Addressing Challenges in Health Equity Research
Methods and Tools to Support Actionable Health Equity Research for Life Science

Kati Copley-Merriman
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Shahnaz Khan
Ashley Davis
Jarrod Bullard
Introduction

Kati Copley-Merriman

Vice President, Market Access and Outcomes Strategy
Health Equity

“The attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes.”

*Centers for Medicare & Medicaid Services (Strategic Plan for Health Equity)*

Addresses the needs of underserved populations

Longstanding systemic inequities have undermined the physical, social, economic, and emotional health of historically underserved populations

- People of color
- Older persons
- People with disabilities
- LGBTQ+ people
- Women
- People living in rural areas
- People who have low or no income
- Underinsured people

“Lack of adequate representation threatens the integrity of science.” —Bibbins-Domingo and Helman (2022)

LGBTQ+ = lesbian, gay, bisexual, transgender, queer, and other identities not covered by the other 5 listed.
Social Determinants of Health (SDOH)

**Education access and quality**
- Educational support and intervention
- Financial assistance for college and other education costs

**Economic stability**
- Employment opportunities
- High-quality childcare
- Availability and access to affordable food, housing, healthcare, and education

**Healthcare access and quality**
- Screening and preventive care
- Medications
- Health insurance
- High-quality providers

**Neighborhood and lived environments**
- Safe neighborhood and workplace
- Clean air and water

**Social and community context**
Family, friends, colleagues, and community
Intersectionality in Health Equity Research

- Multiple social identities and systems of oppression intersect to shape people’s healthcare access and outcomes.
  - More intersections = more barriers to health equity
- Examples for contextualizing inequities and the impact of multiple determinants
  - Developing interventions to reduce diabetes rates among rural Native American adults aged 65+ years
  - Improving COVID vaccination uptake among Latinx immigrant patients in low-income communities
  - Reducing HIV rates among Black transgender women
Learning Objectives

- Examine the socioeconomic drivers of health disparities and populations affected
- Explore methods such as literature reviews and distributional cost-effectiveness analysis
- Understand why health equity is crucial for the biomedical sciences
- Review social determinants data and tools to leverage in health equity research: Introducing RTI Rarity™
A Framework for Understanding Why Health Equity Is Important to the Pharmaceutical Industry

Chad Downey
Associate Director, Project and Proposal Operations
Institutional Drivers of Inequity

Inequities are fueled by systems, regardless of people’s culture or behavior.

- Racism, discrimination, and bias, both structural and interpersonal,\(^1\) are fundamental drivers of health inequities, health disparities, and disease.

- In the US, people of color (Black, Hispanic, and Native Americans, in particular) experience higher rates of poor health and disease for diabetes, hypertension, obesity, asthma, and heart disease, when compared with White individuals. The life expectancy of Black and African American individuals is 4 years less than that of White Americans.\(^2\)

- These health disparities underscore the urgent need to address systemic racism as a root cause of racial and ethnic health inequities and a core element of our public health efforts.

Sources: \(^1\) Jones (2000); \(^2\) National Center for Health Statistics (2023).
Why Health Equity Is Important to the Pharmaceutical Industry

**Improved social impact and brand identity**
- Build trust with historically marginalized communities
- Positively impact brand and product recognition

**Greater consumer benefit**
- Increase medication adherence
- Improve patient outcomes
- Reduce healthcare costs

**Alignment with government and regulatory bodies**
- Legislation
- Regulation
Why Health Equity Is Important to the Pharmaceutical Industry

**Societal awareness of health disparities**
- Disproportionate impacts from events like the COVID-19 pandemic create opportunities for leadership

**Innovation**
- Better understand unmet needs of all patients
- Develop more accessible and beneficial products

**Collaboration or competition with other industries**
- Technology
- Consumer goods
Types of Health Equity Projects: Literature Reviews

Shahnaz Khan
Vice President, Market Access and Outcomes Strategy
Literature Reviews: Framing the Research Question

Types of literature reviews:

- Systematic lit review
- Comprehensive review
- Umbrella review
- Structured lit review
- Literature review
- Evidence review
- Narrative review
- Targeted lit review

Potential topics to be explored via literature reviews:

What disparities exist in terms of **screening or diagnostic** practices?

- Participation, barriers, and facilitators of cancer screening among LGBTQ+ populations: A review of the literature

What disparities exist in terms of **rates/occurrence** of a particular condition?


What disparities exist in terms of **access to care, specialists, or treatments** for patients with a particular condition?

- Access to Care Matters: Remote Health Care Needs During COVID-19

What disparities exist in terms of **outcomes** related to a particular condition or based on a particular treatment?

- Disparities in COVID-19 Outcomes by Race, Ethnicity, and Socioeconomic Status: A Systematic Review and Meta-analysis

What disparities exist in terms of **representation in clinical trials** for a particular condition?

- Sex, Racial, and Ethnic Representation in COVID-19 Clinical Trials: A Systematic Review and Meta-analysis

The power of knowledge. The value of understanding.
Literature Reviews of Health Equity Topics: Source of Information

- **Published Literature**
  - Use standard databases (PubMed, Embase, etc.) to identify studies published within the relevant period, as well as meeting abstracts if indexed

- **Society or Government Websites**
  - WHO, CDC, NIH, CMS, ACS, AHA, ACIP

- **Clinical Trials Registries**
  - ClinicalTrials.gov (US) or ISRCTN (UK)

- **Professional Congresses**
  - ISPOR, AMCP, disease-specific meetings

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**MeSH Terms**

- **Healthcare Disparities** (Introduced 2008)
  Differences in access to or availability of medical facilities and services.

- **Health Status Disparities** (Introduced 2023)
  Variation in rates of disease occurrence and disabilities between population groups defined by various factors, including socioeconomic status, age, ethnicity, economic resources, gender, geography, or similar measures.

- **Socioeconomic Disparities in Health** (Introduced 2022)
  Differences in health based on socioeconomic status.

- **Health Inequities** (Introduced 2008)
  Differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work, and age.

- **Minority Health** (Introduced 2008)
  The concept covering the physical and mental conditions of members of historically marginalized groups.
Work with an experienced library scientist

Focus on specific research questions

Include a broad set of terms related to disparities and SDOH
Reporting and Gap Analysis

- What is known and what remains unanswered?
- What additional questions need to be asked?
- What additional studies need to be conducted?
- How can results be used to affect patients and address disparities?
Objective: To assess disparities in RSV diagnosis, risk factors, and outcomes using data from the published literature and gray literature.

From 701 studies identified, 15 met the inclusion criteria based on study objectives.

Results: Available evidence indicated disparities in diagnosis by race, ethnicity, and SDOH; disparities in risk factors that led to those diagnoses; and disparities in outcomes following the diagnoses (e.g., higher rates of emergency department visits, hospitalization, and mortality).
Types of Health Equity Projects: Distributional Cost-Effectiveness Analysis

Ashley Davis
Senior Director, Health Economics
## Cost-Effectiveness Analysis, an Economic Model

### What it does
- Compares the costs and benefits of an intervention, treatment, or policy with alternative options (e.g., assessing the impact of RSV vaccination)

### Why it is useful
- Allows decision-makers to compare options by considering the associated health and cost outcomes at the population level
- Possible incremental outcomes may include the incremental cost per QALY gained, life-year gained, or case averted

### What are its limitations from a health equity lens?
- Does not consider how an intervention’s benefits are distributed throughout a population:
  - Who benefits most from this intervention?
  - Do underserved groups experience health gains too?
  - Does this intervention increase or decrease existing health disparities?

QALY = quality-adjusted life-year.
### Distributional Cost-Effectiveness Analysis

<table>
<thead>
<tr>
<th>What it does</th>
<th>Why it is useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Expands traditional cost-effectiveness modeling approaches to incorporate fairness in the distribution of costs and effects as well as efficiency/equity tradeoffs for the indicated population</td>
<td>• Provides traditional cost-effectiveness outcomes in the context of whether the intervention also improves or worsens health equity</td>
</tr>
<tr>
<td></td>
<td>• Accounts for disparate effects in an intervention’s uptake and accessibility, efficacy, and opportunity costs within the population</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>When it is used</th>
</tr>
</thead>
<tbody>
<tr>
<td>• When gains do not match needs (e.g., a group with high need receives an intervention at a lower rate or with less effectiveness)</td>
</tr>
<tr>
<td>• When you anticipate that equity will be an important factor for a decision-maker</td>
</tr>
</tbody>
</table>

Source: ISPOR (2023).
Describe current health inequities
Estimate current health metrics for equity-relevant groups (e.g., quality-adjusted life expectancy) based on literature and publicly available data.

Identify potential causes of disparate impact
Consider mechanisms by which disparate impacts may occur (e.g., differences in uptake, adherence, effectiveness across equity groups).

Estimate health outcomes
Calculate the distribution of health benefits and opportunity costs from the intervention, noting which equity-relevant groups incur gains/losses.

Evaluate overall equity impact
Compare the intervention’s equity impact with decision-makers’ attitudes toward reducing inequality. Adjust for value judgements and analyze tradeoffs.

Sources: Asaria et al. (2015); ISPOR (2023).
Cost-effectiveness outcomes can be evaluated across a spectrum of socioeconomic subgroups.

Overall health impacts and cost-effectiveness outcomes are considered in parallel with health equity.

- **I. Win-Win**: Cost-effective, improves equity
- **II. Win-Lose**: Cost-effective, harms equity
- **III. Lose-Lose**: Not cost-effective, harms equity
- **IV. Lose-Win**: Not cost-effective, improves equity

IMDQ = Index of Multiple Deprivation Quintile.
Sources: Asaria et al. (2015); ISPOR (2023).
Kowal et al. (2023)

- **Objective:** How did Medicare funding of inpatient COVID-19 treatment affect health equity in the US?
- **Equity groups:** 15 equity-relevant groups informed by race/ethnic groups and social vulnerability
- **Health equity metric:** Quality-adjusted life expectancy

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B = Black; H = Hispanic; Q = social vulnerability quintile; W = White.
Source: Kowal et al. (2023).
## Recent Distributional Cost-Effectiveness Analyses in Literature

<table>
<thead>
<tr>
<th>Publication</th>
<th>Country</th>
<th>Disease Area</th>
<th>Intervention</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kowal et al. (2023)</td>
<td>US</td>
<td>COVID</td>
<td>Funding hospitalizations</td>
<td>Analyzed health equity impacts across 15 equity-relevant groups informed by race/ethnic groups and SVI. Accounted for different incidence and mortality across the groups.</td>
</tr>
<tr>
<td>Goshua et al. (2023)</td>
<td>US</td>
<td>Sickle-cell disease</td>
<td>Gene therapy</td>
<td>Analyzed health equity impact on male and female patients with sickle-cell disease to measure how gene therapy could close the gaps in health outcomes between these populations.</td>
</tr>
<tr>
<td>Meunier et al. (2023)</td>
<td>UK</td>
<td>Cancer</td>
<td>Atezolizumab vs. docetaxel and alectinib vs. crizotinib</td>
<td>Analyzed health equity impact across 5 socioeconomic groups, classified using an IMD score that incorporates differences in income, employment, education, health, crime, housing, and living environment.</td>
</tr>
<tr>
<td>Quan et al. (2021)</td>
<td>US</td>
<td>HIV</td>
<td>Equity-focused implementation of MOUD, EMR reminders, rapid testing, and ART case management</td>
<td>Analyzed health impact across racial/ethnic groups, focusing on 3 populations (Black, Hispanic, White) to assess whether an equity-focused implementation approach would lead to an equitable distribution of health benefits.</td>
</tr>
</tbody>
</table>

**ART** = antiretroviral therapy; **EMR** = electronic medical record; **IMD** = Index of Multiple Deprivation; **MOUD** = medication for opioid use disorder; **SVI** = Social Vulnerability Index.
Discussion and Limitations

• Most cost-effectiveness models can be readily adapted to the distributional cost-effectiveness analysis framework to explore health equity questions.

• Evaluating the benefits of new interventions from both cost-effectiveness and health-equity perspectives can lead to more informed healthcare decisions.

• Data availability is the biggest challenge.
  – Can we classify the population into important groups with different social vulnerability?
  – Are clinical trial data and other intervention-related impacts (e.g., uptake, adherence) available to compare differences in outcomes between groups?
  – Can we estimate an appropriate inequality aversion parameter (i.e., do we know how much a decision-maker values reducing health inequality)?
Types of Health Equity Projects: Database Studies

Jarrod Bullard
Senior Research Data Scientist, Health Economics
Database Studies in Pharma Research

Database studies can provide critical real-world evidence (RWE) about pharmaceutical product impact on patient outcomes and how outcomes can vary across populations.

<table>
<thead>
<tr>
<th>Type of analysis</th>
<th>Example study purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>• Determine cost now versus cost then</td>
</tr>
<tr>
<td>Comparative</td>
<td>• Compare costs or outcomes for Medication A vs. Medication B</td>
</tr>
<tr>
<td></td>
<td>• Compare costs or outcomes for Patient Group 1 vs. Patient Group 2</td>
</tr>
<tr>
<td>Outcome</td>
<td>• Determine clinical outcomes</td>
</tr>
<tr>
<td></td>
<td>• Determine economic outcomes</td>
</tr>
<tr>
<td>Pharmaceutical trend</td>
<td>• Provide insight into pharmaceutical prescribing and utilization trends</td>
</tr>
<tr>
<td>Epidemiological</td>
<td>• Gain insight of disease activity and how it effects defined patient populations</td>
</tr>
</tbody>
</table>

Source: Sax (2005).
## Common Types of Databases Used in Health Research

<table>
<thead>
<tr>
<th>Type</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reimbursement and administrative</td>
<td>• Useful for tracking healthcare utilization and costs</td>
<td>• Cost data limited to clinical cost drivers. Does not capture complete cost data</td>
<td>• Medicare</td>
</tr>
<tr>
<td></td>
<td>• Includes any service reimbursed by health insurance</td>
<td>• Must request data and be knowledgeable about the process and standards used in claim submissions</td>
<td>• MarketScan</td>
</tr>
<tr>
<td></td>
<td>• Generally, demographic information</td>
<td>• Usually requires lots of data management</td>
<td></td>
</tr>
<tr>
<td>Disease surveillance</td>
<td>• Captures granular disease-specific data</td>
<td>• Varying amounts of healthcare utilization information</td>
<td>• SEER</td>
</tr>
<tr>
<td></td>
<td>• Captures outcome events</td>
<td>• Limited information on individual characteristics</td>
<td>• SEER-Medicare</td>
</tr>
<tr>
<td>Electronic health records (EHR)</td>
<td>• Good clinical context</td>
<td>• Unstructured data</td>
<td>• EPIC</td>
</tr>
<tr>
<td></td>
<td>• Medical and clinical data</td>
<td>• Lack of consistency/data quality</td>
<td>• Cerner</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• May require manual medical record abstraction</td>
<td></td>
</tr>
<tr>
<td>Patient-reported data</td>
<td>• Patient and/or caregiver outcomes</td>
<td>• Literacy, language barriers can lead to underrepresentation</td>
<td>• MEPS</td>
</tr>
<tr>
<td></td>
<td>• Unique perspective</td>
<td>• Can be lost to follow-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Offers additional information on treatment and outcomes beyond a clinical encounter</td>
<td>• Limited confidence in reporting clinical information and utilization information (recall bias)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Obtaining intended compliance information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

EPIC = European Investigation into Cancer and Nutrition; MEPS = Medical Expenditure Panel Survey; SEER = Surveillance, Epidemiology, and End Results.
Source: Gliklich et al. (2014).
Where to Start

Uncover care gaps and understand the drivers

- **Identify the care gap**
  - E.g., low treatment rates
  - Stratify treatment rates, adherence rates, and outcomes by populations to uncover gaps and disparities

- **Identify the drivers**
  - Is it a socioeconomic issue (income, health literacy, etc.)?
  - Is it a lifestyle issue (physical activity, alcohol consumption, diet, smoking, etc.)?
  - Is it an access to healthcare issue (remote or rural, health provider shortage area, etc.)?
  - Is it a transportation issue?

Area-Level Databases

- Accessing area-level data and analyzing how these data affect treatment and adherence rates by therapeutic area can help to uncover the drivers behind the gaps in care and/or outcomes and where efforts should be prioritized to reach full value.
  
  - Publicly available indices such as the Area Deprivation Index (ADI) and the CDC’s Social Vulnerability Index (SVI) are used extensively to identify and account for SDOH and SES at the area level.

<table>
<thead>
<tr>
<th>Composite measure</th>
<th>SDOH domains</th>
<th>Data source(s)</th>
<th>Variables</th>
<th>Geo level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area Deprivation Index (ADI)</td>
<td>Education, employment, SES, housing, transportation, household composition</td>
<td>American Community Survey</td>
<td>17</td>
<td>Census Block</td>
</tr>
<tr>
<td>Social Vulnerability Index (SVI)</td>
<td>SES, household composition and disability, minority status and language, housing and transportation</td>
<td>American Community Survey</td>
<td>15</td>
<td>Census Block, Tract, ZCTA</td>
</tr>
<tr>
<td>Social Deprivation Index (SDI)</td>
<td>Poverty, education, household composition, housing, transportation, employment</td>
<td>American Community Survey</td>
<td>7</td>
<td>County, Census Tract, ZCTA</td>
</tr>
</tbody>
</table>

SES = socioeconomic status; ZCTA = Zip-Code Tabulation Area.
An SDOH curated data set and tool using random forest models to derive Local Social Inequity (LSI) scores, which predict health outcomes in small geographic areas (Census tracts) using 10 domains of social and behavioral factors.

- 200+ variables from over 40 sources
- Data from 1978 through 2022
- Continually adding new measures
- Automated updates to existing measures
## RTI Rarity Compared With Other Social Risk Indices

<table>
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<td><strong>Area Deprivation Index (ADI)</strong></td>
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<td>7</td>
</tr>
</tbody>
</table>
| **Local Social Inequity (LSI)**  | • Educational attainment  
• Healthcare access, coverage, costs, quality  
• Community health, well-being, healthy behaviors  
• Bias, stress, trauma  
• Justice, crime, incarceration  
• Food security, access to healthy food  
• Poverty, inequality, employment  
• Housing adequacy, crowding, structural health  
• Environmental quality  
• Transportation access, infrastructure, safety | More than 40 federal and private data sources | Over 200  |

### Cross-state average variance explained: life expectancy model

<table>
<thead>
<tr>
<th>Composite measure</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>SOVI</td>
<td>6%</td>
</tr>
<tr>
<td>CHR</td>
<td>9%</td>
</tr>
<tr>
<td>CRE</td>
<td>17%</td>
</tr>
<tr>
<td>ADI</td>
<td>29%</td>
</tr>
<tr>
<td>SVI</td>
<td>30%</td>
</tr>
<tr>
<td>SDI</td>
<td>34%</td>
</tr>
<tr>
<td>YI</td>
<td>35%</td>
</tr>
<tr>
<td>COI</td>
<td>37%</td>
</tr>
<tr>
<td>LSI-LE</td>
<td>70%</td>
</tr>
</tbody>
</table>

CHR = County Health Ranking; COI = Child Opportunity Index; CRE = Commercial Real Estate; LSI-LE = Local Social Inequity-Life Expectancy; SOVI = Social Vulnerability Index; YI = Youth Index.
A Merged Solution: RTI Rarity and RWD

- RTI Rarity provides a composite measure of social risk (LSI) for neighborhoods across the US.
- RWD coupled with RTI Rarity can help uncover nonmedical factors that affect diagnosis, treatment, response, and adherence outcomes across multiple populations and geographies.
- RTI Rarity can also help improve diversity in clinical trials by existing as a tool to identify diverse geographies and neighborhoods across a spectrum of demographic and social factors.

RWD = real-world data.
## What Can RTI Rarity Solve?

### Question of interest

- Where, geographically, are there populations with higher prevalence of diabetes or heart disease?
- What areas should I target for recruiting individuals 65 years of age and older?
- Where are the most racially and ethnically diverse neighborhoods?
- What neighborhoods can be targeted to recruit more members of the LGBTQI+ community in a clinical trial?
The Patient Funnel

**Underdiagnosis/Unengagement**
SES is associated with delayed diagnosis and increased morbidity and mortality from diseases like melanoma and prostate cancer.

**Prescribing Patterns**
Underrepresented racial groups with cancer are less likely to be prescribed opioids for pain. Individuals living in high-poverty areas are more likely to develop persistent use of opioids.

**Medication Adherence**
Food insecurity, housing instability, smoking, educational level, and health literacy are influencing factors associated with medication adherence.

**Source:** https://www.mmitnetwork.com/aishealth/spotlight-on-market-access/pharma-is-stepping-up-focus-on-sdoh-urging-use-of-data-driven-approach.
Systemic inequities have undermined the physical, social, economic, and emotional well-being of historically marginalized communities.

Intersectionality is an essential framework for understanding how parts of one's identity interact with systems of power and oppression to affect their experiences and health outcomes.

A targeted or systematic literature review can serve as an initial step for exploring what is known and unknown about a particular topic related to health equity.

The distributional cost-effectiveness analysis framework expands on traditional cost-effectiveness modeling approaches to explore health equity questions. Considering health equity alongside cost-effectiveness may lead to more-informed healthcare decisions.

Databases commonly used in healthcare and economic research lack data on nonmedical factors that influence outcomes, such as social needs and socioeconomic status.

A combination of RWD and specialized databases capturing social risk and needs data can be used for health equity research to identify historically excluded and underincluded populations.
Thank You!

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