Promoting health disparities research by increasing data readiness

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Project Aims

Informing recommendations for data science to create more relevant and impactful research in health equity. Building upon such work as the Malone-Heckler Report, Institute of Medicine's Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care and the ACA. Encompassing broad areas of study and focus on data science in the three following areas:

- Social determinants of health
- Racial and ethnic minorities
- Sexual and gender minorities

Project Impact

This work stands as:

A call to action for researcher and stakeholder ideas.

The background to implement changes in data collection, advocate for different variables and data elements, and the insight to engage in the health disparities research needed most.

Recommendations for increasing research readiness specifically for health disparities research.

An invitation to engage and interact with the recommendations, the research potential they hold, and how they might be implemented.

Methods

The CRG Project Team implemented a comprehensive and systematic process for gathering, analyzing, and formulating qualitative data into recommendations in three phases:

Phase I - Discovery
4 focus groups with investigators and patients and 13 expert interviews.

Phase II - Compilation and Synthesis
Thematic analysis of focus group and interview data to inform recommendation categories.

Preliminary recommendations drafted based on these data.

Phase III - Curation
Draft recommendations circulated to experts and RIGs for feedback and incorporated into a revised draft. Select RIG members and experts convened to finalize recommendations.

Results: The Recommendations

Patient voice

- Prioritize health information that is collected directly from patients using existing measures.
- Develop text fields and repositories of written and oral patient stories for patients' experiences navigating and receiving healthcare.

Accurate and relevant variables

- Improve the accuracy of basic sociodemographics.
- Integrate a core set of individual-level SDH data.
- Integrate data on food insecurity and housing stability.
- Improve the standardization of behavioral risk and protective factors data.
- Develop data fields unique to rural populations.

Additional data

- Create data fields in the CDM for integration of the data sets such as those listed below.
- Incentivize inclusion and completion of emergency department (ED) and hospital data.

Sustainability

- Envisioning the future of the CDM, data science, and health disparities research in general.

- "Relentless iteration:"
  - - Ever-improving, expanding, an increasingly relevant dataset.
  - - Calling researchers to ask key questions, and push for the data they need.

- Prompting researchers to join together to catalyze the changes needed to move towards health equity.

DISCLOSURES

We have no conflicts to disclose.

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