A Guide to Addressing Cultural Competence as a Quality Improvement Issue in HIV Care

K. Clanon, H. Issaq, N. Halloran

Ms. P, a 40 year old African-American woman, is diagnosed with HIV in a community screening program and comes in to the AMC clinic for care. She did not think she was at risk for HIV, and is still unsure about whether the diagnosis was real. On her third visit, her doctor prescribes antiretroviral medications. She doesn’t completely trust her doctor, but doesn’t want to rock the boat, so she keeps quiet about her doubts and accepts the prescription, but does not fill it.

Introduction

Concern about health disparities is intensifying in the HIV treatment community;\textsuperscript{1,2} many studies show troubling differences in important health measures. For example, data presented in 2007 showed African-Americans and Latinos are diagnosed later in disease than whites.\textsuperscript{3} In another large recent study, African-Americans were significantly less likely than whites to be receiving HAART.\textsuperscript{4} A 2006 study showed that African-Americans were less likely to be successful on HAART when they were receiving it; 63% were undetectable after one year of treatment versus 92% of whites.\textsuperscript{5}

In our experience this issue more than any other quality improvement challenge engages people’s attention and passion, but can seem so complex and daunting that it makes them feel helpless to make change. This doesn’t have to be the case; the familiar mechanisms of quality improvement, already in use in Ryan White programs across the nation, offer a practical method for working on health disparities. Quality improvement processes emphasize a system-wide


\textsuperscript{5} Hartzell J, Spooner K, Howard R et al. Race and mental health diagnosis are risk factors for Highly Active Antiretroviral Therapy failure in military cohort despite equal access to care. Journal of Acquired Immune Deficiency Syndrome. 2007; 44(4): 411-416.
approach, use of multidisciplinary teams, steady incremental change, and joint action and accountability in place of finger-pointing. These principles are well-suited to address problems that can seem insurmountable.

Those working in HIV care are used to working with many sensitive issues of identity and culture including race, ethnicity, gender, sexual orientation, and hearing impairment/disabilities. However, data suggest that certain of these differences are more likely to be associated with disparities in outcomes, and we will be focusing on those.

The goal of this document is to give busy, resource-limited programs step-by-step guidance in how to reduce disparities by incorporating cultural competence into their existing performance improvement programs.

The guide also includes specific examples of measures, categorized in several domains (Appendix A), as well as concrete cultural competency resources and organizational assessment tools (Appendix B). Further information and tools can be found on our website at NationalQualityCenter.org.

**Figure 1**

Cultural Competence and Health Disparities

HRSA's Office of Minority Health defines **cultural competence** as:

“A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.”

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**Step One: Get Buy-in**

In every quality management (QM) program there are more opportunities for improvement than energy and time to pursue them. Quality improvement priorities should be data-driven, but often an organization will not commit resources to collecting detailed data until there is a consensus that an issue is worth pursuing. These steps might make your QM committee decide that cultural competence and health disparities are improvement priorities for your program:

- Review the program history and the experiences of the committee members and ask “Should we be concerned?” Programs may decide to work on cultural competence as a result of:
  - **patient complaints** of differential treatment based on race, ethnicity, or language spoken
  - **staff complaints** of culturally-based conflict
  - **concern about mismatches** of staff and clients’ racial or ethnic demographics
  - **differences in retention in care** between different groups
- Break out your clinical quality data by race and ethnicity. The most consistent disparities seem to be in retention, adherence and viral suppression. Do you see indications of disparities in these or any other areas?
- Break out your patient satisfaction survey results. Are there differences in satisfaction in different racial or ethnic groups?
- Survey a sample of patients specifically about the cultural competence of your agency. For example ask: “Do you feel welcome in this clinic or do you feel like an outsider?”
Have you ever felt like you might get better care at your clinic if you were from a different racial or ethnic group?” (See Appendix A outcome measure #19 for more examples.)

- Conduct an assessment of your organization’s level of cultural competence. (See Appendix B for examples of assessments you can use). These organizational assessments reference cultural competence standards of practice similar to the DHHS guidelines we follow in HIV clinical care.

This may be enough to convince your committee and your program. However, if resource concerns make administrators reluctant to take on these challenges, you can refer them to the Federal Standards on Culturally and Linguistically Appropriate Services. Some of the CLAS Standards are mandated for Federal grantees, and because they are linked to receipt of Federal dollars they ensure that every Ryan White-funded grantee has some motivation to focus on cultural competence.

**Step Two: Refine Your Data**

Once you have committed as an organization to incorporating disparities reduction and cultural competence into your quality program, it is time to revisit the data. Data are the cornerstone of quality improvement work, and we know the first stage in any improvement initiative is an ability to defend your data. Make sure you know how and by whom race and ethnicity information are collected at your site. Staff can find it difficult to ask about race, so many organizations rely on staff observation to determine patients’ race or ethnicity. This is not ideal; research suggests that asking patients to identify their own race or ethnicity yields the most reliable answers. Latino, Asian and multiracial patients are particularly likely to be misidentified if staff are making assumptions about patients’ origins. On the other hand, patients are not always comfortable being asked. One large Chicago hospital tested scripts for staff to use when asking for information on race. Patients were most comfortable when told that the information would be used “to monitor care to ensure that all patients get the best care possible.” Training for staff on how and why to collect this information may be an important early step for your program. See Figure 2 for detailed advice on gathering data according to the Federal race and ethnicity categories.

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Figure 2

Classifying Race and Ethnicity

Asking about race and ethnicity can feel like a minefield for staff and patients. In our experience, although this task seems straightforward it is not. HRSA uses the OMB (Office of Management and Budget) classification for race and ethnicity, so you will need those data for reporting. The OMB classification appropriately invites people to identify in more than one category. However, as a practical matter, identification in multiple categories makes it very hard to use race/ethnicity data for tracking performance outcomes. A single category choice will make your data more useful. Here are some practical steps for navigating the minefield:

1. **Decide when, how (by form or interview?) and by whom you will collect the information and pilot test your forms and questions.**

2. **Get staff on board,** via training, on why and how to gather the information. Consistency is important, so there should be a “script” for staff to use. (See text above for an example.)

3. **Ask patients:** “How do you describe your race or ethnicity?” and write down the answer verbatim.

4. **Assign categories:** using the patients’ words, staff should determine which one or more of the following OMB race and ethnic categories match the patient’s self-description:

   - **Hispanic or Latino** - A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."
   - **Not Hispanic or Latino**

The two OMB categories of **ethnicity** are:

The OMB categories of **race** are:

- **American Indian or Alaska Native**
- **Asian**
- **Black or African American**
- **Native Hawaiian or Other Pacific Islander**
- **White**

5. **Ask again:** To get the single-category answer for performance data, staff should also ask patients "What do you consider your primary racial/ethnic affiliation?" Choices on a form should include all the race categories above and:

   - **Hispanic or Latino**
   - **Other**
Step Three: Get It Down on Paper

Once your program is committed to action, and you know how good your data are, the next step is to incorporate the disparities and cultural competence issues into the fabric of your day-to-day quality work by adding it to your written quality management plan. Using the framework for QM plans from the HIVQUAL Workbook⁹, here are some examples of places where cultural competence could be written in:

- **Quality Statement**: In writing the quality statement, the Workbook recommends asking “What do we want to be for our patients and our community?” Make sure your quality statement includes cultural competence and reduction of disparities as part of your vision.

- **Performance Measurement**: Choose 2-3 measures addressing cultural competence to add to your current set (see Appendix A).

- **Annual Quality Goals**: Using results of the organizational cultural competence assessment and patient satisfaction survey, decide on cultural competence quality goals. Include at least one with a short term (3-6 month) improvement horizon, such as gathering and recording race/ethnicity or primary language data on 80% of clients seen during the period; and one with a longer term improvement horizon, such as improving staff diversity.

- **Participation of Stakeholders**: The stakeholders list in the Plan uses job titles, not individuals’ names. Add an annual review of the ethnic makeup of the individuals on your committee, your board, and other stakeholder bodies as a new step to ensure that there is representation that reflects the patient population.

- **Evaluation**: Plan to repeat the organizational cultural competence assessment on an annual basis. Use the results to guide the next year’s plan.

Step Four: Choose a Few Critical Measures

The real goal of improved cultural competence is better health outcomes, so one way to measure the impact of program changes is to see a decrease in race and ethnicity disparities for all your indicators of quality. For example, look for narrowing of racial and ethnic gaps in:

- percent of patients undetectable on ARVs, by race and ethnicity
- percent of patients receiving annual Gyn exam, by race and ethnicity
- percent of clients with no visits within the past 3 months, by race and ethnicity

If improved cultural competence means we communicate more effectively to a patient about why a Pap test is worth having, or to a patient like Ms. P about why HAART might extend her life, then better outcomes are more likely.

For many programs, patient numbers will be too small for changes in outcome measures to be significant in any racial or ethnic subgroup. In this case, as is often true, we need to rely on process measures to give us a sense of our progress. Commonly used process measures for

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⁹ The New York State Department of Health AIDS Institute, National HIVQUAL Project. HIVQUAL Workbook: Guide for Quality Improvement in HIV Care, 2006; it can be downloaded at http://www.ihi.org/IHI/Topics/HIVAIDS/HVDiseaseGeneral/Tools/HIVQUALWorkbookGuideforQualityImprovementinHIVCare.html
cultural competence include indicators of organizational commitment, staff recruitment, staff training about cultural competence, language competence, and use of cross-cultural materials and surveys. Examples of measures that might be appropriate for Ryan White programs include:

- percent of new client assessments that include a cultural health belief inventory (see Figure 3)
- percent of staff whose participation in cultural competence training is included in performance reviews
- percent of key documents and forms that are available in the language of the most prevalent cultural groups served

Appendix A includes a sampling of measures drawn from a HRSA compendium. The full list is available at www.hrsa.gov/culturalcompetence/measures/. For more information on how to develop an indicator and collect performance data, please review the HIVQUAL Performance Measurement Guide\(^\text{10}\).

### Figure 3

**Abbreviated Kleinman’s Health Belief Questions**

- What does your sickness do to you?
- How does it work?
- How severe is it?
- What do you fear most about your disorder?
- What are the chief problems that your sickness has caused for you?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to receive from the treatment?

*Adapted from Arthur Kleinman, Patients and Healers in the Context of Culture, Regents of the Univ. of Calif., 1981.*

### Step Five: Get Going!

With good data, a plan in place, and ways to measure your progress, you have what you need to test and implement improvements in the cultural competence of your services. Familiar quality processes such as the Model for Improvement\(^\text{11}\) will also lend themselves to your cultural competence goals. The model’s three framing questions are:

- What are we trying to accomplish? *(Aim)*
- How will we know that a change is an improvement? *(Measure)*
- What changes can we make that might result in an improvement? *(Changes to Test)*

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Here is how the questions might be used to analyze the problem Ms. P exemplifies and give structure to an improvement effort:

**AMC Clinic, where Ms. P is receiving her care, discovers that only 50% of its African American patients are undetectable on HAART, compared to 75% of its white patients.**

The AMC quality committee applies the Model for Improvement:

**Aim:** Improve the success rate of African American patients on HAART.

**Measure:** Percent of African American patients who are undetectable on HAART increases to at least 75%.

**Changes to test:**

- Provide adherence counseling by peers.
- Offer written materials for patients that are designed by and for African American patients.
- Have a staff member explicitly problem-solve with patients about any concerns regarding different effects of ARVS in different races.
- Case-conferencing.

Which changes will be effective at your site will depend on the people you serve and the unique challenges of your program; it isn’t a ‘one size fits all’ approach. To start discussion in your program, here are some more examples of cultural competence improvement aims, measures, and changes to test:

**HIV Care Delivery (Example 1)**

**Aim:** Better communication with clients through improved understanding of their cultural health beliefs.

**Measures:** Look for improvement in measures #11 and 19 in Appendix A.

**Changes to test:**

- Include health belief questions (Kleinman’s Questions are widely used—see Figure 3) in client intake and see whether important differences emerge between how the patient understands the advice given and how the care team understands it.
- Add questions about spiritual or religious beliefs to intake and develop a resource list of HIV-friendly local religious groups.
- Have a staff member ask clients on HAART whether they have concerns about how the medications work for different racial groups.
- Add a question about clients’ use of alternative health treatments or practitioners.
- Train and support adherence counselors or case managers in using the LEARN Model of Cross-Cultural Communication.
Figure 4  
**The LEARN Model**

This model is one easy-to-remember structure for addressing cultural issues in a one-on-one session with a client or patient.

- Listen with sympathy and understanding to the patient's perception of the problem
- Explain your perceptions of the problem
- Acknowledge and discuss the differences and similarities
- Recommend treatment
- Negotiate agreement


HIV Care Delivery (Example 2)

**Aim:** Improve clients’ trust and comfort with the program by reflecting the race/ethnicity of the people served.

**Measures:** Look for improvement in measures #13 and 19 in Appendix A.

**Changes to test:**
- Ask your Community Advisory Board (CAB) or a special patient advisory group to pick decorations and photos in waiting areas and offices to reflect the predominant race/ethnic groups served.
- Hold a group visit with patients of the same race/ethnicity to discuss nutritional habits and how these habits could contribute to disease status. Offer culturally appropriate alternatives.
- Offer clients choices of whom to get adherence counseling from; include at least one staff member of the client’s race, where possible, and one non-professional/peer staff member.

HIV Care Delivery (Example 3)

**Aim:** Improve patients’ access to interpreter services and materials in their primary language.

**Measures:** Look for improvement in measures #8, 10, and 18 in Appendix A.

**Changes to test:**
- Morning “huddle” with staff to highlight in advance which patients will need interpreters and notify/remind the interpreter services department.
- Put out materials about the importance of Pap testing in Spanish and Vietnamese in the waiting room.
- Include an assessment of health literacy as part of intake for all limited English proficiency patients.
Consumer Involvement (Example 4)

Aim: Incorporate consumers’ ideas and preferences by getting culturally-specific feedback and input from clients.

Measures: Look for improvement in measure #19 in Appendix A.

Changes to test:
- Focus one CAB meeting on feedback about and improvements in the cultural competence of the organization.
- Add questions about cultural competence to consumer satisfaction surveys (see measure 19 in Appendix A for examples of this).
- Ask clients after visits if cultural issues were discussed and whether they were satisfied with the provider’s sensitivity to their culture.

Organization/Infrastructure (Example 5)

Aim: Increase organizational awareness of cultural issues and accountability for addressing organizational weaknesses in this realm.

Measures: Look for improvement in measures #1, 2 and 12 in Appendix A.

Changes to test:
- Add measurable cultural competence goals to the work plan and assign responsibilities and timelines.
- Collect and report quality data broken down by race and ethnicity.
- Change the procedure for collecting race/ethnicity data to use client’s self-description.
- Begin using an organizational assessment on a regular basis (at least once per year) and use it to decide on improvement priorities. Test different ways of communicating results to staff, leadership, and patients.

Organization/Infrastructure (Example 6)

Aim: Increase alignment of personnel policies and procedures with cultural competence goals.

Measures: Look for improvement in measures #5 and 6 in Appendix A.

Changes to test:
- Include cultural competence training in staff training plans.
- Add performance on cultural competence-related tasks (like data collection) to all job descriptions and evaluations.
- Develop and use a list of places to advertise new jobs that are likely to be seen by applicants who reflect the agency’s client population.

Take this as your start-up kit; your own organizational assessment and data will guide you in choosing a few tailored projects to undertake, this year, to make a difference for your patients and your program.
Conclusion

We know that minorities in care for HIV have worse outcomes than their white counterparts, and we know that care that pays attention to the cultural values and expectations of patients results in better communication, more trust and probably better health outcomes. Behind these statistics are thousands of daily clinical and support interactions with individual patients. Each of these encounters represents an opportunity to make a difference. Using these steps to add cultural competence and health disparities performance to your quality improvement program can make it the vehicle for your agency to move from paralysis to progress.

The QM Committee at the AMC clinic tries a test of change; for one week, every patient with a detectable viral load meets with the most culturally appropriate nursing staff and is asked whether they have any concerns about whether HIV medication works for people like them. Ms. P shares her health beliefs and confesses her doubts to the African-American nurse. Subsequently, the nurse shares her conversation in the next case-conference. Ms. P’s case manager follows-up with her, letting her know that the care team is glad that she shared her worries with them and that if she has any further concerns, she can speak to anyone on the staff. Ultimately, Ms. P starts HAART and becomes undetectable on treatment.

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15 Brach C and Frasier I. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. Medical Care Research and Review. 2000; 57 (supp. 1):181-217
<table>
<thead>
<tr>
<th>Type of Measure</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Process Measures</strong></td>
<td><strong>Organizational Commitment &amp; Capability</strong></td>
</tr>
<tr>
<td>1</td>
<td>Organizational commitment to cultural competence as measured by the following indicators:17</td>
</tr>
<tr>
<td></td>
<td>• Does the organization’s mission/vision statement commit to the delivery of culturally and linguistically competent services?</td>
</tr>
<tr>
<td></td>
<td>• Does the organization have a cultural competence plan and procedures for updating the plan?</td>
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<td></td>
<td>• Does the organization perform a cultural competence assessment at least annually?</td>
</tr>
<tr>
<td></td>
<td>• Does the organization have a cultural competence committee or another group that addresses cultural competence issues?</td>
</tr>
<tr>
<td></td>
<td>• Is the work of the cultural competence committee or other group integrated into QM program and QI projects?</td>
</tr>
<tr>
<td></td>
<td>• Does the racial and ethnic makeup of the governing board, advisory committees, and other policymaking and influencing groups reflect the community demographic?</td>
</tr>
<tr>
<td></td>
<td>• Does the racial and ethnic makeup of the consumers giving program input reflect the community demographic?</td>
</tr>
<tr>
<td></td>
<td>• Does the organization survey staff about their perceptions of cultural competence within the organization?</td>
</tr>
<tr>
<td>2</td>
<td>Organizational capability as measured by the following indicators:</td>
</tr>
<tr>
<td></td>
<td>• Does the organization collect validated patient data by race/ethnicity and/or primary language?</td>
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<tr>
<td></td>
<td>• Does the organization characterize the patient population by other cultural elements such as:</td>
</tr>
<tr>
<td></td>
<td>• % various religions represented</td>
</tr>
<tr>
<td></td>
<td>• % refugees and immigrants</td>
</tr>
<tr>
<td></td>
<td>• % income distribution levels18</td>
</tr>
<tr>
<td></td>
<td>• Are quality indicator results stratified by race, ethnicity, and primary language?</td>
</tr>
<tr>
<td></td>
<td>• Does the agency have documented policies and procedures on how to recruit and retain diverse staff?</td>
</tr>
<tr>
<td></td>
<td>• Does the organization provide and require cultural competence training for all staff on at least a yearly basis?</td>
</tr>
</tbody>
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16 This tool draws from the assessment tools cited below as well as from the resources listed in Appendix B.

<table>
<thead>
<tr>
<th>Type of Measure</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staff hiring, recruitment and training</strong></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>% of staff from the 1\textsuperscript{st} and 2\textsuperscript{nd} most represented ethnic and racial minority groups compared to the % of patients served from the same groups</td>
</tr>
<tr>
<td>4</td>
<td>% of multilingual staff compared to the % of Limited English Proficiency patients served</td>
</tr>
<tr>
<td>5</td>
<td>% of staff who participate in training and activities that address cultural issues\textsuperscript{19}</td>
</tr>
<tr>
<td>6</td>
<td>% of staff whose participation in cultural competence training is included in performance reviews\textsuperscript{20}</td>
</tr>
<tr>
<td><strong>Language competence</strong></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>% of clients whose initial assessments are conducted in their primary language</td>
</tr>
<tr>
<td>8</td>
<td>% of program operating hours that trained interpreters are available for the most represented cultural groups</td>
</tr>
<tr>
<td>9</td>
<td>% of staff proficient in languages of the most prevalent communities</td>
</tr>
<tr>
<td>10</td>
<td>% of key documents and forms that are available in the languages of the most prevalent cultural groups\textsuperscript{21}</td>
</tr>
<tr>
<td><strong>Care delivery</strong></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>% of new client assessments that include a cultural health belief inventory</td>
</tr>
<tr>
<td>12</td>
<td>% of providers who complete cultural competence self-assessment at least annually</td>
</tr>
<tr>
<td><strong>Outcome Measures</strong></td>
<td></td>
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<tr>
<td><strong>Health outcomes</strong></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>% of patients undetectable on HAART, by race and ethnicity</td>
</tr>
<tr>
<td>14</td>
<td>% of female patients receiving Gyn care, by race and ethnicity</td>
</tr>
</tbody>
</table>

\textsuperscript{18} Mayeno, L.


\textsuperscript{20} Mayeno L, 2003.

<table>
<thead>
<tr>
<th>Type of Measure</th>
<th>Examples</th>
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</thead>
<tbody>
<tr>
<td><strong>Retention in care</strong></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>% of clients with broken appointments/no shows, by race and ethnicity</td>
</tr>
<tr>
<td>16</td>
<td>% of clients meeting the agency definition of ‘lost to follow-up’, by race and ethnicity</td>
</tr>
<tr>
<td><strong>Access to care</strong></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>% of clients served by the program by race and ethnicity, compared to the demographic breakdown of PWHIV in the target population</td>
</tr>
<tr>
<td><strong>Patient/family satisfaction w/care</strong></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>% of clients reporting satisfaction with interpreter services received</td>
</tr>
<tr>
<td>19</td>
<td>% of clients rating the program high for cultural competence as measured by cultural questions on patient satisfaction survey. For example, patients state:</td>
</tr>
<tr>
<td></td>
<td>• Staff are willing to be flexible and provide alternative approaches to services to meet my cultural/ethnic treatment needs.</td>
</tr>
<tr>
<td></td>
<td>• Staff respect my belief in God, a Supreme Being or Higher Power.</td>
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<tr>
<td></td>
<td>• I feel welcomed in this clinic.</td>
</tr>
<tr>
<td></td>
<td>• I have sometimes felt like I might get better care at the clinic if I were from a different racial or ethnic group.</td>
</tr>
<tr>
<td></td>
<td>• Staff understand some of the different ideas that I and others from my racial or ethnic group may have about my illness.</td>
</tr>
<tr>
<td></td>
<td>• Staff informed me of resources in my local community where I could find help.</td>
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Appendix B

Organizational Assessments and General Cultural Competence Resources

1. Cultural Competence Resources for Healthcare Providers

http://www.hrsa.gov/culturalcompetence

This website, last updated in June 2006, contains links to several tools and other websites that address cultural competence. It is HRSA’s gateway site for cultural competence tools and curricula.

2. Indicators of Cultural Competence in Health Care Delivery Organizations: An Organizational Cultural Competence Assessment Profile

http://www.hrsa.gov/culturalcompetence/indicators/

HRSA sponsored a project in 2002 to develop indicators for cultural competence in health care systems. The aim of this report was to help organizations answer the question “How do we know cultural competence when we see it?” In addition to providing an exhaustive collection of indicators for cultural competence, the report includes descriptions of best practice settings that have been recognized for their work in cultural competence.

3. AIDS Education and Training Centers, Guiding Principles for Cultural Competency

http://www.aidsetc.org/aidsetc?page=etres-display&resource=etres-177

The AETC developed this guide in October 2006 to help AETC faculty, providers and administrators to address cultural competence in their organizations. It contains six guiding principles for organizations to use when trying to increase their cultural competence and includes common concepts and themes found throughout various cultural competence definitions.

Organizational Assessment Tools:

1. Mayeno L. Organizational Assessment for Multicultural Development to Improve Access for Out-of-Care People Living with HIV. 2003


3. Cultural Competence Health Practitioner Assessment (CCHPA).
   http://www11.georgetown.edu/research/gucchd/nccc/features/CCHPA.html