Creating Client-Centered & Culturally Responsive Research Sites

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Introduction

• Key Concepts
  – Client-centered approach
  – Cultural competence
  – Cultural responsiveness

• Significance of Self-Assessing Individual & Organizational Level Cultural Responsiveness

• Assessing Your Clinical Research Site
Client-Centered Care

• Giving care that is respectful of and responsive to individual
  – Preferences
  – Needs
  – Values

• Ensuring that patient values guide all clinical decisions

Institute of Medicine, 2010
Culture
Cultural Competence

- Having a system of behaviors, attitudes, policies, and structures that enables people to work effectively across cultures.
Cultural Responsiveness

• Building on the knowledge, experiences, & skills of other people
• Being mindful of the influence your own culture has on your interactions when planning & delivering services
Significance of Self-Assessing Individual & Organizational Level Cultural Responsiveness

• Culture is central to the way we interact with and understand one another

• HIV/AIDS affects everyone, thus we must work collectively in a global community to stop its spread

• Yet, the communities bearing the biggest burden of the HIV have also been afflicted by many intersecting epidemics
Historical trauma maintained by modern systems
Many of us come from a legacy of trauma & resilience

When Mexico sends its people, they’re not sending their best. They’re sending people that have lots of problems, and they’re bringing those problems with us. They’re bringing drugs. They’re bringing crime. They’re rapists. And some, I assume, are good people.

- Donald Trump
US presidential Candidate
Homophobia & Transphobia Amidst Other Issues
### National Transgender Discrimination Survey, 2012

<table>
<thead>
<tr>
<th>Category</th>
<th>General U.S. Population</th>
<th>Overall Transgender Community</th>
<th>Black Transgender Community</th>
<th>Latino/a Transgender Community</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment/Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployment</td>
<td>5.1%</td>
<td>14%</td>
<td>28%</td>
<td>18%</td>
</tr>
<tr>
<td>Underemployment (over-qualified)</td>
<td></td>
<td>44%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household income &lt;$10,000/year</td>
<td>7%</td>
<td>15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Suicide</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attempted Suicide</td>
<td>0.60%</td>
<td>41%</td>
<td>45%</td>
<td>44%</td>
</tr>
<tr>
<td><strong>Housing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homeless</td>
<td>7.4%</td>
<td>19%</td>
<td>41%</td>
<td>29%</td>
</tr>
<tr>
<td><strong>Medical provider/institution Experiences</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Denied equal treatment in a Drs office or hospital</td>
<td>24%</td>
<td>32%</td>
<td>32%</td>
<td>32%</td>
</tr>
<tr>
<td>Experiences of harassment or disrespect in a doctor’s office or hospital</td>
<td>25%</td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
</tr>
<tr>
<td>Experiences of harassment or disrespect in an emergency room (ER)</td>
<td></td>
<td></td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Uninformed providers – having to teach doctors about transgender care</td>
<td></td>
<td></td>
<td>50%</td>
<td></td>
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<tr>
<td><strong>Avoiding/Postponing medical care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postponing care due to discrimination</td>
<td>28%</td>
<td>38%</td>
<td>38%</td>
<td>38%</td>
</tr>
<tr>
<td>Postponing care due to inability to afford it</td>
<td>48%</td>
<td>58%</td>
<td>58%</td>
<td>58%</td>
</tr>
<tr>
<td><strong>Criminal Justice System</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incarceration (lifetime/jailed for any reason)</td>
<td>0.91%</td>
<td>16%</td>
<td>47%</td>
<td>25%</td>
</tr>
<tr>
<td>Harassment by police</td>
<td>22%</td>
<td>38%</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>Physical assault in jail/prison</td>
<td>16%</td>
<td>33%</td>
<td>21%</td>
<td></td>
</tr>
<tr>
<td>Sexual assault in jail/prison</td>
<td>15%</td>
<td>34%</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td><strong>HIV</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV rates</td>
<td>0.60%</td>
<td>2.64%</td>
<td>24.9%</td>
<td>10.9%</td>
</tr>
</tbody>
</table>
Revisiting Cultural Responsiveness

• Another definition
  – Being mindful of how attitudes, norms, policies & practices can **increase quality of services & create better outcomes**

• As we assess ourselves & our organizations
  – **Seek** information learned from underserved communities
  – **Integrate** information learned from underrepresented communities
  – **Transform** systems in collaboration with underserved communities
Assessing Your Clinical Research Site

• Because maintaining a culturally responsive site is an ongoing effort, we should self-assess at multiple levels
  – Education & Engagement
  – Recruitment
  – Inclusion in Materials
  – Organizational Structure
  – Organizational Culture
Assessing Education & Engagement

Self-Assessing

- Who gave input in the development of your programs? How are target communities involved?
- Who is the learner? Who is the teacher? Who is presenting?
- Where do you have events?
- Does you CAB/CAG reflect underserved populations in your area? How are they involved in your events?

Other Assessments

- Survey attendees

Assessing Materials

Inclusion in Materials

• Engage staff and CAB/CAG in
  – Short evaluations of effective messages, images, & mediums of dissemination
  – Focus groups to assess & brainstorm ideas

• Do your materials show populations you want to engage?

• How do you learn about culture relevant to the people to seek to engage? Is that knowledge incorporated into your materials?
Assessing Recruitment

Recruitment

- Periodically look at the demographics of your recruitment data to see where you are reaching & where you are not
  - Where do you recruit?
  - Where are the populations you seek to engage?
  - If they don’t align, why?
- How do you discuss, describe, & dialogue with people who don’t trust medical research?
Assessing Organizational Structure

Organizational Structure
• Asking for gender pronoun(s), pronoun cards
• All staff listing gender pronouns in signatures
• All gender bathrooms
• Diverse staff on both community & clinical teams
• Having & observing non-discrimination policies

Other Assessments
• Survey participants to identify blind spots you may not see
Assessing Organizational Culture

Organizational Structure

• Ensuring that all staff both at your clinical research site & in your building are given tools to be culturally responsive

• Mandated, ongoing training for all CRS & building staff
  – Racial humility
  – Cultural competence
  – Transgender health
  – Gay/bisexual health

• Make a culture of acknowledging one another
Summary

- Assessing both yourself & your organization is an ongoing process
- Cultural is central to how we interact, so we must work to understand the perspectives of people we want to engage
- Seek > Integrate > Transform
Summary of Assessment Tools

• Johari window is a useful tool for blind spots
• Internal, short evaluations with staff & CAG
• Review race, culture, LGBTQ training for CRS & other staff on site
• All gender bathrooms
• Pronoun cards
• Self reflection
References


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