Collecting Data for Equitable Change

At the request of CRHESI's community partners, this project examines how we collect sociodemographic (SD) data from clients. This process, ultimately aimed at reducing inequities, makes frequent stops along the way to this goal.

CRHESI Research & Action for Health Equity

Western HealthSciences

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- Health inequities can cause disadvantages, worsening health outcomes.
- Data collection and analysis help us to understand barriers, and tailor and improve services and systems.
- Understanding clients' needs equips us to address health inequities and target needs, such as chronic health and disability issues.

Guiding Principles

- Do good work, respect people, enact justice & fairness.
- Consider who owns, has access to and can share data; ensure that individuals, groups & organizations have a say in, and consent to, how their data are used.
- Collecting SD data alone is not enough to reduce inequities: we must focus on addressing the social & structural determinants of health.

Standardizing Data Collection

Key Issue: Incomplete data on race, ethnicity, and other socio demographics means we don't know who we are serving.

Recommendations

- Develop consistent methods with client needs prioritized.
- Ensure data domains are consistent and do not infringe on Human Rights.
- Increase diversity of data collectors.
- Streamline data sharing across agencies.

Organizational Culture

Key Issue: Power imbalances may lead to fear, anxiety, and distrust.

Recommendations

- Implement culturally safe, trauma- & violence-informed approaches, including respectful & inclusive spaces; embed this in mission statements.
- Provide health equity training for all staff, including common language, scripts & case scenarios.
- Ensure the purpose of data collection & usage is clear & transparent.
- Consent should be voluntary & continuous; assure that the withdrawal of consent is not met with negative consequences.
- How data are used, stored, & shared should be clearly communicated.

Collaboration

Key Issue: Lack of resources & funding for effective implementation

Recommendations

- Develop, learn from and build on established and collaborative models.
- Collective action is necessary to reduce structural barriers and increase equity among organizations.

Engage and Protect

Key Issue: Potential for harms, individual- to structural-level

Recommendations

- Engage representative communities, establish Indigenous advisory groups & hold listening sessions.
- Establish standard protocols for secure data handling and security (e.g., encryption & restricting access and audits).
- Create and observe data governance agreements.