



HPTN

HIV Prevention
Trials Network

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



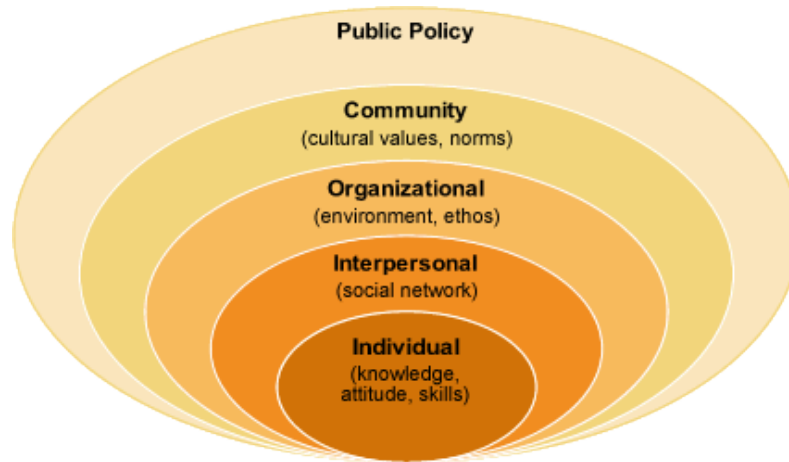
- Giving care that is **respectful of** and **responsive to** individual
 - Preferences
 - Needs
 - Values
- Ensuring that patient values guide all clinical decisions

Culture



Cultural Competence

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



Cultural Responsiveness

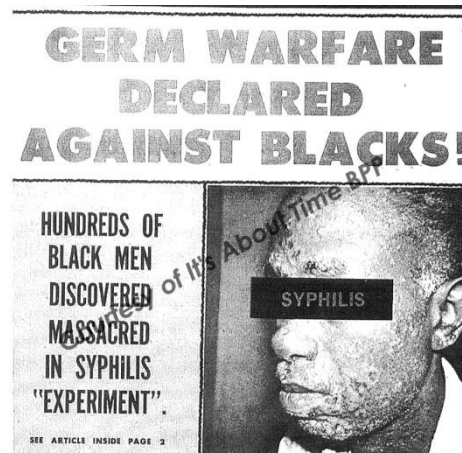
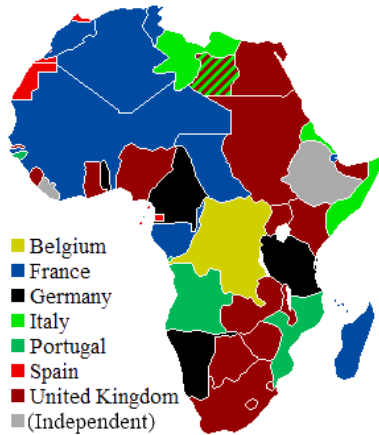
- Building on the knowledge, experiences, & skills of other people
- Being mindful of the influence your own culture has on your interactions when planning & delivering services



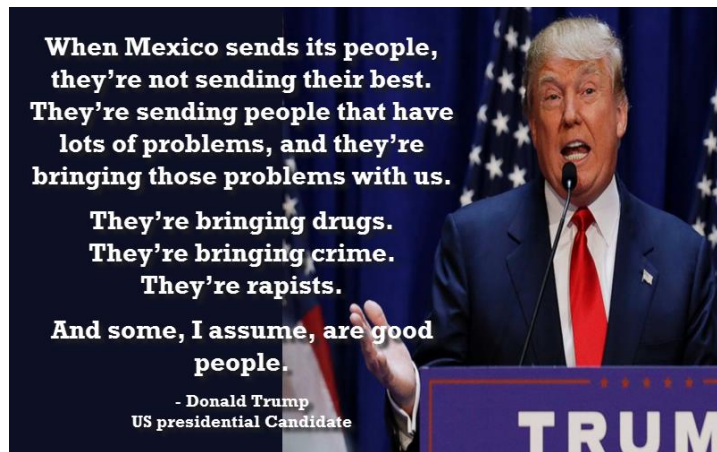
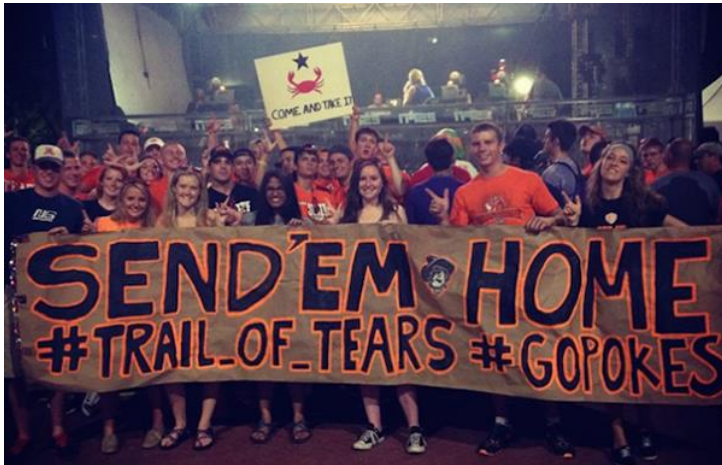
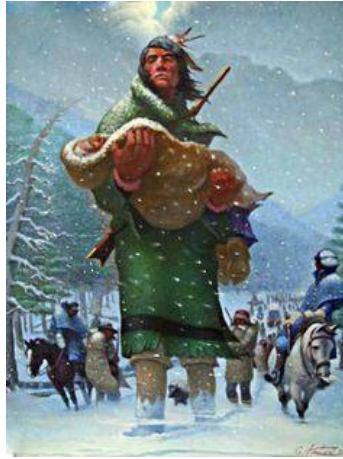
Significance of Self-Assessing Individual & Organizational Level Cultural Responsiveness

- 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



Homophobia & Transphobia Amidst Other Issues



National Transgender Discrimination Survey, 2012

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

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 your CAB/CAG reflect underserved populations in your area? How are they involved in your events?

Other Assessments

- Survey attendees

	Known by Self	Unknown by Self
Known by Others	OPEN ARENA	BLIND SPOT
Unknown by Others	FACADE	UNKNOWN

Luft, J.; Ingham, H. (1955)

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

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