



Mapping and Visualizing Demographic Information in Structured and Unstructured Clinical Data

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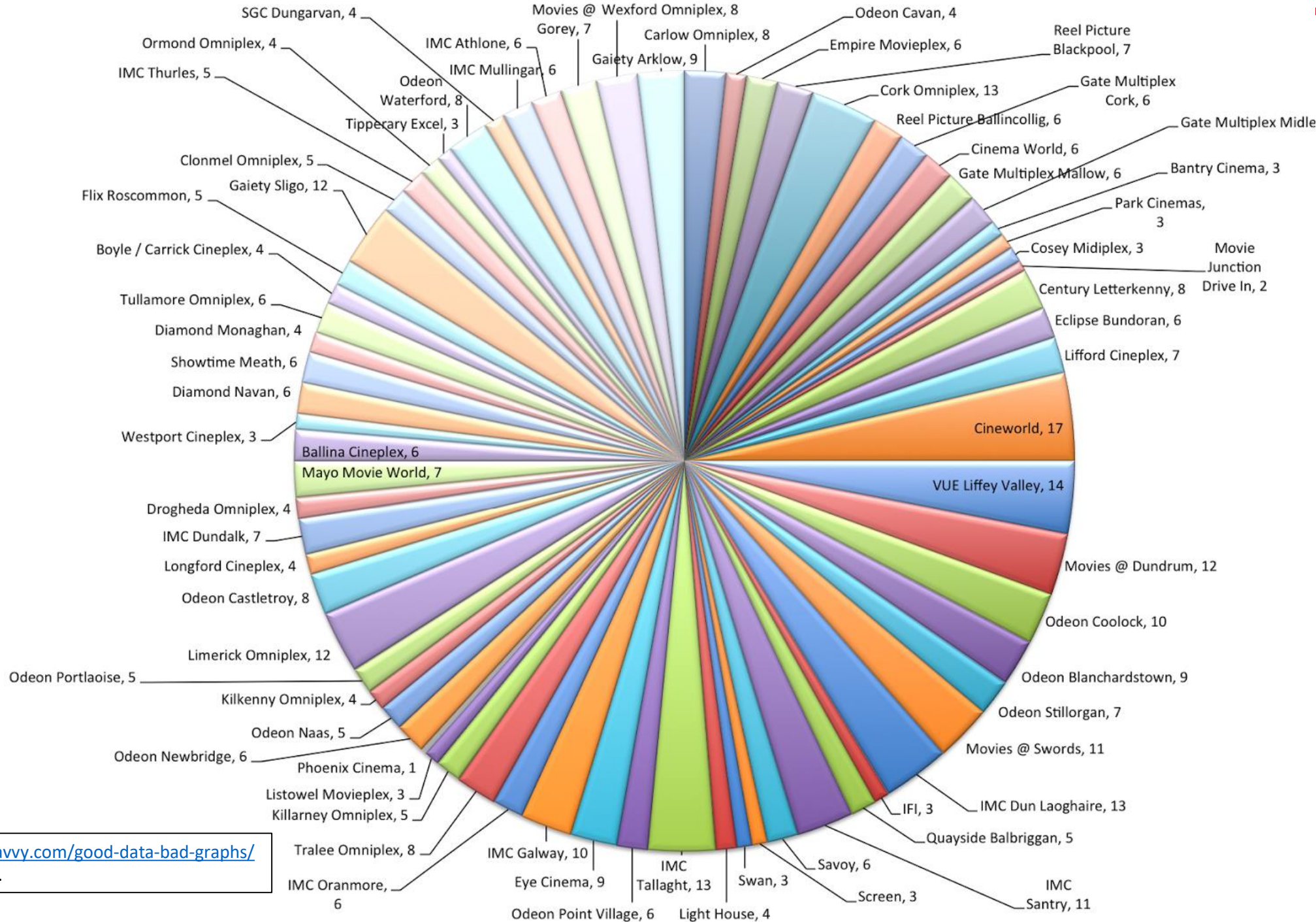
- We have no conflicts of interest to disclose.

Overview

- Problem
- Design
- Literature-based Example
- Data-driven Example
- Summary and Future Directions

Playing Both Sides: Visualizing Structured and Unstructured Data

- Why do we care?
 - Two patients with same diagnosis might require vastly different treatment regimens or prognoses
 - Such determinants might be in clinical notes
- Why record structured and unstructured data?
 - Medicine is often unpredictable
 - Doctors are human
- Why do we visualize?
 - Easier to process
 - Can be processed more quickly
 - Summarizes large volumes of data

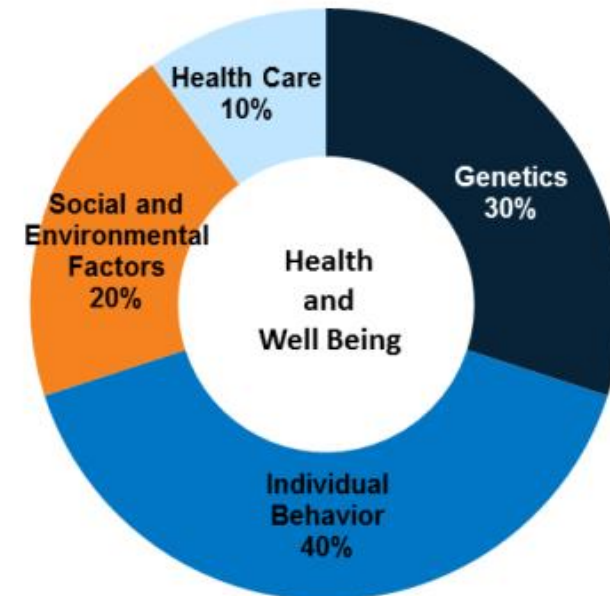


See <https://methodsavvy.com/good-data-bad-graphs/> for more information.

Social Determinants of Health (SDOH)

- Conditions and circumstances that affect health risks and outcomes
- Examples include:
 - Income level
 - Educational opportunities
 - Gender inequity
 - Racial segregation
 - Availability of transportation

Figure 2
Impact of Different Factors on Risk of Premature Death



SOURCE: Schroeder, SA. (2007). We Can Do Better — Improving the Health of the American People. *NEJM*. 357:1221-8.

Gender Identity as SDOH

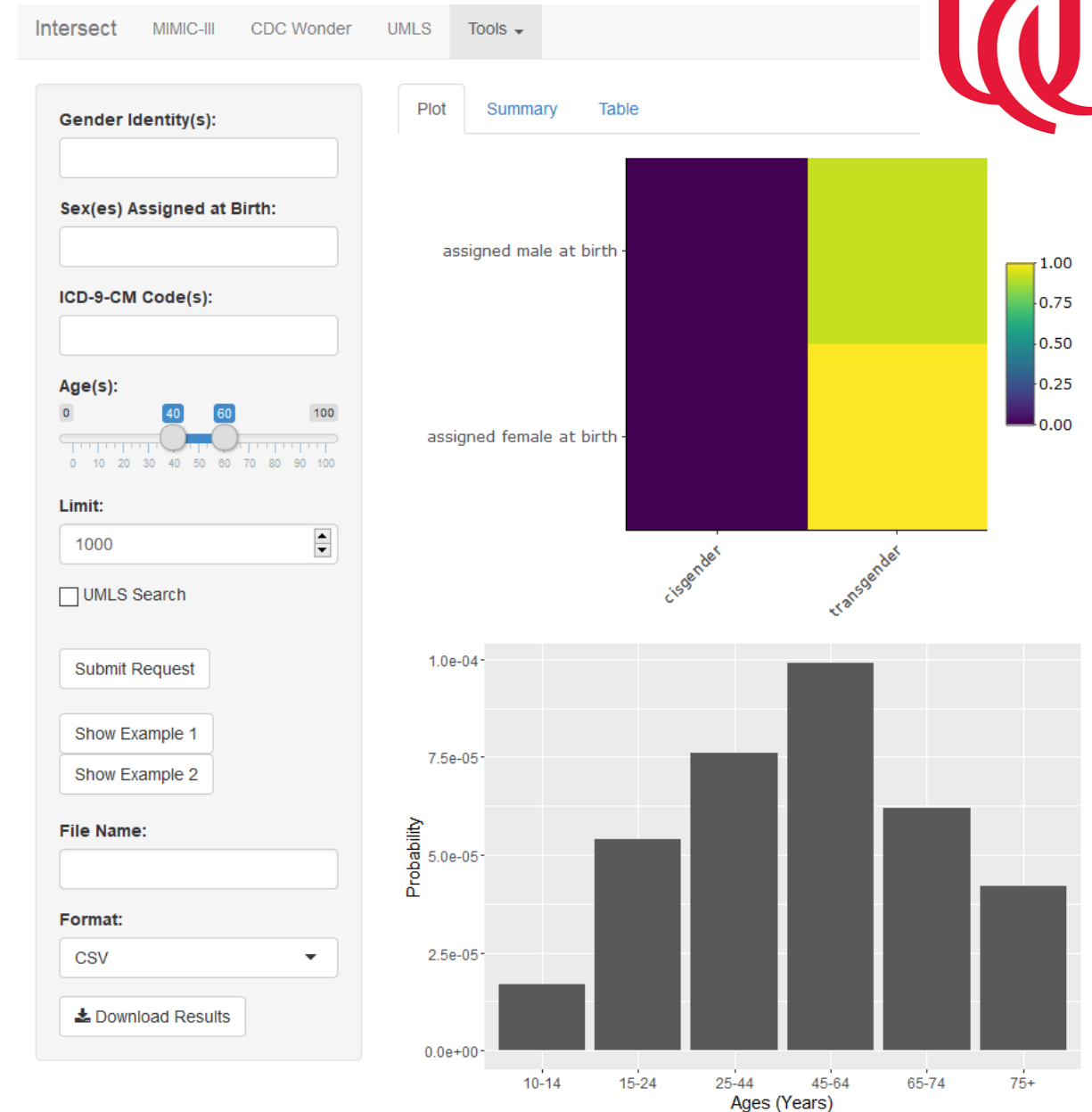
- Gender Identity
 - “One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.”
(Human Rights Campaign)
- ~1.4 million Americans identify as transgender
- Cisgender = Not transgender
- Known health concerns include social stigma, abuse, harassment, neglect, physical/sexual violence, STI prevalence, substance misuse, depression, anxiety, suicidal ideation, etc.
- We considered breast cancer, suicidal ideation, and depression before deciding to focus on suicide and depression

A quick note...

- Note that this demo only includes transgender men and women and not non-binary or third gendered people (e.g. *hijra*, *māhū*) simply because the data sources utilized do not contain any such individuals.
- Recording other gendered people in electronic health records (EHRs) should be a priority moving forward as it has been shown that different risk factors are associated with non-binary people versus binary transgender people.

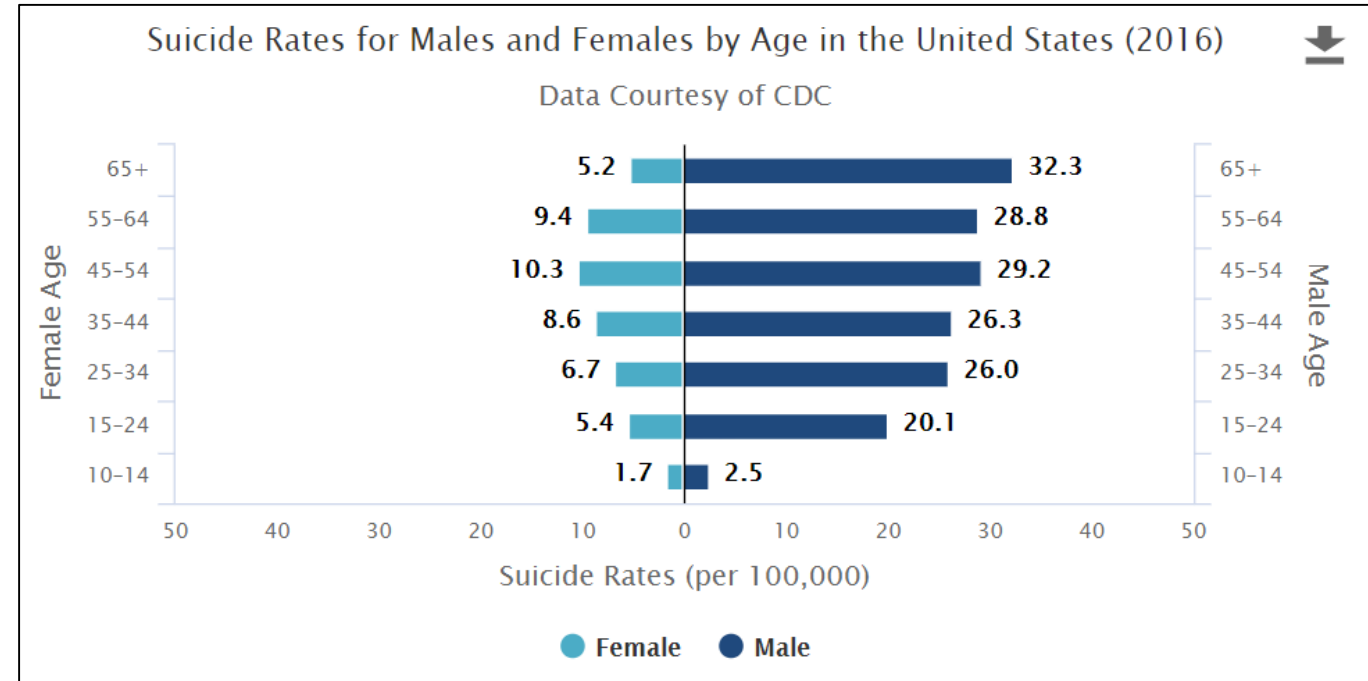
Constructing an Interface

- Text entry/dropdown for gender identity, sex assigned at birth, ICD-9 codes
- Age range slider
- Limit for quicker load times
- UMLS search uses terminology mappings from ICD-9 to other terminologies
- Can download as file in multiple formats



Literature-Based Example: Suicide

- Suicide rate among women was highest for ages 45-54 (10.3 per 100,000)
- Suicide rate among men with highest for ages 65+ (32.3 per 100,000)
- National Transgender Discrimination Survey found 46% of trans men had attempted suicide and 42% of trans women had attempted suicide.
- How does this affect prognosis and treatment?



Statistics and image derived from
<https://www.sciencedirect.com/science/article/pii/S0924933817318357>,
<https://www.verywellmind.com/men-and-suicide-2328492>,
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4539867>,
<https://www.suicideinfo.ca/resource/women-and-suicide/>.

Gender Identity(s):

Sex(es) Assigned at Birth:

ICD-9-CM Code(s):

Age(s):



Limit:

UMLS Search

Submit Request

Show Example 1

Show Example 2

Show Example 3

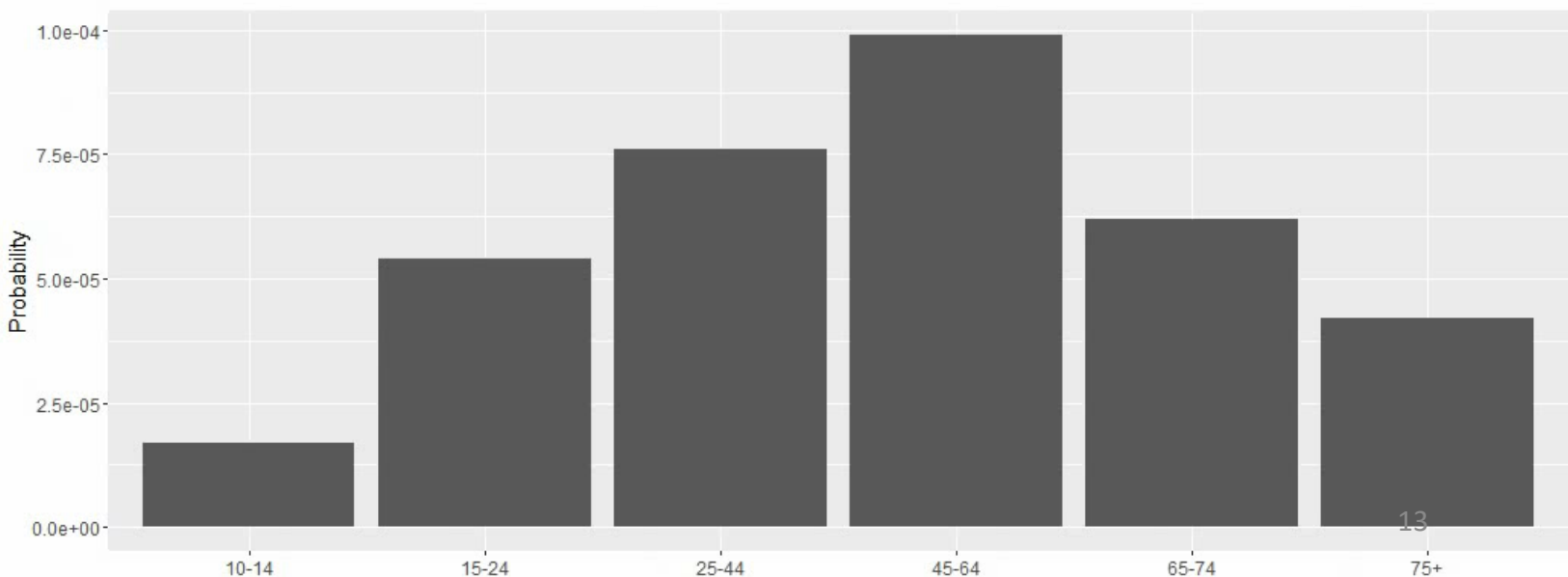
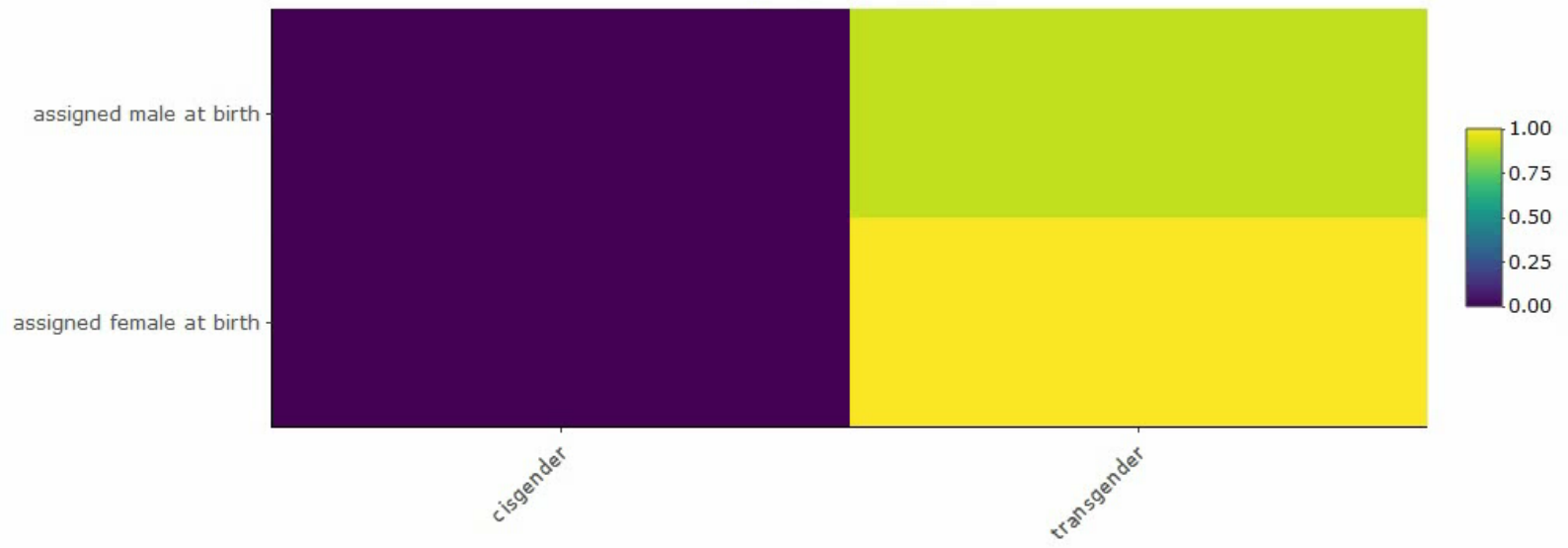
File Name:

Format:

Download Results

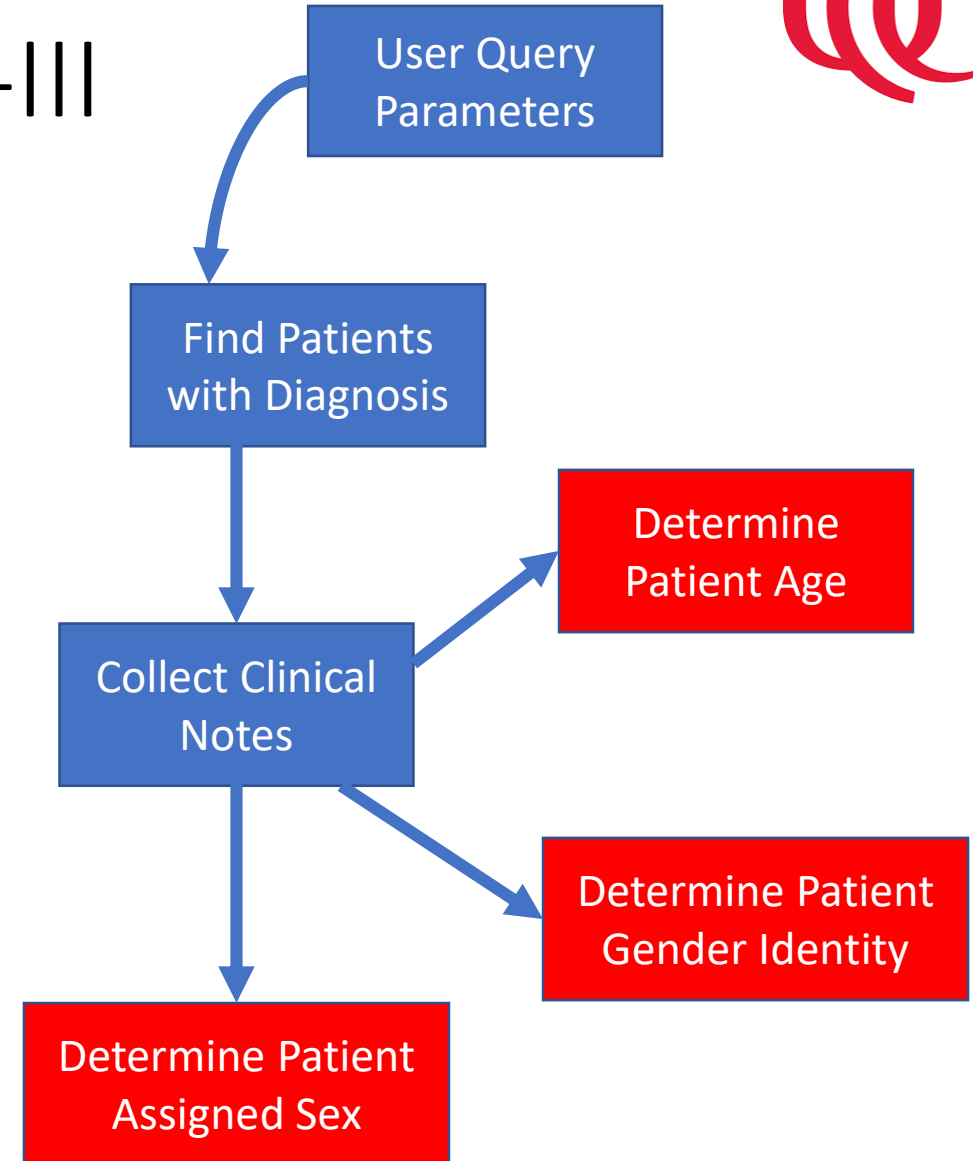
Plot Summary Table

Suicide (Example 3)



Real World Example: MIMIC-III

- Medical Information Mart for Intensive Care
- Patients admitted to critical care units at large tertiary care hospital
- Includes components of electronic health records (EHRs):
 - Diagnostic Codes (Structured)
 - Clinical Notes (Unstructured)



Case Study with MIMIC-III: Depression

- MIMIC-III includes 6 individuals with transgender-related ICD-9 codes
- 13 trans individuals are detectable using terminology derived from the Gender, Sex, and Sexual Orientation (GSSO) ontology.
- Most common diagnoses were mental health related (depression, ADHD) and substance abuse related (tobacco, cocaine, etc.)
- How does this affect prognosis and treatment?

| | MIMIC-III | UC Health |
|---------------------------------------|-----------|-----------|
| Date of Birth | No | Yes |
| Diagnosis | Yes | Yes |
| Keywords for Deriving Gender Identity | Yes | Yes |

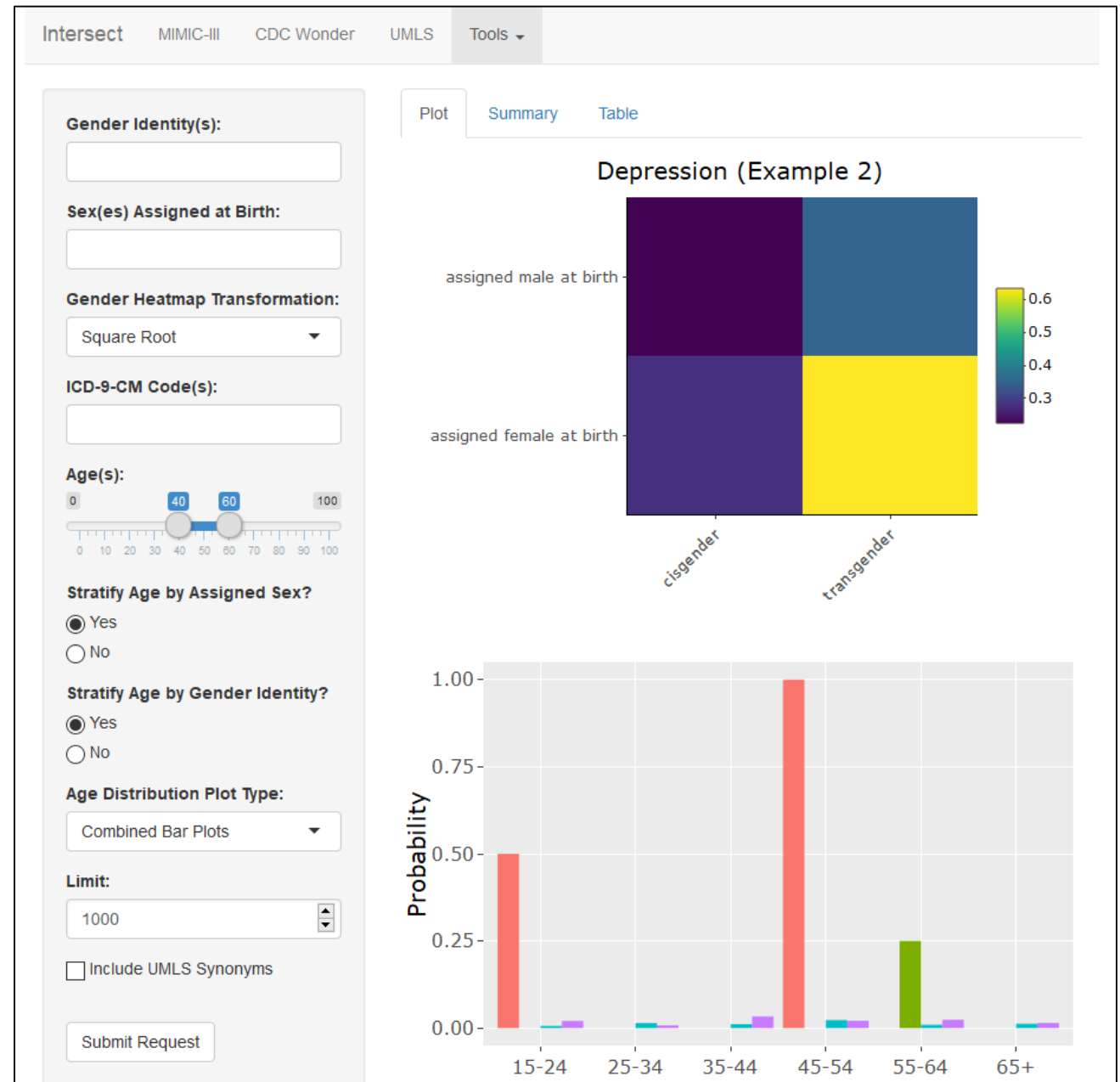
Gender Identity(s):**Sex(es) Assigned at Birth:****ICD-9-CM Code(s):****Age(s):****Limit:** UMLS Search**File Name:****Format:**[Plot](#)[Summary](#)[Table](#)

Literature Versus MIMIC-III

- Mental Health America notes that women experience depression at roughly twice the rate of men
 - MIMIC-III data: 1.56 times depressive cisgender women (1,604 / 20,392) versus depressive cisgender men (1,319 / 26,115)
- Reisner et al. (2015) noted that transgender youth are four times more likely to experience depression than their cisgender peers
 - MIMIC-III data contained 3.67 times depressive transgender people (3 / 13) versus cisgender people (2,923 / 46,507)

User Feedback and Suggestions

- The challenge of leveraging population health and individual health care
- Additional customization options such as scaling and classification by multiple factors (gender and age, for instance)
 - Added seven transformations and two stratification methods following this comment



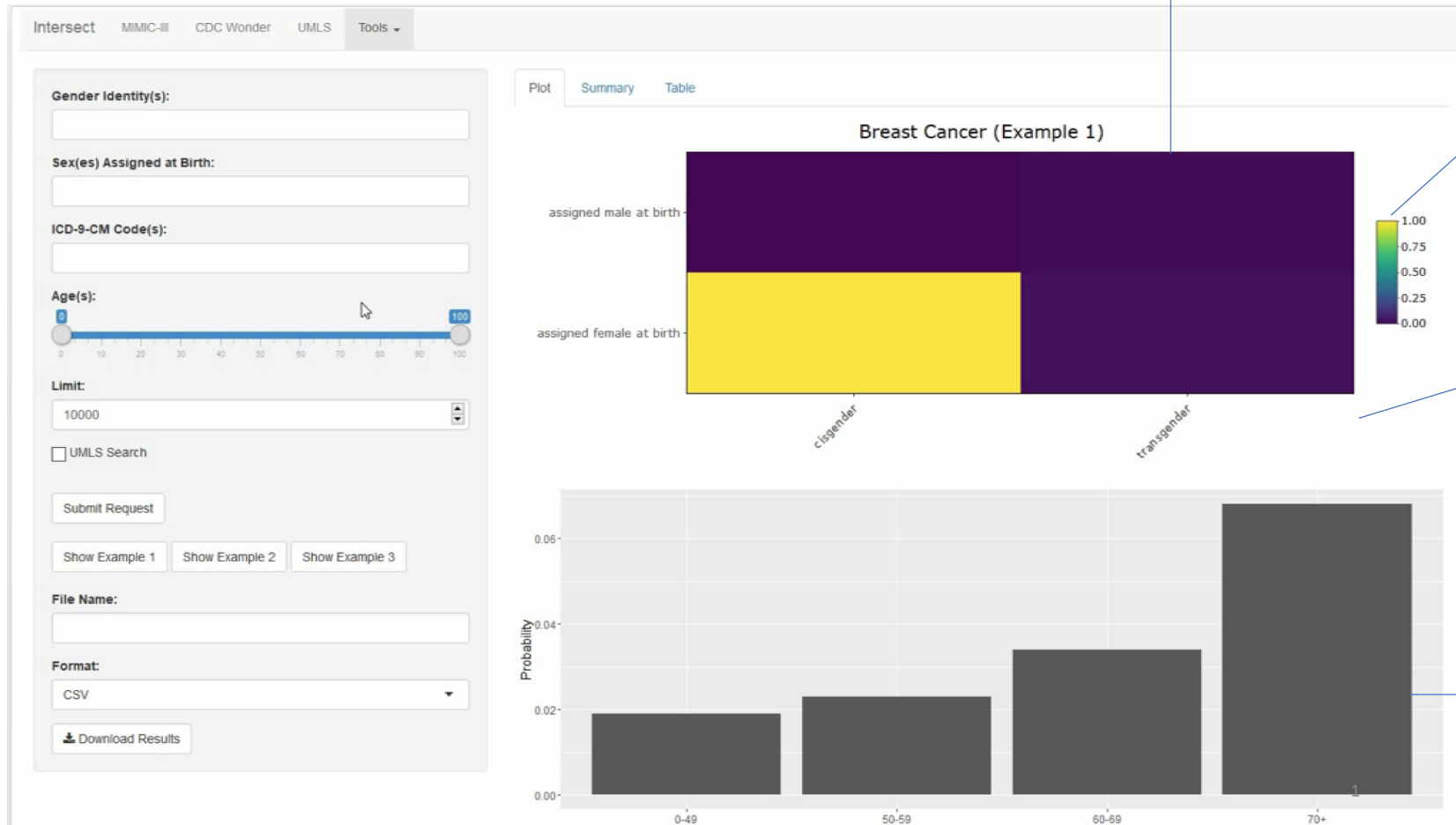
User Feedback and Suggestions

Difficult to distinguish four groups due to imbalanced data

Heatmap colors chosen for the visually impaired, but not considered intuitive

Lack of direct relationship between the heatmap and the age distribution

Age distribution doesn't allow comparison between gender identities or assigned sexes



Mockup of Changes

Gender Identity(s):

Sex(es) Assigned at Birth:

ICD-9-CM Code(s):

Age(s):



Limit:

UMLS Search

Submit Request

Show Example 1

Show Example 2

Show Example 3

File Name:

Format:

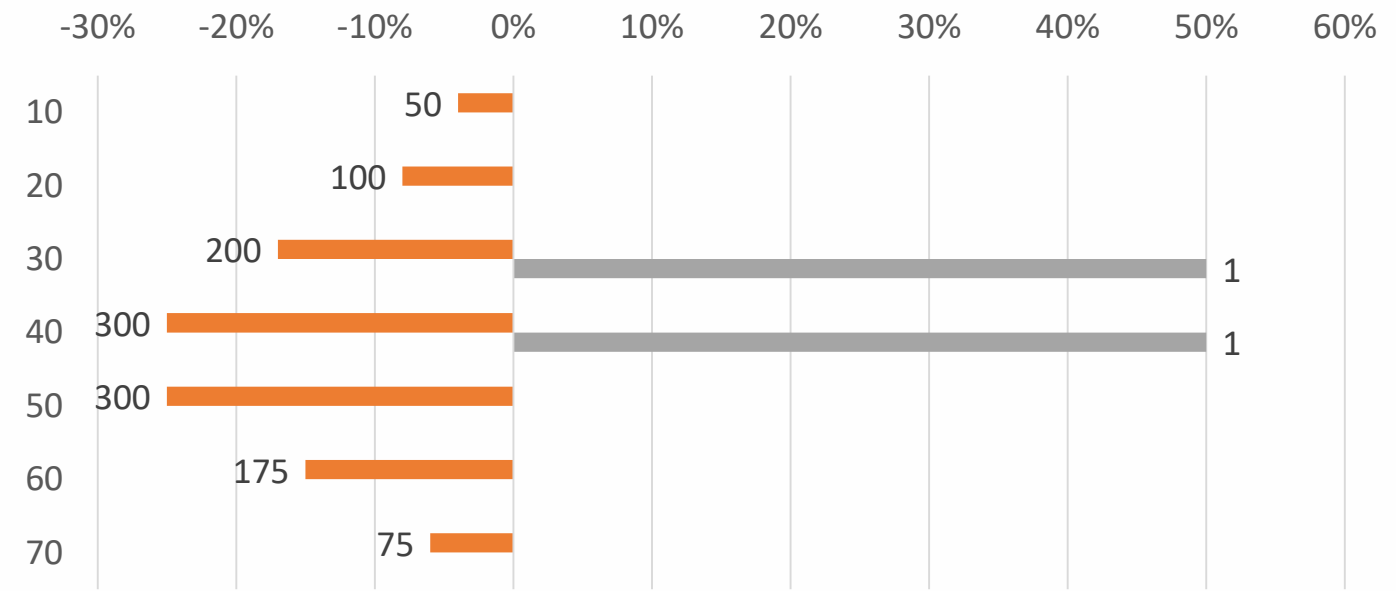
Download Results

Plot Summary Table

| | | |
|---------------------|------------|-----------|
| Men (1202) | 1200 | 2 |
| Women (1701) | 1700 | 1 |
| | Cis (2900) | Trans (3) |

| Scale | Adjusted |
|-------|----------|
| 1,700 | 64 |
| 1,200 | 59 |
| 2 | 12 |
| 1 | 10 |

Men (Cis vs Trans)



Gender Identity(s):

Sex(es) Assigned at Birth:

ICD-9-CM Code(s):

Age(s):



Limit:

UMLS Search

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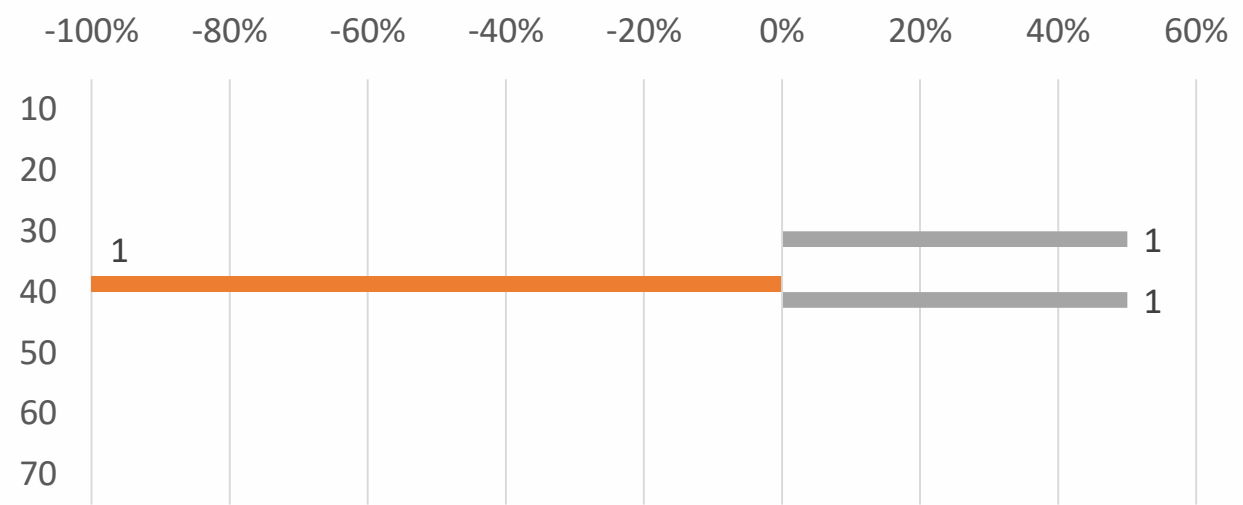
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| Scale | Adjusted |
|-------|----------|
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| 2 | 12 |
| 1 | 10 |

Trans (Men vs Women)



Future Directions

- **Data:** Discussing recruitment of trans* people and analyzing provided clinical notes
 - Larger sample size needed in order to calculate false positive rates
- **Ontology:** Refining the ontology used for identifying trans* individuals and terminology
 - Gender, Sex, and Sexual Orientation ontology, available for comment here: <https://github.com/Superraptor/GSSO>
- **System:** Moving away from R Shiny toward a more customizable system like Django or Ruby on Rails
- **Interface:** Prioritization of user feedback
- **Other:** Working on implementing links to other datasets (such as the CDC Wonder API)
 - Public health link

References

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