panel vary by population group?

• What proportion of the African American/PWD/LGBT patients with diabetes in your practice receive optimal care and their diabetes is well-controlled?
Data Matters!

“We can not manage what we can not measure.”

Kindig, University of Wisconsin School of Medicine
Data is Essential!

- Identify / understand existing health disparities and inequities
  - Access, Use and Outcomes
  - Social Determinants of Health
- More objectively assess community needs
- More effectively plan programs and service interventions that would address the identified needs
- Raise awareness more broadly to rally support & resources for change
- Prioritize intervention strategies
- Monitor effectiveness of strategies deployed
Example

Promoting Breastfeeding in Massachusetts
Percent of Mothers Breastfeeding
Massachusetts

State: 70%
Target: 75%
Percent of Mothers Breastfeeding by Race/Ethnicity, Massachusetts

- Asian: 77%
- Hispanic: 71%
- State: 70%
- White, Non-Hispanic: 70%
- Black, Non-Hispanic: 68%

DATA TO UNDERSTAND HEALTH INEQUITIES IN NH

Diabetes
Example: Diabetes

People who have diabetes are at higher risk of serious health complications:

- **BLINDNESS**
- **KIDNEY FAILURE**
- **HEART DISEASE**
- **STROKE**
- **LOSS OF TOES, FEET, OR LEGS**

Risk of death for adults with diabetes is **50% HIGHER** than for adults without diabetes.
Example: Diabetes

- Diabetes is well understood with clear guidelines for improved:
  - prevention
  - diagnosis
  - care/treatment
  - control/management
  - prevention of long-term complications
Age-Adjusted Prevalence of Diagnosed Diabetes Among US Adults

2014

US Total = 8.5%

## U.S. Prevalence Adults with Diabetes by Race/Ethnicity and Disability

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2014 Percent</th>
<th>2014 Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
<td>7.3</td>
<td>1</td>
</tr>
<tr>
<td>Black / African American</td>
<td>13.4</td>
<td>1.8</td>
</tr>
<tr>
<td>American Indian / Native American</td>
<td>17.6</td>
<td>2.4</td>
</tr>
<tr>
<td>Asian</td>
<td>7.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>12.2</td>
<td>1.7</td>
</tr>
<tr>
<td>Native Hawaiian &amp; Pacific Islanders</td>
<td>17.6</td>
<td>2.4</td>
</tr>
</tbody>
</table>

2013 Percent

<table>
<thead>
<tr>
<th>Disability Status</th>
<th>2013 Percent</th>
<th>2013 Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Disability</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Persons with Disabilities</td>
<td>20</td>
<td>3.33</td>
</tr>
</tbody>
</table>


https://drive.google.com/file/d/0BxNlb__OgMsZZDVVEN3djNG1Jcnc/view
How about here in NH?

Let’s check out WISDOM!
WISDOM - https://wisdom.dhhs.nh.gov
Diabetes Prevalence NH Adults by Age

Diabetes prevalence (adults)
Percent of adults who have diabetes: 2014
State: New Hampshire
Both genders
Both genders, all ages
95%CI

Estimated percent of population

18 to 24
25 to 34
35 to 44
45 to 54
55 to 64
65 or older

Age group

Note: * State rate is computed with CDC ranked weight and may not be feasible to compare with sub-state regions.
Source: wisdom.dhhs.nh.gov
Diabetes Prevalence NH Adults by Sex

Diabetes prevalence (adults)
Percent of adults who have diabetes; 2014
State: New Hampshire

Female  Male  --- Female, all ages  --- Male, all ages  | 95%CI

30.0
25.0
20.0
15.0
10.0
5.0
0.0

18 to 24  25 to 34  35 to 44  45 to 54  55 to 64  65 or older

Estimated percent of population

Note: * State rate is computed with CDC ranked weight and may not be feasible to compare with sub-state regions.
Source: wisdom.dhhs.nh.gov
Diabetes Prevalence NH Adults by Disability Status
Diabetes Prevalence NH Adults by Race / Ethnicity
What if there is no data?
WHAT IS ESSENTIAL?
To our data collection for disparities identification efforts?
Data Standards
Activity & Dialogue

Think, pair, share...
STANDARDS / BEST PRACTICES
OMB Standards

ETHNICITY QUESTION:
• Do you consider yourself Hispanic or Latino?
  • Yes
  • No

RACE QUESTION:
• Which category(ies) best describes your race?
  (Select one or more)
  • American Indian or Alaska Native
  • Asian
  • Black or African American
  • Native Hawaiian or Other Pacific Islander
  • White

OMB Standards

DISABILITY STATUS:

• Please check one of the boxes below:
  • Yes, I have a disability (or previously had a disability)
  • No, I don’t have a disability
  • I don’t wish to answer

### Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status

#### I and II. Race and Ethnicity

**Ethnicity Data Standard**  
Are you Hispanic, Latino/a, or Spanish origin  
- a. No, not of Hispanic, Latino/a, or Spanish origin  
- b. Yes, Mexican, Mexican American, Chicana/o  
- c. Yes, Puerto Rican  
- d. Yes, Cuban  
- e. Yes, another Hispanic, Latino, or Spanish origin  

**Categories**  
These categories roll-up to the Hispanic or Latino category of the OMB standard.

#### III. Sex

**Sex Data Standard**  
What is your sex?  
- a. Male  
- b. Female

#### IV. Primary Language

**Data Standard for Primary Language**  
How well do you speak English? (5 years old or older)  
- a. ___ Very well  
- b. ___ Well  
- c. ___ Not well  
- d. ___ Not at all

**Data Collection for Language Spoken (Optional)**

1. Do you speak a language other than English at home? (5 years old or older)  
   - a. ___ Yes  
   - b. ___ No  

   For persons speaking a language other than English (answering yes to the question above):  
   2. What is this language? (5 years old or older)  
      - a. ___ Spanish  
      - b. ___ Other Language (Identify)

#### V. Disability Status

**Data Standard for Disability Status**

1. Are you deaf or do you have serious difficulty hearing?  
   - a. ___ Yes  
   - b. ___ No  

2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?  
   - a. ___ Yes  
   - b. ___ No

3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)  
   - a. ___ Yes  
   - b. ___ No  

4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)  
   - a. ___ Yes  
   - b. ___ No  

5. Do you have difficulty dressing or bathing? (5 years old or older)  
   - a. ___ Yes  
   - b. ___ No

6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (15 years old or older)  
   - a. ___ Yes  
   - b. ___ No
Best Practices for SOGI

Gender Identity & Sexual Orientation

1. What sex were you assigned at birth, on your original birth certificate?
   - Female
   - Male

2. What is your current gender identity? (Check all that apply)
   - Female
   - Male
   - Trans female / Trans woman
   - Trans male / Trans man
   - Genderqueer / Gender non-conforming
   - Different identity (please state): ______

3. Do you think of yourself as:
   - Bisexual
   - Lesbian or Gay
   - Straight
   - Something else
   - Don’t know
DATA STRATEGIES
Improving Data Collection

- Advocate for subpopulation identifiers
- Work with WISDOM
- Partner with public health programs & initiatives
Example: Quitline

• Adults with cognitive limitations are significantly more likely to smoke (52%) than adults without cognitive limitations (32%) (BRFSS, 2015)
• Difficult to distinguish between behavioral health and intellectual disability
Example: Quitline

1. Serious difficulty walking or climbing stairs?
2. Condition that makes it difficult in general for you to learn (e.g., ADHD, dyslexia)?
3. Developmental disability or disorder (e.g., Down syndrome, autism)?
Example: Quitline

<table>
<thead>
<tr>
<th>Self-Reported Impairment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty climbing stairs</td>
<td>35 (30%)</td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>15 (13%)</td>
</tr>
<tr>
<td>Developmental disability</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>13 (11%)</td>
</tr>
</tbody>
</table>

Total # of individuals completing an intake: 115
Example: Medicaid Claims

- NH is one of six states with CDC funding specifically to use Medicaid claims data to identify people with IDD in order to:
  - Estimate prevalence
  - Examine healthcare utilization & cost
  - Look for inequalities related to quality of care
- Planned intervention
Effectively Using Data We Do Have

- Strategic planning
- Evidence-based action
- Research to practice
Example: NHCDD Strategic Plan

- DPH used Medicaid data to investigate health outcomes among people with intellectual and developmental disabilities (IDD). Based on these analyses, the NHCDD elected to focus their 5-year plan on health promotion efforts for people with IDD in the North Country.
Example: Fit Squad

- People with IDD experience higher rates of obesity, and are less likely to be physically active and less likely to consume fruits and vegetables.
Example: **Fit Squad**

- Partnered with Dartmouth & a local area agency as they are working to adapt the InSHAPE® evidence-based health & wellness program
- DPH’s role: evaluating pilot of the adapted program
Example: CCC – Equity Work Group

- IOD Kim & Sara
- DHHS BCCP & Karla Armenti
- Office of Health Equity
- Innovative approach to “finding” some of the people missed by existing data sources
- Employment as a key social determinant of health
Example: Suicide Prevention

Both the Bhutanese and LGBTQ communities experience higher rates of suicide.
Example: Health Equity Dashboard
Example: **REaL Data Work Group**

Increase the capacity in NH for the collection of high quality Race, Ethnicity and Language (REaL) data across all systems at the state and local level to identify disparities and promote utilization of data to inform improvements, policies and procedures.

www.equitynh.org
SHARING DATA FINDINGS
Importance of Dissemination

• Raise awareness
• Rally support
• Promote policy options
• Encourage evidence-based interventions
• Community-engaged data interpretation
WHEN IT COMES TO BREAST & CERVICAL CANCER:

Be your own advocate...it could save your life.

What we tell ourselves...  
"It won't happen to me."

THE REALITY...

Among women, breast cancer is the second leading cause of death.

THE GOOD NEWS...

Breast & cervical cancer screening saves lives.
Cancer screenings can find cancer earlier when it is easier to treat.

FREE screenings available!  
free pop tests & mammograms.

Go to www.gencare.org to find out where to call for free screenings.

1 in 8 women  
will be diagnosed with breast cancer.

Cervical cancer is the most common cancer in women under 35.

Screenings offered near you.  
31 locations in NH

To schedule your free screening, call: 603.271.4886

*Free pop tests in women 31-64 and free mammograms to women 55-64. Free screenings cover women who are uninsured, underinsured, and meet low income criteria. Talk with your provider about when you should begin getting screened for breast or cervical cancer.

When you go to the hospital, 
1 de cada 8 mujeres
serán diagnosticadas con cáncer de seno (mama).

CUANDO SE TRATA DE EL CÁNCER DE SENO (MAMA) Y CUELLO UTERINO:

Sea su propio defensor...podría salvar su vida.

Lo que nos desempeña a como las mujeres.
"Estoy no se va a suceder a mi"

LA REALIDAD...

Entre las mujeres, el cáncer de seno (mama) es la Segunda causa principal de muerte.

LAS BUENAS NOTICIAS...

Las pruebas de detección de cáncer de seno (mama) y cuello uterino salvan vidas.
Las pruebas de detección de cáncer pueden encontrar el cáncer más temprano cuando es más fácil de tratar.

1 de cada 8 mujeres
son diagnosticados con cáncer de seno (mama).

El cáncer de cuello uterino es el tipo más común de cáncer en las mujeres menores de 35 años.

Las pruebas de detección se ofrecen cerca de usted.
31 lugares en NH

Para programar su prueba de detección gratuita, llame al: 603.271.4886

*Pruebas de detección gratuitas a las mujeres de 21-64 y mammogramas gratuitos a mujeres de 55-64. Las pruebas de detección gratuitas cubren mujeres que no tienen seguro médico, el seguro médico no cubre las pruebas de detección y cupón es valido para los pruebas de detección gratuitas.

¡Las pruebas de detección son GRATIS!

Pruebas de Pop y mamografías gratis*

Visit www.gencare.org para aprender más sobre las pruebas de detección gratuitas.

¡GRATIS!

¡Cerca de USTED!
2017 New Hampshire Disability & Public Health Report
Health Disparities: NH Adults with Mobility & Cognitive Limitations

Social Determinants of Health
An individual’s socio-economic environment, such as educational attainment, employment status, and income, strongly affects health behaviors and health outcomes. NH adults with mobility and/or cognitive limitations have lower educational attainment, lower annual incomes, and are less likely to be employed.

- Mobility & Cognitive
  - Less than high school diploma: 29%
  - Not currently employed: 72%
  - Annual income less than $15,000: 32%

- Mobility Only
  - Less than high school diploma: 16%
  - Not currently employed: 66%
  - Annual income less than $15,000: 16%

- Cognitive Only
  - Less than high school diploma: 15%
  - Not currently employed: 85%
  - Annual income less than $15,000: 17%

- Neither Disability
  - Less than high school diploma: 7%
  - Not currently employed: 33%
  - Annual income less than $15,000: 4%

Health Behaviors
NH adults with mobility and/or cognitive limitations experience differences in healthy lifestyle behaviors and are less likely to meet daily recommendations for physical activity and less likely to eat fruits and vegetables.

- Insufficient daily physical activity: 54%
- Consumers fruit & vegetables less than once a day: 30%

Employment & Cognitive Disabilities

Health Outcomes
NH adults with mobility and/or cognitive limitations are more likely to self-report their health as “fair or poor.” Also, NH adults with mobility limitations are more likely to be obese.

- “Fair or Poor” Health: 71%
- Obese: 47%

* Asterisks indicate a statistically significant difference compared to "Neither Disability."
New England Regional Health Equity Council & REPORT
Small Group Activity

• Review the data you have been provided
• Your task is to conceptualize a 1-2 page data brief
• Please do the following:
  • Generate the headline
  • Succinctly state the problem
  • Describe how you will summarize the evidence (e.g., table, graph, visual you will use)
  • Offer recommendations

• Keep in mind the following:
  • Who is your audience?
  • What are you asking them to do?
  • How will you disseminate?
MAKING FINDINGS ACCESSIBLE
Understanding Accessibility

• Design for diversity
• Easy to read or understand
• Alternative formats
**Introduction**

Breast cancer is the most common type of cancer and the second leading cause of cancer-related deaths among women in the United States. Each year, about 210,000 women are diagnosed with breast cancer, and nearly 41,000 women die from the disease. Breast cancer survivors are among the most prevalent cancer survivors. According to a recent estimate, about 22% (or 2.9 million women) of the 13.7 million cancer survivors were breast cancer survivors. By 2022, the number of female breast cancer survivors is expected to increase to 3.7 million.

Overall incidence and mortality rates of breast cancer have been declining at a rate of approximately 2% per year since 1996, likely the result of widespread screening and earlier detection via mammograms and improved therapies. However, evidence suggests that African American women suffer disproportionately from breast cancer mortality. African American women diagnosed with breast cancer are 40% more likely to die from the disease than white women (32.0 vs. 22.8/100,000) and are less likely to survive 5 years after diagnosis (77% vs. 90%). Whitman et al. recently published that African American women die from breast cancer at a higher rate (range 24%-109%) in many urban centers across the country, leading to the excess mortality compared to white women.

Death from breast cancer can be reduced substantially if the cancer is discovered at an early stage. Clinical trials have demonstrated that mammography is the most effective method for detecting these early malignancies and reducing deaths. Breast cancer deaths can be reduced through increased adherence to recommendations for regular mammography screening. The recent decrease in deaths from breast cancer in white women is attributed to greater use of breast cancer screening in regular medical care. However, deaths due to breast cancer in African American women have not decreased to the same extent, in part because of later stages at diagnosis and delayed treatment. Results from some national surveys show mammography screening prevalence among African American women to be equal to that of white women, although low-income women and women with little education are less likely to have had a timely mammogram. Given their greater prevalence for late stage diagnoses and higher mortality, African American women should be encouraged to have timely and regular mammograms.

---

**ACCESSING CARE**

Here are some tips to prepare for a successful mammogram.

**Before the Mammogram**

Describe any accommodations you may need, so the health care staff can be prepared to help you. Will you need assistance with:

- Completing forms?
- Undressing from the waist up?
- Holding still in a position?
- Sitting up without support?
- Lifting your arms?
**People First Language**

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: “a person who ...”, “a person with ...” or, “person who has...”

Here are suggestions on how to communicate with and about people with disabilities.

<table>
<thead>
<tr>
<th>People First Language</th>
<th>Language to Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with a disability</td>
<td>The disabled, handicapped</td>
</tr>
<tr>
<td>Person without a disability</td>
<td>Normal person, healthy person</td>
</tr>
<tr>
<td>Person with an intellectual, cognitive, developmental disability</td>
<td>Retarded, slow, simple, moronic, defective or retarded, afflicted, special person</td>
</tr>
<tr>
<td>Person with an emotional or behavioral disability, person with a mental health or a psychiatric disability</td>
<td>Insane, crazy, psycho, maniac, nuts</td>
</tr>
<tr>
<td>Person who is hard of hearing</td>
<td>Hearing impaired, suffers a hearing loss</td>
</tr>
<tr>
<td>Person who is deaf</td>
<td>Deaf and dumb, mute</td>
</tr>
<tr>
<td>Person who is blind/visually impaired</td>
<td>The blind</td>
</tr>
<tr>
<td>Person who has a communication disorder, is unable to speak, or uses a device to speak</td>
<td>Mute, dumb</td>
</tr>
<tr>
<td>Person who uses a wheelchair</td>
<td>Confined or restricted to a wheelchair, wheelchair bound</td>
</tr>
</tbody>
</table>
Web Accessibility Resources

• Web Accessibility Initiative
  http://www.w3.org/WAI/

• Testing for access
  www.wave.webaim.org
IN CONCLUSION....
Objectives

• Define key terms related to health equity
• Describe barriers to effective use of data
• Discuss strategies and best practices in using data to promote health equity
NH Disability & Public Health Project

Sara Rainer
sara.rainer@unh.edu
(603) 862 4320 | Relay 711
http://nhdisabilityhealth.org/

Kimberly Philips, PhD
kimberly.phillips@unh.edu

NH Office of Health Equity

Trinidad Tellez, MD
Director
trinidad.tellez@dhhs.nh.gov

Amy Parece-Grogan, MEd
Cultural & Linguistic Competence Coordinator
amy.parece-grogan@dhhs.nh.gov