

# Improving Cultural Competence To Reduce Health Disparities



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Effective Health Care Program

# *Comparative Effectiveness Review*

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## **Improving Cultural Competence To Reduce Health Disparities**

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## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of systematic reviews to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. These reviews provide comprehensive, science-based information on common, costly medical conditions, and new health care technologies and strategies.

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In designing the study questions, the EPC consulted several Key Informants who represent the end-users of research. The EPC sought the Key Informant input on the priority areas for research and synthesis. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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Peer Reviewers must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

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# Improving Cultural Competence To Reduce Health Disparities

## Structured Abstract

**Objective.** To examine existing system-, clinic-, provider-, and individual-level interventions to improve culturally appropriate health care for people with disabilities; lesbian, gay, bisexual, and transgender (LGBT) populations; and racial/ethnic minority populations.

**Data sources.** Ovid MEDLINE<sup>®</sup>, PsycINFO<sup>®</sup>, Ovid Embase<sup>®</sup>, and the Cochrane EPOC (Effective Practice and Organisation of Care) register; hand searches of references of relevant studies.

**Review methods.** Two investigators screened abstracts and full-text articles of identified references for eligibility. Eligible studies included randomized controlled trials (RCTs), prospective cohort studies, and other observational studies with comparators that evaluated cultural competence interventions aimed at reducing health disparities in the formal health care system. Two investigators abstracted data and assessed risk of bias. Given the sparse and patchy literature, which precluded pooling, a qualitative analysis is provided.

**Results.** Over 37,000 nonduplicated English-language citations were reviewed; 56 unique studies were identified as of June 2015: 20 randomized controlled trials (RCTs) and 5 observational studies for individuals with disabilities; 5 RCTs (6 manuscripts) and 6 observational studies for LGBT populations; and 14 RCTs (15 manuscripts), 4 observational studies, and 2 systematic reviews for members of racial and ethnic minorities. Interventions fell into four broad categories: (1) provider trainings and education; (2) interventions providing alteration of an established protocol, or the delivery of an established protocol, to meet the needs of a target population; (3) interventions prompting patients to interact with the formal health care system or health care providers; and (4) interventions aimed at providing culturally competent care at the point of service.

Educational programs and trainings to improve professional students' and providers' cultural competence behavior are the most prevalent type of cultural competence intervention. Two existing high-quality systematic reviews of provider educational interventions for racial/ethnic minority populations found low-strength evidence that cultural competence training had mixed effects for intermediate outcomes and no effect on treatment outcomes. Sixteen studies aimed at changing provider attitudes and beliefs through training or curriculums were identified for the disability population. Eleven of these studies focused on reducing professional stigma toward people with serious or chronic mental illness; five focused on changing professional attitudes and beliefs about people with physical or intellectual disability. Three educational interventions were identified for the LGBT population. Several short-term effects were evaluated; however, long-term effects of provider training on provider cultural competence behavior in the clinical setting and subsequent patient health outcomes have not been evaluated for the disability and LGBT populations. Two included studies reported a potential harm from provider training: an increase in negative attitudes or stigma resulting from intervention.

Interventions providing alterations of an established protocol were concentrated in the racial/ethnic minority populations. The 12 studies of culturally tailored health care interventions



for racial/ethnic minority populations focused primarily on treatment of chronic physical or mental health conditions (e.g., diabetes, depression, substance abuse). Two psychological interventions were also tailored for members of the LGBT population.

Another common type of intervention was to provide additional resources to encourage or empower patients to interact with the formal health care system and/or health care providers. The stated aims of these types of interventions were to increase receipt of screenings for which disparities are well documented (e.g., Pap tests for people with mobility impairments or colorectal cancer screening among Latino immigrants) or to help patients engage in medical decisionmaking. These studies met inclusion criteria if the intervention was conducted by a medical professional in a formal health care system. One potential limitation of these types of interventions is that they rely on strong identification with a common culture. The population groups highlighted in this review are large and diverse. Creating an intervention for “African Americans” or “women who have sex with women” may be differentially effective for specific subpopulations.

The most common culturally competent point-of-service interventions were documents, similar to a hand-held medical record, that patients carried to their appointments to prompt providers to evaluate areas of known disparity for a specific population. These interventions may be coupled with provider notices or trainings. Virtual interventions were also considered culturally competent point-of-service interventions for some people with disabilities, as they create access in a unique way. These interventions are seen as conceptually parallel to infrastructure changes that improve access for people with physical disabilities.

For the majority of included studies, the risk of bias was high. The most common methodological problems were lack of randomization to treatment, lack of attention control, little or no followup, and failure to report unintended consequences. Large segments of vulnerable or disadvantaged populations—such as children with disabilities; people who are gender nonconforming or transgender; or numerous racial or ethnic groups, including Native Americans or Alaskan Natives—remain essentially invisible in the cultural competence literature. The issue is compounded for people who are members of more than one priority population.

**Conclusions.** None of the included studies measured the effect of cultural competence interventions on health care disparities. Most of the training interventions measured changes in professional attitudes toward the population of interest but did not measure the downstream effect of changing provider beliefs on the care delivered to patients. Interventions that altered existing protocols, empowered patients to interact with the formal health care system, or prompted provider behavior at the point of care were more likely to measure patient-centered outcomes. The medium or high risk of bias of the included studies, the heterogeneity of populations, and the lack of measurement consensus prohibited pooling estimates or commenting about efficacy in a meaningful or responsible way. The term “cultural competence” is not well defined for the LGBT and disability populations, and is often conflated with patient-centered or individualized care. There are many gaps in the literature; many large subpopulations are not represented.

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# Chapter 1. Introduction

## Background

The U.S. health care system needs to reduce health disparities and achieve better equity for patients. Culturally competent care is seen as foundational for reducing disparities. Culturally competent care respects diversity as well as the cultural factors that can affect health and health care, such as language, communication styles, beliefs, attitudes, and behaviors.<sup>1</sup> The Office of Minority Health, Department of Health and Human Services, has established national standards for culturally and linguistically appropriate services (CLAS) in health and health care (National CLAS Standards). These provide a blueprint for implementing appropriate services to improve health care in the United States.<sup>2</sup> The standards cover governance, leadership, workforce, communication and language assistance, organizational engagement, continuous improvement, and accountability.

A lack of conceptual clarity around cultural competence persists both in practice and among researchers. Cultural competence is defined, conceptualized, and operationalized in a variety of ways. This variance leads to disagreement around the training needed for providers to attain cultural competence.<sup>3</sup> The populations to which the term cultural competence applies are also ill-defined. Often, the term cultural competence is applied only to racial and ethnic minority populations. This narrow application omits other marginalized groups who may be ethnically and racially similar to a provider but nonetheless at risk for stigmatization or discrimination, or who have differences in health care needs that result in health disparities. This broader concept may be termed “diversity competence.” In keeping with this broader view, this systematic literature review considers three populations experiencing health disparities in the U.S. health system: individuals with disabilities; lesbian, gay, bisexual, and transgender (LGBT) populations; and racial and ethnic minority populations. These groups are not mutually exclusive; the cultural competence movement continues to evolve in response to an increasingly multicultural society.

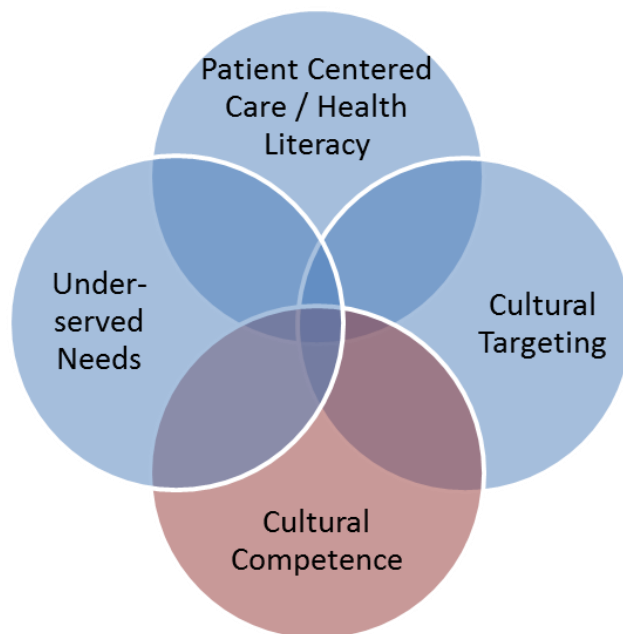
In addition to provider education and training, changing clinical environments can also be key to improving culturally competent care. Changes in provider knowledge, attitudes, and skills are necessary, but for those gains to translate into culturally competent behaviors the structures and culture of health care systems and organizations must also change. This review focuses on the effectiveness of interventions at the provider and system level. Policy level interventions are important, but beyond the scope of this review.

Interpretation and significance of outcomes differ by priority population. Access is important to all priority populations. However, individuals with disabilities may face multiple barriers, such as transportation to facilities and accessibility of exam rooms and their contents. Similarly, linguistic competence means something different in relation to a person for whom English is not his/her first language compared with a person with an expressive communication limitation who uses an augmentative communication system or a person who may be gender nonconforming or transgender.

The concept of cultural competence overlaps with several other concepts related to providing high-quality, appropriate care. Figure 1 illustrates a few of these overlapping concepts. Conducting a systematic review requires clarity about whether interventions fall inside or outside of the inclusion criteria. The criteria are built to provide a specified scope of cultural competence. For this review, we focus mainly on whether cultural competency interventions change the clinicians’ attitudes or behaviors (e.g., stereotypes, communication and clinical decisionmaking), the patient-provider relationship, and/or clinical systems to result in better

outcomes for patients from the populations of interest. This review focuses on interventions that promote equity, thus the primary outcomes of interest are reductions in disparities between populations for a given health outcome measure.

**Figure 1. Health services research concepts that overlap with cultural competence**



Includable interventions that lie within the cultural competence circle in Figure 1 are defined as:

- Interventions that take place at the system level, engineering a system that prompts physicians to pay attention to areas of known disparity, such as interventions prompting equitable receipt of preventive care or chronic disease.
- Interventions that address physical barriers to access.
- Interventions that improve the ability of providers to provide health care services to patients from a population of interest. Targeted providers can include physicians, nursing staff, allied health professionals, paraprofessionals, and clinic staff who have regular contact with patients, or health system factors intended to engineer the system to support and sustain cultural competence.
- Interventions that help providers better understand cultural components of clinical encounters with different populations and their own inherent biases.
- Interventions that assist patients from a population of interest to competently navigate the patient-provider relationship and the larger health system

As the overlapping circles in Figure 1 suggest, some interventions targeted at meeting underserved needs fall outside our scope, such as interventions to address access problems due to finance/insurance coverage issues (such as Medicare/Medicaid), individualized or patient-centered care that is not culturally tailored (such as implementing a medical home model or a computer-assisted cancer risk assessment for all patients), and general patient health literacy interventions that are not provided by a health care professional or do not track patient interactions with the formal health care system. Some public health outreach activities, such as community-based HIV education in underserved African American neighborhoods, or school-

based empowerment programs for young people with disabilities, may also address an unmet need. However, given our focus on the patient-provider interaction and the system of care surrounding that interaction, such studies are not included in this review. Within the clinical context, interventions aimed at improving care for all patients (such as patient-centered care), are excluded unless the intervention is specifically tailored to one of this review's populations of interest.

## Report Organization

This report is organized in several chapters. The next sections of this introductory chapter present the Key Questions, analytic framework, and brief overview of study selection methods for the three populations of interest. Following this introductory chapter, we present the systematic reviews conducted for each of the populations. Each of these chapters are intended to stand alone for readers interested in specific priority populations. Chapter 2 presents the systematic review of literature for the disability populations, while Chapters 3 and 4 present the reviews for the LGBT communities and the racial and ethnic minorities, respectively. The report concludes with Chapter 5, a review of the models that have contributed to different conceptualizations of cultural competence, and an overarching discussion of cross-cutting themes identified in the reviews in Chapters 2-4.

## Key Questions and Analytic Framework

The Key Questions (KQs); the populations, interventions, comparators, outcomes, timing, and settings (PICOTS); and analytic framework, developed with input from key informants, were posted for public comment from February 6, 2014, to February 26, 2014.

**KQ 1:** What models have been used to conceptualize cultural competence and culturally appropriate care in health contexts, and how do those models compare?

**KQ 2:** What is the effectiveness of interventions to improve culturally appropriate care for LGBT adolescents (ages 13-17), young adults (18-25), and adults?

A. Provider intermediate outcomes

- Provider training and motivation outcomes, such as post-test competencies, knowledge, changes in attitudes
- Provider beliefs/cognitions about the priority population, such as reducing stereotyping and stigmatization
- Improved specific knowledge of health needs unique to LGBT community
- Provider behavior, such as clinical decisionmaking, communication

B. Patient intermediate outcomes

- Patient learning/knowledge, including linguistic competence regarding gender-diversity
- Improved access to health services
- Utilization of health services
- Patient experience and satisfaction, such as improved perceptions of care
- Patient health behaviors, such as tobacco use or health seeking behaviors
- Use of preventive services

C. Final health or patient-centered health outcomes, including but not limited to:

- Improved mental health outcomes, such as depression, anxiety, suicidality, peer/familial/intimate relationships, substance use
- Improved medical health outcomes, such as reduction in obesity, improved sexual health

D. Adverse events; unintended negative consequences of intervention

**KQ 3:** What is the effectiveness of interventions to improve culturally appropriate health care for children and adults with disabilities?

E. Provider intermediate outcomes

- Provider training and motivation outcomes, such as post-test competencies, knowledge, changes in attitudes, willingness to serve and perceived competence for people with disabilities
- Provider behavior, such as clinical decisionmaking and communication
- Provider beliefs/cognitions about the priority population, such as reducing stereotyping and stigmatization

F. Patient intermediate outcomes

- Improved access to health services
- Utilization of health services
- Patient experience and satisfaction, such as improved perceptions of care

G. Final health or patient-centered health outcomes, including but not limited to:

- Improved mental health outcomes, such as depression, substance use
- Improved medical health outcomes, such as reduction in obesity, metabolic disorders, heart disease, breast cancer
- Patient health behaviors, such as tobacco use or health seeking behaviors
- Use of preventive services, and other access to care measures

H. Adverse effects; unintended negative consequences of interventions

**KQ 4:** What is the effectiveness of interventions to improve culturally appropriate health care for racial/ethnic minority children and adults?

I. Provider intermediate outcomes

- Provider training and motivation outcomes, such as post-test competencies, knowledge, changes in attitudes, willingness to serve and perceived competence for racial/ethnic minority children and adults
- Provider behavior, such as clinical decisionmaking, communication
- Provider beliefs/cognitions about the priority population, such as reducing stereotyping and stigmatization

J. Patient intermediate outcomes

- Patient beliefs/attitudes such as improved trust, perceived racism
- Utilization of health services
- Patient experience and satisfaction, such as improved perceptions of care
- Patient health behaviors, such as tobacco use or health-seeking behaviors
- Use of preventive services, and other access to care measures

K. Final health or patient-centered health outcomes, including but not limited to:

- Improved mental health outcomes, such as depression, substance use
- Improved medical health outcomes, such as reduction in obesity, kidney disease, heart disease, breast cancer, sickle cell disease

L. Adverse effects; unintended negative consequences of interventions



**KQ 5:** What is the effectiveness of organizational or structural interventions for promoting culturally appropriate care for each of the priority populations across providers?

Table 1 provides the PICOTS by the Key Questions, and Figure 2 shows the analytic framework.

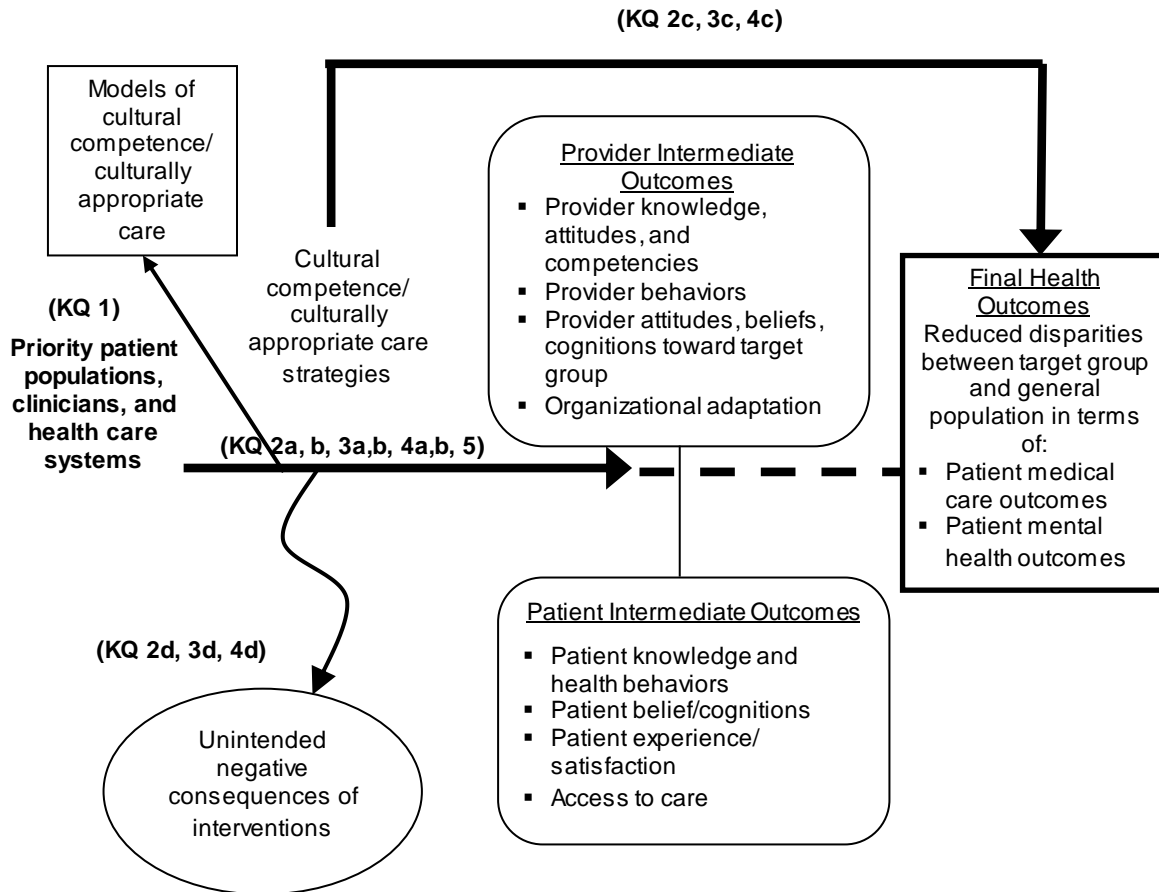
**Table 1. Review PICOTS**

| PICOT             | KQ 2   | KQ 3  | KQ 4  | KQ 5   |
|-------------------|--|---|---|--|
| Population        | LGBT adolescents (ages 13-17), young adults (ages 18-25) and adults.<br>Overall gender disparities experienced by women (in relationship to men) and biological sexual development and disorders of sexual development are excluded.   | Children and adults with disabilities, with older adults, focus on aging with a disability, rather than aging into a disability.  | Racial/ethnic minority children and adults  | Based on populations for KQs 2-4   |
| Intervention      | <ul style="list-style-type: none"> <li>• Cultural competence/culturally appropriate care provider education and training</li> <li>• Cultural competence/culturally appropriate care clinic-based interventions targeted to patients</li> <li>• Cultural competence/culturally appropriate care clinic-based interventions targeted to providers</li> </ul>   | Same as KQ 2  | Same as KQ 2  | <ul style="list-style-type: none"> <li>• Cultural competence/culturally appropriate care interventions targeted at the organizational level, including physical/ environmental factors.</li> </ul>   |
| Comparator groups | <ul style="list-style-type: none"> <li>• Usual care</li> <li>• Head-to-head trials of different strategies</li> </ul>  | Same as KQ 2  | Same as KQ 2  | Same as KQ 2   |
| Outcomes          | <p>Intermediate outcomes</p> <ul style="list-style-type: none"> <li>• Provider knowledge, attitudes, and competencies (skills) in providing culturally competent health care</li> <li>• Provider behavior, such as clinical decisionmaking, communication</li> <li>• Provider beliefs/cognitions about the priority population, reducing stereotyping, stigmatization</li> <li>• Provider improved specific knowledge of health needs unique to LGBT community</li> <li>• Patient learning/knowledge</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> </ul> | <p>Intermediate outcomes</p> <ul style="list-style-type: none"> <li>• Provider knowledge, attitudes, and competencies (skills) in providing culturally competent health care</li> <li>• Provider behavior, such as clinical decisionmaking, communication</li> <li>• Provider beliefs/cognitions about the priority population, reducing stereotyping, stigmatization</li> <li>• Improved access to health services</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> </ul> <p>Final health or patient-centered</p> | <p>Intermediate outcomes</p> <ul style="list-style-type: none"> <li>• Provider knowledge, attitudes, and competencies (skills) in providing culturally competent health care</li> <li>• Provider behavior, such as clinical decision-making, communication</li> <li>• Provider beliefs/cognitions about the priority population, reducing stereotyping, stigmatization</li> <li>• Patient beliefs/cognitions such as improved trust, perceived racism</li> <li>• Improved access to health services</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> <li>• Patient health behaviors</li> </ul> | <p>Intermediate organizational adaptation outcomes</p> <ul style="list-style-type: none"> <li>• Process measures</li> <li>• Availability of culturally competent health care across population groups</li> <li>• Structural changes</li> </ul> |

| PICOT   | KQ 2   | KQ 3   | KQ 4   | KQ 5         |
|---------|--|--|--|--------------|
|         | <ul style="list-style-type: none"> <li>• Patient health behaviors</li> <li>• Use of preventive services and other access to care measures</li> </ul> <p>Final health or patient-centered outcomes – reduced disparities in terms of:</p> <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, anxiety, suicidality, substance use, peer/familial/intimate relationships)</li> </ul> <p>Adverse effects of intervention(s)</p> <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> | <p>outcomes – reduced disparities in terms of:</p> <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, substance use)</li> <li>• Patient health behaviors</li> <li>• Use of preventive services and other access to care measures</li> </ul> <p>Adverse effects of intervention(s)</p> <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> | <ul style="list-style-type: none"> <li>• Use of preventive services and other access to care measures</li> </ul> <p>Final health or patient-centered outcomes – reduced disparities in terms of:</p> <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, substance use)</li> </ul> <p>Adverse effects of intervention(s)</p> <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> |              |
| Timing  | Variable – depends on the purpose of the intervention  | Same as KQ 2   | Same as KQ 2   | Same as KQ 2 |
| Setting | Inpatient, outpatient, and community settings in which patients from priority populations are interacting with health care providers.  | Same as KQ 2   | Same as KQ 2   | Same as KQ 2 |

LGBT = lesbian, gay, bisexual, and transgender; KQ = Key Question; PICOT = population, intervention, comparator, outcome, timing, setting.

**Figure 2. Analytic framework for improving cultural competence to reduce disparities in priority populations**



KQ = Key Question.

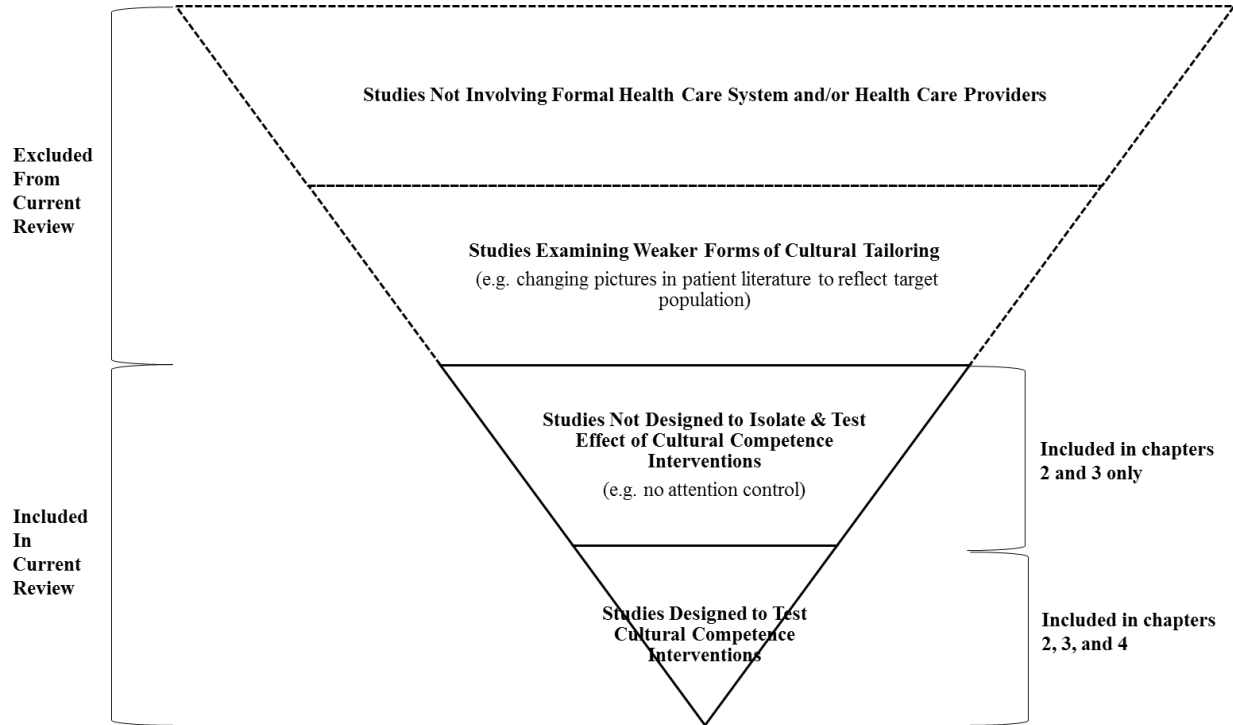
For analytic frameworks, all actions are linked by solid single-headed arrows, pointing from the precursor situation to the result. Links between outcomes that occur through association or time are represented by a dotted line. Health outcomes (or other target outcomes for non-health interventions) are represented by a square-edged box, while intermediate or process outcomes are in boxes with rounded corners. Harms (unintended consequences) are represented in ovals.

## Methods Overview

Because each of the populations of interest is categorically different from the others, unique search algorithms, inclusion/exclusion criteria, and decision rules for identifying the included literature set were established for each population. Figure 3 illustrates the hierarchy used to identify relevant studies. In the screening process, all the populations of interest were similar in that the study design needed to test an intervention that was part of the formal health care system (e.g., located at clinic, led by nurse, or treatment of a specific health condition that could be delivered within the formal health care system) and that it went beyond framing the study as addressing a health disparity by using an intervention explicitly tailored to be more culturally competent. For the disability and LGBT populations, studies that passed through screening to this level were included. Because the racial/ethnic minority populations have a longer history of

cultural competence interventions, we further required that the study explicitly tested the cultural competency component of the intervention.

**Figure 3. Study selection by strength of study design to test cultural competence within the health care system**



CC = cultural competence.

Studies that specifically addressed cultural competence varied in the degree to which interventions were tailored to incorporate key components of cultural competence and the directness of the test of culturally competent health care. For racial/ethnic minority populations, we excluded interventions in which cultural tailoring was limited to language translation, patient-provider concordance, or culturally-tailored media (e.g., brochures, videos). The intervention had to be designed to improve cultural competence of the health care system. Only translating or adding multicultural features to materials was not sufficient.

We anticipated sufficient literature to apply full systematic review methods including possible meta-analysis. Anticipated methods were outlined in the protocol. However, given the paucity of literature identified using systematic review search methods, the heterogeneity of the study populations and interventions, small study samples, the lack of details for complex interventions and comparators, and the high risk of bias assessment for most of the included studies, we determined the strength of evidence for cultural competence interventions, in general, to be insufficient, and thus we were unable to draw meaningful conclusions from the literature. Therefore, results are summarized in evidence tables and qualitatively synthesized by common characteristics of interventions and outcome measures. Barriers to forming inferences from study results are also presented. Where we were able to use previously published systematic reviews that evaluated strength of evidence, we report that review's strength of evidence finding.

# Chapter 2. Disability Populations

## Introduction

Americans with disabilities represent a large and heterogeneous segment of the population. The prevalence of disability varies by age group and definition. Based on the U.S. Census Bureau's 2013 *American Community Survey* (ACS), which describes disability in terms of functional limitations, 12.6 percent of the civilian U.S. noninstitutionalized population (which excludes people living in institutional settings such as nursing homes) has a disability (defined as difficulty in hearing or vision, cognitive function, ambulation, self-care, or independent living). The U.S. Department of Education (2012), which uses categorical disability labels, estimates that 13 percent of children and youth ages 3 to 21 have a disability (defined as specific learning disabilities, speech or language impairments, intellectual disability, emotional disturbance, hearing impairments, orthopedic impairments, other health impairments, visual impairments, multiple disabilities, deaf-blindness, autism, traumatic brain injury, or developmental delay).

## Health Disparities

The International Classification of Functioning, Disability, and Health (ICF) describes body functions and structures, activities and participation, environmental factors, and personal factors that interact to influence a person's function and disability.<sup>4</sup> Within the ICF framework, health disparities research examines how differences in health activities, health care participation, and health outcomes relate to differences in body function or structure, personal characteristics (such as age, sex, race, sexual orientation, health conditions, fitness, life experience, individual psychological assets, education, socioeconomic status), or features of the immediate (settings such as home, workplace and school) or societal (such as social structures, services, social networks, laws, rules, attitudes, and ideologies) environment in which a person lives.

People with disabilities experience many health disparities. Some documented disparities include poorer self-rated health; higher rates of obesity, smoking, and inactivity; fewer cancer screenings (particularly mammography and Pap tests); fewer breast conserving surgeries when breast cancer is diagnosed; and higher rates of death from breast or lung cancer.<sup>5</sup>

Health disparities research has developed through four generations: (1) documenting the disparities, (2) exploring possible reasons for the disparities, (3) providing evidence for solutions, and (4) moving towards structural, multi-level interventions.<sup>6</sup> This review focuses on studies that test interventions to reduce health disparities (third and fourth generation disparities research). However, disability health disparities research is largely first generation,<sup>7</sup> focused on accurately documenting the health care disparities experienced by its diverse subpopulations. Documenting health care disparities is difficult for many reasons, including the presence of multiple disability subpopulations and ways of defining these subpopulations, and the lack of national surveillance data for specific subpopulations that results in many small, convenience sample studies.<sup>8</sup>

## Cultural Competence

Cultural competence has been widely promoted as one approach to reduce health disparities. Since cultural competence remains variously defined and operationalized, it has become a blanket term to describe a broad range of system- or provider-level interventions. Initially, cultural competence focused mostly on racial and ethnic differences. More recently, it has been

expanded to other marginalized population groups who are at risk for stigmatization for reasons other than race and ethnicity and/or who have differences in health care needs that result in health disparities. People with disabilities comprise some of these other populations. Culture competence implies the existence of a shared culture. Gill described the values of disability culture to include: viewing interdependence and helping as typical; accepting diversity in all its forms; being able to laugh at one's situation; planning for multiple potential outcomes and maintaining the ability to adapt; and being able to read people well under various conditions.<sup>9</sup> Eddey and Robey described professional competencies related to the culture of disability, including: communicating with patients who have verbal deficits; understanding the values of people with disabilities and of disability culture including interdependence; and encouraging self-advocacy for patients and families.<sup>10</sup> The authors acknowledge that, similar to other populations that experience health disparities, the degree to which a person identifies with disability culture varies and depends on a number of factors, including: the stage of life in which a disability is acquired; the visibility and/or severity of the disability; and the amount of organizational support for disability culture in the area where one lives.<sup>11</sup> The interventions described in this review attempt to reduce disparities for persons with disabilities by affecting change in providers or health care systems. This review tries not to take a position on the concept of disability culture.

## **Scope and Key Questions**

### **Scope of the Review**

This review examines the evidence for the effectiveness of system- or provider-level cultural competence interventions designed to address known or suspected health disparities among individuals with disabilities. We do not address policy-level evaluations. Because the language of cultural competence has not been widely applied to disabilities, and interventions have not necessarily been framed as targeting cultural competence, clarity about which interventions fall within the scope of cultural competence is important but challenging. We focus mainly on interventions that aim to change clinicians' behaviors (such as communication and clinical decisionmaking), the patient-provider relationship, and/or clinical systems to result in better outcomes for patients with disabilities. Within the clinical context, interventions aimed at improving care for all patients (such as patient-centered care, patient-centered medical homes, health literacy), are excluded.

### **Key Question**

**KQ:** What is the effectiveness of interventions to improve culturally appropriate health care for children and adults with disabilities?

### **PICOTS**

Table 2 provides the populations, interventions, comparators, outcomes, timing, and settings (PICOTS) of interest. The analytic framework can be found in Chapter 1 and Appendix A.

**Table 2. Review PICOTS—disability populations**

| PICOTS            | Criteria   |
|-------------------|--|
| Population        | Children and adults described as having disabilities, with older adults' focus on aging with a disability, rather than aging into a disability   |
| Intervention      | Cultural competence/culturally appropriate care provider education and training<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to patients<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to providers   |
| Comparator groups | Usual care<br>Head-to-head trials of different strategies  |
| Outcomes          | Intermediate outcomes <ul style="list-style-type: none"> <li>• Provider training and motivation outcomes (competencies, knowledge, changes in attitudes)</li> <li>• Provider behavior, such as clinical decisionmaking, communication</li> <li>• Provider beliefs/cognitions about the priority population, reduction in stereotyping and stigmatization</li> <li>• Improved access to health services</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> <li>• Patient health behaviors</li> <li>• Use of preventive services and other access to care measures</li> </ul> Final health or patient-centered outcomes—reduced disparities in terms of: <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, substance use)</li> </ul> Adverse effects of intervention(s) <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> |
| Timing            | Variable—depends on the purpose of the intervention  |
| Setting           | U.S. inpatient, outpatient, and community settings in which patients from priority populations are interacting with health care providers  |

PICOTS = population, intervention, comparator, outcomes, timing, and setting.

## Methods

This review followed the methods suggested in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at [www.effectivehealthcare.ahrq.gov/methodsguide.cfm](http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm)); certain methods map to the PRISMA checklist.<sup>12</sup> We recruited a technical expert panel to provide high-level content and methodological expertise feedback on the review protocol. The protocol was posted on July 8, 2014 at [www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov). This section summarizes the methods used.

## Literature Search Strategy

We searched Ovid MEDLINE®, PsychInfo, and Cochrane EPOC from 1990 to June 2015. Because the concept of cultural competence interventions in the disability community is not well defined, the initial search cast a wide net into the disability literature. Searches were performed iteratively to identify concept boundaries and tighten the working definitions and eligibility criteria to balance search sensitivity and specificity with feasible numbers of references to screen. The initial search strategy included cultural competence specific intervention terms, adapted from the race/ethnicity literature, and more general terms targeting health accessibility and health promotion. These more general terms were included because the exemplar articles identified by members of the technical expert panel were focused on improving physical access to care for individuals with disabilities and reminding providers to see the “whole person” with regard to providing preventive care and care for comorbid conditions. The health promotion, primary prevention, and health service accessibility terms had the greatest yield and were,



therefore, the focus of the revised search. Other terms included in the revised search highlighted attitudes of health personnel, health care disparities, and the presence of stigma. The final search algorithms are provided in Appendix B. We also manually searched reference lists from systematic reviews and used back and forward searching of key articles recommended by experts.

## Study Selection

We reviewed bibliographic database search results for randomized controlled trials (RCTs) systematic reviews, nonrandomized controlled trials, before and after observational studies with comparators, and interrupted time series studies published in English language relevant to our PICOTS framework. All studies identified by title and abstract as potentially relevant by either of two independent investigators underwent full-text screening. Two investigators independently performed full-text screening to determine if inclusion criteria were met. (Excluded articles at full text provided in Appendix C with reasons for exclusion.)

The full team vetted initial search results and adopted inclusion decision rules to clarify search results to address the review scope. This led to several refinements to the inclusion criteria. Patients with nonsevere mental health conditions, such as mild to moderate depression, did not meet our disability criteria; therefore, interventions integrating mental health services into primary care did not meet inclusion criteria. However, interventions targeting the attitudes of physicians toward people with mental illness, to the extent the condition qualifies as a disability, were eligible and included.

We had difficulty drawing tight boundaries around the interventions because the disability literature is often not identified by the terms “cultural competence” or “culturally appropriate.” Under our normative definition of cultural competence for this population, remote (e.g., web- or phone-based) medicine as an intervention was deemed culturally competent to the extent that it increases access for people whose disabilities make travel difficult. Although these interventions are not “clinic-based,” virtual interventions involving the formal health system (essentially replacing the need to travel to the doctor’s office) create access in a unique way for the target population. These interventions are seen as conceptually parallel to infrastructure changes that improve access for people with physical disabilities.

Interventions aimed at improving physician or patient knowledge of existing treatment guidelines for conditions experienced by people with a disability are not included unless they also targeted physician perceptions and/or patient access to care. School-based interventions targeting the attitudes of teachers, classmates, and other professionals were excluded as outside the scope of this review, as were studies aimed at changing the attitudes of providers of long-term disability supports and services in community settings. Only studies that examined interactions with formal health care providers were included. As a result, several trials aimed at improving wellness and secondary disease prevention among people with disabilities in home and community settings, including some virtual interventions, were excluded.

Due to the limited available literature, we also expanded the criteria to include studies from other developed countries that tested interventions that could possibly transfer to U.S. health care.

In order to focus on the literature most likely to be informative, we also found it necessary to create decision rules for study comparators. Studies that used comparators that did not allow for direct testing of the cultural competence intervention/intervention component were excluded.

Differences of opinion regarding eligibility were resolved through consensus adjudication.

## Risk of Bias, Data Extraction, Synthesis, and Presentation

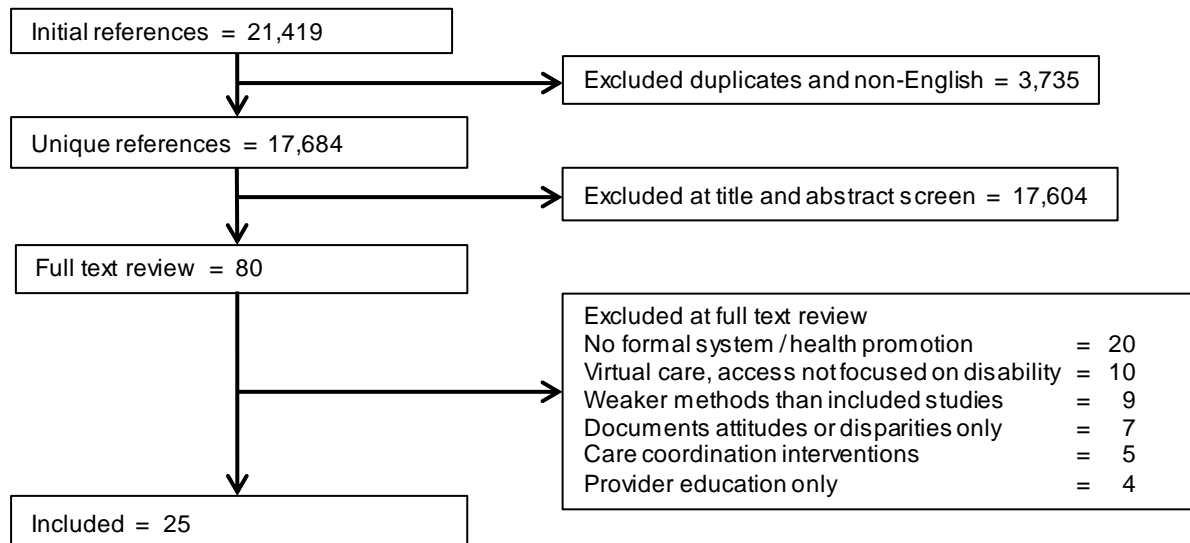
We evaluated the risk of bias in included studies according to study design using criteria from the Cochrane risk-of-bias tool in interventional studies (Appendix D). Given the heterogeneity of the study populations and interventions and the high risk of bias assessment for most of the included studies, we were unable to draw meaningful conclusions from the literature. Because the literature did not provide adequate studies for quantitative analysis, results are summarized into evidence tables and qualitatively synthesized by common characteristics of interventions and outcome measures. Barriers to forming inferences from study results are also presented. One investigator abstracted the relevant data from eligible trials directly into evidence tables. A second investigator reviewed evidence tables and verified them for accuracy.

## Results

### Literature Search Results

We identified 17,684 unique English language citations (Figure 4) from 1990 to June 2015. After excluding articles based on title and abstract, full texts of 80 articles were reviewed to determine final inclusion.

**Figure 4. Literature flow diagram—disability populations**



Examples of studies excluded at full text for methodological reasons included: studies with a pre-post design or analysis,<sup>13-15</sup> studies with a weaker comparator population than included studies,<sup>16,17</sup> or studies where the intervention or outcomes were difficult abstract or interpret.<sup>18-20</sup>

Twenty of the 25 included studies were RCTs; five were controlled trials.<sup>21-25</sup> Included studies fall into three main categories: interventions, predominantly trainings and curricula, aimed at changing professionals' attitudes towards individuals with disabilities (n=16); interventions aimed at increasing quality at the point of care by prompting patient and physician interaction (n=5); and interventions aimed at reducing barriers to accessing care (n=4). Table 3 describes the included studies by intervention type, disability population, and provider population. Studies were generally high risk of bias (Appendix D). Since the risk of bias and heterogeneity of the studies precluded any strength of evidence other than insufficient, we describe the studies by emergent patterns.

**Table 3. Cultural competence intervention type by disability and provider populations**

| Type of Cultural Competence Interventions  | Number of Studies | People With a Mental Illness or Substance Use Disorder   | People With a Physical Disability   | People With an Intellectual or Learning Disability   | People With Lower Back Pain                                   | Children With ADHD  | People With Multiple Sclerosis   | People With Arthritis   |
|--|-------------------|--|---|--|---|---|--|---|
| Trainings and curricula aimed at changing professional attitudes towards individuals with disabilities     | 16                | <i>Student nurses</i> Clement, 2012 <sup>26</sup><br><i>Medical Students</i> Bannatyne, 2015 <sup>27</sup><br>Cutler, 2012 <sup>28</sup><br>Friedrich, 2013 <sup>29</sup><br>Kassam, 2011 <sup>21</sup><br>Papish, 2013 <sup>30</sup><br><i>Pharmacy Students</i> Nguyen, 2012 <sup>25</sup><br>O'Reilly, 2011 <sup>31</sup><br>Patten, 2012 <sup>32</sup><br><i>Mental Health Nurses</i> Munro, 2007 <sup>33</sup><br><i>Mental Health Providers</i> Michaels, 2014 <sup>34</sup> | <i>Nursing Students</i> Goddard, 1998 <sup>22</sup><br><i>Medical Students</i> Kirby, 2011 <sup>35</sup><br>Symons, 2014 <sup>23a</sup> | <i>Medical Students</i> Symons, 2014 <sup>23a</sup><br><i>Primary Care Nurses</i> Melville, 2006 <sup>24</sup>                     | <i>Physical Therapy Students</i> Domenech, 2011 <sup>36</sup> | NF  | NF   | NF  |
| Interventions prompting interaction between patients and physicians or patients and the health care system | 5                 | NF   | <i>Primary Care Screening</i> Peterson, 2012 <sup>37</sup>  | <i>Primary Care Physicians</i> Lennox, 2007 <sup>38</sup><br>Turk, 2010 <sup>39</sup><br><i>Dentists</i> Meurs, 2010 <sup>40</sup> | NF  | <i>Primary Care Physicians</i> Wolraich, 2005 <sup>41</sup> | NF   | NF  |
| Virtual interventions that reduce barriers to accessing care   | 4                 | <i>Clinical Psychologists</i> Knaevelsrud, 2010 <sup>42</sup>  | NF  | NF   | NF  | NF  | <i>Occupational therapists</i> Finlayson, 2011 <sup>43</sup><br><i>Masters Level Therapists</i> Patten, 2012 <sup>32</sup> | <i>Masters Prepared Counselor</i> Shigaki, 2013 <sup>44</sup> |

ADHD = attention-deficit hyperactivity disorder; NF = not found.

<sup>a</sup>The Symons et al.<sup>23</sup> curriculum addresses physician attitudes toward various disability types including: sensory, physical, and intellectual disabilities. Therefore, this article appears in two population categories.

Among the 16 studies aimed at changing professionals' attitudes through training or curricula, the majority focused on changing the attitudes and beliefs of medical (n=7),<sup>21,23,27,29,30,35,45</sup> nursing (n=2),<sup>22,26</sup> pharmacy (n=3),<sup>25,31,32</sup> or physical therapy (n=1)<sup>36</sup> students. Three studies targeted practicing professionals: one studied primary care practice nurses;<sup>24</sup> and two studied mental health professionals.<sup>33,34</sup> Eleven of the 16 studies focused on physician attitudes toward people with a mental illness,<sup>21,25-27,29-34,45</sup> three focused on attitudes toward people with a physical disability,<sup>22,23,35</sup> two studies focused on attitudes toward people with an intellectual disability,<sup>23,24</sup> and one study focused on attitudes towards people with lower back pain.<sup>36</sup> One study focused on a dually diagnosed population that had mental health and substance use concerns.<sup>33</sup>

Five included studies attempt to reduce disparities at the point of care. Four of the five studies provide additional information about the patient and prompt physicians to pay attention to areas of known disparities during the routine clinical exam. One study teaches and empowers women with mobility impairments to get Pap tests and mammograms. All five studies promoting interaction between patients and physicians (or patients and the health care system) were conducted in the primary care setting; three focused on people with intellectual or learning disabilities, one focused on children with attention-deficit hyperactivity disorder, and one focused on women with mobility impairments.

The studies aimed at reducing barriers to accessing care were delivered by psychologists, occupational therapists, and masters prepared counselors. One of the four studies targeted people with mental illness, one focused on people with arthritis, and two focused on people with multiple sclerosis.

## Interventions Aimed at Changing Health Professionals' Attitudes

The framing of these articles generally spoke to reducing stigma,<sup>26,27,29-31,34,45</sup> changing stereotypic views,<sup>21,33</sup> filling gaps in training and understanding,<sup>23,24</sup> and familiarizing physicians with supportive equipment.<sup>35</sup> Table 4 summarizes the 16 studies of trainings or curricula aimed at changing health professionals' attitudes toward persons with disabilities.

**Table 4. Summary of interventions targeting provider attitudes by disability type**

| Study, Design, Setting   | Aim  | Sample Size Population           | Intervention Comparators  | Reported General Findings   |
|--|--|----------------------------------|---|---|
| Bannatyne, 2015 <sup>27</sup><br><br>Randomized trial<br><br>Queensland<br>Australia | To compare the effect of biogenic education versus traditional multifactorial education versus no education on volitional stigma towards patients with anorexia nervosa. | 41 fourth-year medicine students | The two active interventions were one-time, 3 hour courses that were identical in all respects, except information regarding the etiology of anorexia nervosa: the biogenetic arm emphasized potential genetic underpinnings of the disease: the multifactorial arm emphasized interaction between psychological and social etiologies. | Participants in both the biogenic and multifactorial arms had significantly less overall stigma, blame and responsibility associated with the patient with anorexia, and were significantly less likely to consider anorexia a vain or selfish illness, compared with the no intervention control. There were fewer significant findings between active intervention types. |

| Study, Design, Setting   | Aim  | Sample Size Population   | Intervention Comparators   | Reported General Findings  |
|--|--|--|--|--|
| Clement, 2012 <sup>20</sup><br>Randomized trial<br>University, UK                | To compare the effect of a DVD or a live intervention followed by discussion, and a lecture control in reducing stigma about mental illness                                      | 216 student general nurses   | Video vs. live interventions with similar content: personal narratives and experiences from mental health consumers and providers vs. lecture on stigma  | Both intervention formats decreased stigmatizing attitudes and increased intended social proximity compared with control.  |
| Cutler, 2012 <sup>45</sup><br>Controlled study<br>University, U.S.               | To determine the effect of a one-time exposure to an art exhibit featuring art created by people with chronic mental illness on medical student attitudes.                       | 174 pre-clinical medical students enrolled in a psychiatric medicine course                                | 64 students toured the art studio that was housed in state psychiatric facility, 44 of the 64 interacted with an artist (a person with a chronic mental health condition). The control group consisted of 110 students who had not visited the exhibit | Overall students who visited the museum had more positive feelings toward people with chronic mental illness and identified more positive personality traits in the population. However, among those who spoke directly to a person with a chronic mental health condition, there was an increase in perceived hopelessness of people with chronic mental illness. |
| Domenech, 2011 <sup>30</sup><br>Cluster-randomized trial<br>University, Spain    | To determine the effect of two brief educational modules (biopsychosocial or biomedical) on the attitudes of students and changes in the recommendations given to their patients | 170 second-year physical therapy students  | Education based on the biopsychosocial model of lower back pain management vs. lectures on the biomechanics of the spine   | Intervention participants had more positive attitudes and less fear in recommending general physical activity for people with lower back pain.   |
| Friedrich, 2013 <sup>29</sup><br>Randomized trial<br>Four medical schools, UK    | To determine the effect of a voluntary training to reduce mental health stigma on medical students' mental health-related knowledge, attitudes, and intended behavior            | 1,452 third-year medical students at baseline, 625 immediately after intervention, 137 at 6 month followup | Lecture, stories from patients and providers about mental health problems and stigma and role plays in small groups vs. no intervention  | Intervention group had improvements in mental health stigma-related knowledge, attitudes, intended behavior at immediate followup but not at 6 months.   |
| Goddard, 1998 <sup>22</sup><br>Pre-Post, historical control<br>University, Texas | To determine the effect of Sensitivity Lab on students' attitudes toward persons with disabilities immediately after the lab and at 6 weeks and 6 months                         | 121 nursing students enrolled in course on a chronic illness   | Sensitivity Lab, 8 hours: (1) simulation of various disabilities, (2) panel presentations by persons with disabilities and their caregivers, (3) small groups discussion vs. same course with no sensitivity lab                                       | Nursing students had relatively positive scores on the Attitudes Toward Disabled Persons scale, with no significant differences among groups.  |
| Kassam, 2011 <sup>21</sup><br>Clustered trial<br>University, UK                  | To compare the effect of 3 interventions on students' mental illness related knowledge, attitudes and behavior toward people with mental illness                                 | 188 third-year medical students at baseline, 110 with pre- and post-scores                                 | Presentation (1 hour) on mental illness related stigma including personal testimonies from a patient and caregiver and discussion vs. presentation plus role-plays (20 minutes) vs. no intervention  | Knowledge increased in both of the intervention arms compared with the control, but with no differences in physician attitudes or behaviors.   |

| Study, Design, Setting  | Aim   | Sample Size Population  | Intervention Comparators   | Reported General Findings  |
|---|---|---|--|--|
| Kirby, 2011 <sup>30</sup><br>Randomized trial<br>University, Canada                                     | To assess the effect of workshop tailored for undergraduate medical students in improving wheelchair-related knowledge, skills, and attitudes                                   | 26 first- and second-year medical students  | Wheelchair Education Workshop (4 hours: 45 minutes lecture, 2 hours wheelchair skill practicing, 1 hour community experience, a 15 minute debrief) vs. no intervention   | Intervention group had higher scores on the written wheelchair knowledge test and practical wheelchair skills examination, with no difference in attitudes between the groups.   |
| Melville, 2006 <sup>24</sup><br>Controlled trial<br>Glasgow, Scotland                                   | To assess the effect of training for nurses designed to reduce access barriers for people with intellectual disabilities on nurses' knowledge and self-efficacy                 | 123 nurses in primary care  | Training pack (45 pages) plus face-to-face training (3 hours, on knowledge and self-efficacy in care for people with intellectual disability) vs. training pack only vs. no intervention   | The combination group had increased knowledge and self-efficacy compared with the no intervention, with no difference between the training pack only group and the other two arms.   |
| Michaels, 2014 <sup>34</sup><br>2 Randomized controlled trials<br>Maryland, U.S.                        | To assess the effect of a workshop designed to reduce stigma surrounding mental illness for people with mental illness and providers of services to people with mental illness. | 127 people with mental illness and 131 mental health service providers were randomized.               | The 3 hour Anti-Stigma Project workshop (ASP) includes: a facilitated small-group discussion in which participants share their own experience of stigma, a video on the impact of public stigma on mental health services, and a group discussion of ways to combat public stigma on both a personal and systemic level. The control arms watched 3-hour videos on unrelated topics. | For providers, the workshop significantly improved awareness of stigma, reduced levels of prejudice towards people with psychiatric disabilities, and increased acceptability of a wide variety of personal goals of persons with disabilities. The intervention did not significantly improve providers' opinions regarding the potential for recovery from mental illness. |
| Munro, 2007 <sup>33</sup><br>Randomized trial<br>Mental health, community or hospital-based<br>Scotland | To assess the impact of training on the therapeutic attitudes and knowledge of nurses who work with people with co-existing substance use and mental health problems            | 49 mental health nurses   | 4 days of training including small interactive groups and lectures vs. no intervention   | Intervention group had improved attitudes immediately following the intervention and sustained at 6 months. Knowledge improved over time for both groups with no difference them.  |
| Nguyen, 2012 <sup>20</sup><br>Controlled study<br>Australia   | To compare the effect of direct versus indirect contact with mental health consumers on stigma  | 244 3 <sup>rd</sup> and 4 <sup>th</sup> year pharmacy students had complete, paired data for analysis | The direct contact arm attended a 2 hour workshop led by 3-4 mental health consumer educators and 2 pharmacists where consumers shared their personal experiences of mental illness with students. The indirect arm was 90 minutes and featured videos of consumers being interviewed as well as videos of clinical scenarios.   | There was no difference in social distance by delivery method. While both delivery methods significantly decreased stigmatizing beliefs, the direct contact arm showed additional gains on several items, compared to the indirect arm.  |

| Study, Design, Setting  | Aim   | Sample Size Population  | Intervention Comparators  | Reported General Findings   |
|---|---|---|---|---|
| O'Reilly, 2011 <sup>31</sup><br>Randomized trial<br>University of Sydney, Australia     | To assess the impact of delivering MHFA training for pharmacy students on their mental health literacy and stigma towards mental illness                                  | 272 (60 intervention, 212 control) third-year undergraduate pharmacy students   | MHFA course (12 hours) plus standard curriculum (9 hours plus community pharmacy placement) vs. standard curriculum only  | Intervention group improved in social distance, ability to correctly identify a mental illness, and confidence in providing services in mental illness.   |
| Papish, 2013 <sup>30</sup><br>Cluster-Randomized trial<br>University of Calgary, Canada | To examine the impact of a one-time contact-based educational intervention on stigma of mental illness among medical students enrolled in a multimodal psychiatry course  | 111 second-year medical students  | Contact-based intervention (2 x 1-hour patient stories of mental illness) at the beginning vs. end of 4-week mandatory psychiatry course  | Stigma toward mental illness improved for both groups after the course, with no difference between groups in the primary analysis. Stigma remained greater for mental illness than type 2 diabetes mellitus.  |
| Patten, 2012 <sup>32</sup><br>Randomized trial<br>University of Calgary, Canada         | To examine the impact of a contact-based intervention on stigma toward persons with schizophrenia or bipolar disorder.  | 74 third and fourth year pharmacy students from three Universities had data for all three time points (56.5%) of randomized population. | One-time, contact-based intervention varied in length by participating university (60-120 minute discussion featuring 2-3 consumer speakers) compared with a wait list control.   | Intervention group had significantly more positive attitudes and less stigma towards people with mental illness compared with wait list controls overall, and at two of the three participating Universities. |
| Symons, 2014 <sup>23</sup><br>Controlled study<br>Two public medical schools, NY        | To examine the effect of a longitudinal curriculum designed to improve medical students' knowledge, attitudes, and skills pertaining to care of persons with disabilities | 244 medical students  | First 3 years of 4-year curriculum addressing care for people with disabilities integrated into existing curricula (lectures from community agencies, interactions with individuals with disabilities, presentations of clinical encounters, and a precepted clinical experience treating a person with a disability) vs. standard curriculum | Intervention group improved in comfort with people with disabilities, but worsened in negative perceptions that people with disabilities are resentful and expect special treatment.                          |

MHFA = Mental Health First Aid.

Table 5 summarizes the common characteristics and modalities of included interventions aimed at changing provider attitudes toward persons with disability. The majority of interventions included direct contact with a person with a disability. Of the 16 included articles in this category, 11 interventions included direct contact with people with disabilities,<sup>21-23,25,26,29-32,34,45</sup> three included role playing with people with disabilities or actors playing the part of a person with a disability,<sup>21,23,29</sup> and two included a person with a disability as a trainer.<sup>24,25</sup> Twelve studies used one-time trainings or experiences of varying intensity,<sup>21,22,24-26,29,31-35,45</sup> two developed university curricula,<sup>23,30</sup> and two tested different approaches to teaching subject matter (biomedical versus psychosocial models of lower back pain; and biogenetic versus multifactorial etiological framings of anorexia nervosa).<sup>27,36</sup> One older study used a simulation in which providers “assumed various disabilities” for a certain amount of time<sup>22</sup> and one focused on medical students learning to use wheelchairs.<sup>35</sup> These last two simulation studies may be



considered controversial or outdated methods of competency training by members of the disability community. Simulation exercises do not accurately portray the experience of having a disability and may have the effect of reinforcing negative stereotypes toward members of the population, and make disability an individual instead of societal problem.<sup>46</sup>

**Table 5. Aggregate of interventions targeting provider attitudes by disability type**

| Disability Population                                     | Target of Intervention |                  |                   |                           |        |                         | Intervention Characteristics |              |                         |            | Modalities                              |   |
|---|------------------------|------------------|-------------------|---------------------------|--------|-------------------------|------------------------------|--------------|-------------------------|------------|---|---|
|   | Medical Students       | Nursing Students | Pharmacy Students | Physical Therapy Students | Nurses | Mental Health Providers | Direct Contact               | Role Playing | Trainer with Disability | Simulation | Training Sessions / One-time Experience | University Curricula / Theoretical Approach |
| People with a mental illness <sup>21,20-27,29-34,40</sup> | 5                      | 1                | 3                 |                           | 1      | 1                       | 8                            | 2            | 1                       |            | 9                                       | 2   |
| People with a physical disability <sup>22,23,35a</sup>    | 2                      | 1                |                   |                           |        |                         | 2                            | 1            |                         | 2          | 2                                       | 1   |
| People with an intellectual disability <sup>23,24 a</sup> | 1                      |                  |                   |                           | 1      |                         | 1                            | 1            | 1                       |            | 2                                       | 1   |
| People with lower back pain <sup>36</sup>                 |                        |                  |                   | 1                         |        |                         |                              |              |                         |            |   | 1   |

<sup>a</sup>The Symons et al.<sup>23</sup> curriculum addresses physician attitudes toward various disability types including: sensory, physical, and intellectual disabilities. Therefore, this article appears in two population categories.

The form of the comparators varied. For the five studies that used no-intervention or wait-list control, the duration of the five interventions ranged from 4 hours to 4 years.<sup>22,23,29,33,35</sup> Four studies that used the equivalent of a “usual care” control group generally embedded education or training components within curriculum that was otherwise relevant compared with the curriculum without the added component.<sup>30-32,36,45</sup> For example, one study compared a 12-hour Mental Health First Aid (MHFA) training program plus the standard mental health curriculum to the standard mental health curriculum alone for pharmacy students.<sup>31</sup> Another study provided a 60-90 minute, contact-based experience as part of a mental health pharmacy course; students who had the experience later in the semester served as the comparator population.<sup>32</sup> Two studies compared the effect of differing educational approaches, or disability framings, on student attitudes and beliefs.<sup>27,36</sup> Michaels et al. used a video attention control on an unrelated topic.<sup>34</sup> In addition to testing whether training is more effective than no training or usual care, four studies considered the comparative effectiveness of delivery modality<sup>25,26</sup> and intensity.<sup>21,24</sup> For example, one study had three arms: watching a DVD of individuals with mental health disabilities and their caregivers describe their experiences of mental health stigma followed by a researcher-facilitated discussion; the same testimonies delivered live, followed by a research-facilitated discussion delivered live; or a lecture on stigma provided by a mental health nurse researcher (no direct or indirect contact with consumers or care providers).<sup>26</sup> All three arms were roughly 75 minutes long.<sup>26</sup>

Table 6 organizes the studies by outcomes studied. No studies examined clinical outcomes with a controlled design, although one of the included studies assessed nurses’ self-reported changes in clinical behavior following the intervention to improve the accessibility of care for people with intellectual disabilities.<sup>24</sup>

**Table 6. Reported key study outcomes for trials aimed at changing provider attitudes**

|                               | Reducing Stigma or Changing Attitudes   | Knowledge                                      | Self-Efficacy or Treatment Confidence          | Intended Social Proximity or Behavior  |
|-------------------------------|---|--|--|--|
| Bannatyne, 2015 <sup>27</sup> | ↑ (Biogenic or multifactorial vs. control – sustained for 8 weeks)            | NM   | NM   | NM   |
| Clement, 2012 <sup>26</sup>   | ↑ (DVD or live vs. control)   | ↔ (DVD or live vs. control)                    | NM   | ↑ (DVD or live vs. control)  |
| Cutler, 2012 <sup>45</sup>    | ↑↓ (mostly positive, no effect on beliefs about recovery from mental illness) | NM   | NM   | NM   |
| Friedrich, 2013 <sup>29</sup> | ↔ (Initial gains lost at 6 months)  | ↔ (Initial gains lost at 6 months)             | ↔ (Initial gains lost at 6 months)             | ↔ (Initial gains lost at 6 months)   |
| Goddard, 1998 <sup>22</sup>   | ↔   | NM   | NM   | NM   |
| Kassam, 2011 <sup>21</sup>    | ↔   | ↑ (Either intervention arm vs. control)        | NM   | NM   |
| Melville, 2006 <sup>24</sup>  | NM  | ↑ (Live vs. control)<br>↔ (Packet vs. control) | ↑ (Live vs. control)<br>↔ (Packet vs. control) | NM   |
| Michaels, 2014 <sup>34</sup>  | ↑   | NM   | NM   | NM   |
| Munro, 2007 <sup>33</sup>     | ↑ (Sustained for 6 months)  | ↔  | NM   | NM   |
| Nguyen, 2012 <sup>25</sup>    | ↑ (Direct contact more effective than indirect on several items)              | NM   | NM   | ↔ (No difference between direct contact & indirect contact arms – both improved social distance) |
| O'Reilly, 2011 <sup>31</sup>  | NM  | ↑  | ↑  | ↑  |
| Papish, 2013 <sup>30</sup>    | ↑ (Course vs. control)<br>↔ (One-time vs. control)                            | NM   | NM   | NM   |
| Patten, 2012 <sup>32</sup>    | ↑   | NM   | NM   | NM   |
| Symons, 2014 <sup>23</sup>    | ↓   | NM   | NM   | NM   |

↑ Significant positive findings; ↔ No significant findings; ↑↓ Positive and negative statistically significant findings; NM = not measured.

Common outcomes included measures of stigma or attitudes,<sup>21-27,29-31,33,34,45</sup> knowledge,<sup>21,24,29,31,33</sup> self-efficacy or treatment confidence,<sup>24,29,31</sup> and intended social proximity or behavior (e.g., comfort working with someone with a mental health problem).<sup>25,26,29,31</sup> Scales used to measure stigma or attitudes included: the Attitudes toward Persons with Disabilities Scale,<sup>22,35</sup> Community Attitudes toward the Mentally Ill (CAMI) scale,<sup>29</sup> Opening Minds Scale for Health Care Providers (OMS-HC),<sup>30,32</sup> Mental Illness: Clinicians Attitudes Scale (MICA) scale,<sup>21,26</sup> Self-Determination Scale (SDS),<sup>34</sup> Recovery Scale (RS),<sup>34</sup> Causal Attributions Scale,<sup>27</sup> Attribution Questionnaire (AQ-9),<sup>25,34</sup> Opinions Scale,<sup>27</sup> Eating Disorder Stigma Scale,<sup>27</sup> and the Emotional Reactions to Mental Illness Scale (ERMIS).<sup>26</sup> Cutler et al. developed a 24-item instrument to rate the attitudes and feelings of medical students toward people with chronic mental illness.<sup>45</sup> Michaels et al. developed the Awareness Questionnaire (AwQ) to measure recognition of stigma in the mental health system and its impact on people with mental illness, and a stigma measure disguised as a knowledge test to circumvent social desirability.<sup>34</sup> Intended

social proximity was measured by Reported and Intended Behaviour Scale (RIBS)<sup>26,29</sup> and the Social Distance Scale.<sup>25</sup> Knowledge was measured using the Mental Health Knowledge Schedule (MAKS).<sup>29</sup> The Jefferson Scale of Physician Empathy was used by one study.<sup>29</sup> Munro developed a knowledge questionnaire called the Comorbidity Problems Perceptions Questionnaire (CMPPQ).<sup>33</sup>

Reported results were mixed. Twelve of the 16 studies measured physician stigma, attitudes, or beliefs.<sup>21-23,25-27,29,30,32-34,45</sup> In six of the 12 studies, the intervention significantly improved attitudes/reduced stigma;<sup>25-27,32-34</sup> four of the 12 studies found no significant effect of the intervention on attitudes/stigma;<sup>21,22,29</sup> two of the 12 studies found both positive and negative effects of the intervention on attitudes toward people with a disability;<sup>23,45</sup> one study found arms to be differentially effective on provider attitudes and stigma.<sup>30</sup> Knowledge was measured in six of the 16 studies.<sup>21,24,26,29,31,33</sup> Interventions improved provider knowledge in three studies;<sup>21,24,31</sup> no significant effects on knowledge were found in three studies.<sup>26,29,33</sup> Treatment confidence was measured in three of the 12 studies.<sup>24,29,31</sup> Significant increases in confidence were found in two studies;<sup>24,31</sup> no significant effects on treatment confidence was found in one study.<sup>29</sup> Provider intended social proximity was measured in four studies;<sup>25,26,29,31</sup> half of the interventions showed significant improvements on these outcomes.<sup>26,31</sup> The medium to high risk of bias and different PICOT combinations in the included studies does not allow for further analysis and synthesis of these reported effects.

Two trials reported outcomes that did not fit into Table 6. One study found students with the biopsychosocial lower back pain education had more positive attitudes and less fear in recommending general physical activity for people with lower back pain leading to more guideline consistent recommendations for work and activity.<sup>36</sup> In the other study, knowledge and skills measured were specific to wheelchairs.<sup>35</sup> Students in the intervention had statistically higher scores on the written wheelchair knowledge test and practical wheelchair skills examination compared with controls.<sup>35</sup> No difference in attitudes was observed between the intervention and control groups.<sup>35</sup>

## **Interventions Prompting Interaction Between Patients and Physicians or the Health Care System**

Table 7 summarizes five trials that prompt interactions between patients with disabilities and their physicians and health systems. Four of the five trials tested the effect of providing information or prompting clinician behavior at the point of patient interaction on the care received during that interaction.<sup>38-41</sup> One trial provided screening education tailored to women with mobility impairments and followed up the women to determine if care was received.<sup>37</sup> These interventions aimed to reduce disparities in provision of health or preventative care.

**Table 7. Interventions targeting patient/provider interactions for disability**

| Study, Design, Setting  | Aim   | Sample Size Population   | Intervention Comparators   | Reported General Findings  |
|---|---|--|--|--|
| Lennox, 2007 <sup>30</sup><br><br>Clustered-randomized trial at the general practitioner level<br><br>Primary care, Australia | To determine the effectiveness of a CHAP vs. usual care on health promotion and prevention among adults with IDs  | 453 adult participants with ID in 34 clusters of primary care physicians                     | CHAP (21-page booklet: medical history; prompt for physician to perform a targeted examination; list of commonly unrecognized or poorly managed conditions within the ID population; guide for caretaker to complete a health action plan) vs. usual care  | Most health promotion and disease prevention outcomes in the CHAP arm were significantly increased compared with control.  |
| Meurs, 2010 <sup>40</sup><br><br>Randomized trial<br><br>Two dental care centers, Netherlands                                 | To investigate whether information about a patient who is intellectually disabled would result in better cooperation during a first dental visit.                     | 58 people with ID  | Questionnaire (e.g., on patient communication preferences, completed by guardians) read by the dentist prior to the visit vs. limited patient information (age, medical condition)   | Providing additional information to the dentists did not increase patient cooperation during the dental encounter, regardless of disability severity.  |
| Peterson, 2012 <sup>37</sup><br><br>Randomized trial<br><br>Oregon, U.S.  | To assess the effect of a program to encourage women with mobility impairments to get recommended mammograms and pap tests on receipt of these screening services.    | 211 women with mobility impairments were randomized, 156 completed pre- and post-tests (74%) | 90-120 minute small group (4 women) workshop educating women on breast and cervical cancer risk, overcoming barriers to screening, and building skills to communicate with physicians followed by monthly calls for 6 months post-intervention. Intervention led by women with mobility disabilities. Control group received written material on health promotion. Both arms received money and small gifts for participation. | Intervention significantly improved receipt of pap test (among those not up-to-date) compared with control; there was no significant difference in mammography screening at 6 months (among those not up-to-date) compared with control. All outcomes self-reported. |
| Turk, 2010 <sup>39</sup><br><br>Cluster-randomized trial at practice level<br><br>UK  | To test the effect of a patient-carried PHP for people with learning disabilities on number of visits per year, communication, and number of health problems reported | 201 adults with learning disabilities in 40 practices  | PHP (hand held health record with overview of relevant conditions and dependent on participation of both providers and patients or caregivers) vs. usual care  | No difference between groups in annual visits, knowledge, or communication; increased reporting of health outcomes in the PHP group.   |

| Study, Design, Setting                                       | Aim  | Sample Size Population   | Intervention Comparators  | Reported General Findings  |
|--|--|--|---|--|
| Wolraich, 2005 <sup>41</sup><br><br>Longitudinal<br><br>U.S. | To test the effect of an information and communication session between parents, teachers, and primary care providers of children with ADHD on coordination of care | 234 students (Only 34% of students randomized to the intervention arm had a parent receive the intervention, and only 19% had a PCP receive the intervention.) | 1-hour session with the child, parent, teacher, and/or physician (focused on sharing information about the student with ADHD between all parties) vs. no intervention. Tools included: teacher, parent, and PCP contact sheets; daily report cards; medication side-effects checklists; and a parent ADHD manual. | The intervention did not increase communication, defined as the number of times there was verbal or written communication between physicians and teachers. |

ADHD = Attention Deficit Hyperactivity Disorder; CHAP = Comprehensive Health Assessment Program; IDs = intellectual disabilities; PCP = primary care provider; PHP = personal health profile.

Four of the five studies focused on individuals with intellectual or neurobehavioral learning disabilities.<sup>38-41</sup> The United Kingdom and Australia have implemented health checks for individuals with intellectual disabilities on a large scale. The strongest trial in this grouping is from Australia and tests the effect of a Comprehensive Health Assessment Program (CHAP).<sup>38</sup> The CHAP is a 21-page booklet divided into three sections: a medical history completed by the carer and carried to the doctor's office on the day of the appointment; a section completed by the doctor that documents he/she has reviewed the carer's completed medical history, completed a targeted examination, and developed a health action plan with the carer; the last section has a list of commonly unrecognized or poorly managed conditions and disability-specific comorbidities.<sup>38</sup> Four hundred fifty-three people with intellectual disabilities participated in the cluster randomized trial. People with the intervention were significantly more likely to: have sensory deficits identified, receive a tetanus/diphtheria booster or hepatitis B serology, have their weight recorded, and women were significantly more likely to have a Pap smear and mammogram.<sup>38</sup> Many of the effect sizes were large. The United Kingdom and Australia have implemented health checks for individuals with intellectual disabilities on a large scale.

The other three studies that attempted to prompt physician behavior at the point of interaction had major theoretical and methodological limitations.<sup>39-41</sup> Unlike the CHAP tool that clearly prompted physician behavior (similar to checklist interventions), the Meurs et al. questionnaire provided a large amount of information without a pathway for action. The authors identified not giving dentists enough time to "digest" this information as a potential study limitation.<sup>40</sup> The intervention drew additional attention to the limitations of the person with the disability without assisting the dentist to identify strategies to change his or her approach to be more culturally competent. Further, this study offered no opportunity for patients and/or caregivers to rate the physicians on the interaction. The Turk and Wolraich studies had low participation rates.<sup>39,41</sup> In Turk et al., 20 percent of care providers in the intervention arm stated they had not been given a personal health profile (PHP) at followup, only 18 percent of patients and 39 percent of care providers who said they received the PHP reported using the tool, and less than a third of care providers who said they received the PHP reported taking the tool to a primary care visit.

The four previously described studies prompt physician action or physician-patient interaction at the point of care. The last study in this category prompts patients to interact with

the health care system.<sup>37</sup> Women with mobility disabilities participated in a two-hour small group (four women) workshop led by women who also had mobility disabilities. The workshop covered not only general screening benefits, but also ways to overcome physical barriers to screenings and how to communicate with physicians to facilitate screenings.<sup>37</sup> Participants in the intervention arms also received structured phone calls for 6 months. Compared with a written information control, women in the intervention group self-reported receiving significantly more pap testing; there was no significant difference in mammography rates between the attention and control groups. The two major weaknesses of this study are the lack of attention control and the self-reported screening outcomes.

## **Interventions Improving Access to Care**

The four trials on access to care are part of a much larger literature on virtual care for people with disabilities. Many virtual access articles were excluded during title/abstract screening because the intervention occurred outside the formal health care system; that is, the study did not involve health care practitioners delivering health care virtually, or the focus of the study was not creating access based on the nature of the disability. For example, Morland conducted two trials of virtual care for veterans with post-traumatic stress disorder (PTSD).<sup>47,48</sup> However, the remote care required people in remote areas to travel to a central location for group therapy. This intervention seemed more focused on creating access due to workforce shortages than creating a way to deliver care that would feel safer and less stigmatizing.

The inclusion status of the final set was influenced by article framing. Articles were framed as follows: “Despite the findings supporting the Managing Fatigue program [for people with multiple sclerosis], its major limitation to date has been its inaccessibility to individuals who cannot travel to the community sites where the program is offered;” (p.1131)<sup>43</sup> “The Internet might provide an alternative information and treatment opportunity for people who avoid care because of concerns about the stigma of receiving mental health treatment;” (p.73)<sup>42</sup> “For individuals with RA, travel may be difficult due to pain or functional limitations;” (p. 1578)<sup>44</sup> and “Telephone counseling was selected as the intervention delivery mode because it is an effective behavior change approach that overcomes barriers to participation such as distance, accessibility, and limited transportation, barriers that may be even more prominent among people with MS.”(p.90).<sup>49</sup>

Table 8 summarizes the included studies providing virtual access to care.

**Table 8. Summary of interventions providing virtual access to care**

| Study Design Setting   | Aim   | Sample Size Population | Intervention Comparators   | Reported General Findings  |
|--|---|------------------------|--|--|
| Bombardier, 2013 <sup>49</sup><br><br>Randomized trial<br><br>U.S.         | To determine the effect of a telephone-based intervention to reduce severity of major depression in persons with MS by using motivational interviewing to change levels of physical activity. | 92 people with MS      | An initial in-person visit was followed by seven, 30 minute telephone counseling calls and a final in-person visit compared with a wait list control group. The intervention was delivered by master's level counselors. | There was no clinically significant difference in depression symptom severity or remission rate among the treated. However, there were statistically significant differences found on secondary outcome, including: mean change in depressive symptoms, depression severity, negative affect, clinical diagnostic criteria for major depression or dysthymia, and MS-related side-effects. |
| Finlayson, 2011 <sup>43</sup><br><br>Randomized trial<br><br>U.S.          | To test the effect of a small-group teleconference on fatigue management among adults with MS   | 191 people with MS     | Six 70 minute weekly group teleconferences delivered by licensed occupational therapists vs. waitlist  | Intervention had improved fatigue impact, sustained at 6 months, but no difference in fatigue severity, self-efficacy.   |
| Knaevelsrud, 2007 <sup>50</sup><br><br>Randomized trial<br><br>Netherlands | To test the effect of a therapist-led CBT writing intervention on PTSD symptoms   | 95 people with PTSD    | A CBT-based writing intervention delivered by doctoral-level clinical psychologists via email (10 over 5 weeks) vs. waitlist   | Intervention group has improved PTSD and mental health symptoms, sustained at 18 months, with no difference in physical health.  |
| Shigaki, 2013 <sup>44</sup><br><br>Randomized trial<br><br>U.S.            | To test the effect of an RA self-management intervention and weekly phone call on symptoms, self-efficacy, quality of life  | 108 people with RA     | RA help (10 week online cognitive-behavioral self-management group program) plus weekly one-to-one 15-30 minute phone call vs. waitlist  | Intervention group has improved self-efficacy and quality of life, sustained at 9 months, with no effect on health status or pain.   |

CBT = cognitive behavioral therapy; MS = multiple sclerosis; PTSD = post-traumatic stress disorder; RA = rheumatoid arthritis.

While all of the studies in this group used a virtual access to care intervention, each study used different populations, intervention characteristics, and targeted outcomes. Use of waitlist controls was the only element common across studies.

The primary outcome for the counseling intervention to decrease major depression by increasing physical activity in people with MS was a reduction in depression severity, as measured by the Hamilton Depression Rating Scale (HAM-D).<sup>49</sup> A clinically significant response to treatment was defined as a 50 percent decrease in the total HAM-D score. There was no clinically significant difference in depression severity between the treatment control groups. However, treating HAM-D scores as continuous, there was a significant decrease in depression severity among the treated, negative affect, and number of people meeting the criteria for major depressive disorder or dysthymia among the treated.<sup>49</sup>

The primary outcomes for the teleconference intervention aimed at managing fatigue in individuals with MS include: fatigue severity (measured using the Fatigue Impact Scale [FIS]), fatigue impact (measured using the Fatigue Severity Scale [FSS]), and health-related quality of

life (measured using the SF-36 Quality of Life Scale).<sup>43</sup> An intent to treat analysis found significant effects of the intervention on all three subscales of the fatigue impact severity measure and the role physical subscale of the SF-36; fatigue severity, self-efficacy, and the other seven domains of the SF-36 did not differ significantly.<sup>43</sup>

Primary outcomes of the therapeutic writing intervention for PTSD include measures of: symptoms of posttraumatic stress (Impact of Event Scale, IES-R), depression and anxiety (SCL-90), self-reported physical and psychological function (SF-12), and patient and therapist agreement (Working Alliance Inventory [WAI]).<sup>42,50</sup> Participants in the intervention arm showed significant improvements over time on all measures except physical health, compared with the waitlist control.<sup>50</sup>

Rheumatoid arthritis (RA) online outcomes included rheumatic disease specific self-report of health status and well-being (Arthritis Impact Measurement Scales 2, AIMS2), an arthritis specific self-efficacy measure (Arthritis Self-Efficacy Scale [ASES]), depression (Center for Epidemiologic Studies Depression Scale, CES-D), quality of life (QLS-15), measure of joint and pain tenderness (Rapid Assessment of Disease Activity in Rheumatology, RAPID), a measure of social connectedness (Social Provisions Scale, SPS), and a measure of loneliness (University of California, Los Angeles Loneliness Scale, version 3, LS-3).<sup>44</sup> Immediately after interventions, significant gains in self-efficacy and quality of life were observed; these gains were maintained for 9 months post-intervention.<sup>44</sup>

## Discussion

### Overview

Despite the difficulty in locating studies that fit a cultural competence for disabilities concept due to the lack of commonly used indexing terms and the minimal application of the cultural competence concept to disability research, we identified 25 intervention studies. These 25 studies map to only a small portion of the many and diverse groups that comprise the overall set of people with disabilities.

The most traditional cultural competence intervention, provider training, was also the most common type of study found in this review. This literature was dominated by interventions aimed at reducing stigma and changing provider attitudes toward people with mental illness. Only four studies attempted to change provider attitudes and beliefs about people with physical or intellectual disabilities, two of which attempted to do so through having students participate in a disability simulation (an approach with the potential to confound stereotypic thinking). Contact-based interventions, in which providers interacted with a person with a disability, were the most common intervention type; two contact-based interventions resulted in more negative attitudes among some participants.<sup>23,45</sup> Twelve of the 16 included trainings or curricula studies developed for students, not working professionals. Many of the available studies were not designed to capture how well initial knowledge gains or changes in attitudes are sustained over time. Of those that did have a longitudinal design, one study found changes were not sustained for 6 months,<sup>29</sup> two studies found changes were sustained for 2 and 6 months respectively.<sup>27,33</sup> The effectiveness of these interventions depends on students applying their pre-service training to their work in clinical settings.

We considered two other types of interventions in this review: the patient or physician prompt at the point of care; and virtual care that creates disability sensitive access. Lennox and colleagues are pioneering low-tech, seemingly effective ways to prompt universal screenings for



areas of known disparities for persons with intellectual disabilities. While promising, we did not find additional high quality trials to support this work. If there is little evidence for upstream interventions, such as provider trainings,<sup>51</sup> the research community may want to also focus on downstream, point of care interventions. Interventions that prompt the physician at the point of care work hand-in-hand with interventions that empower the person with disabilities to talk to their doctor.<sup>37</sup>

We also broadened our definition of cultural competence to include virtual interventions that addressed disability related barriers to access including difficulty traveling and not wanting to get care because of stigma. These studies have the most patient-centered outcomes. Just as focusing on the point of care does not mean giving up on changing provider attitudes and beliefs, creating a parallel system for care does not preclude making the mainstream system more disability competent.

## Research Directions

The risk of bias for most of the included studies was high (Appendix D). The major weaknesses of this literature are the lack of attention controls, lack of appropriate comparators, attrition, and social desirability bias of pre- post attitude scales. Michaels et al. is the only included study to try to address social desirability among respondents.<sup>34</sup> More well-designed studies are needed to test the effectiveness of disability competence interventions, particularly for nonmental health related disabilities. We need to be looking for unintended effects of trainings, and the effect of trainings and one time interventions on patient-centered outcomes. Without attending to methodological concerns, it will remain difficult to answer whether such interventions improve care and reduce health disparities.

Cultural competence is not a one-size-fits-all concept across populations that experience health disparities. Much of the team's work during this review was spent defining the concept of cultural competence for the disability population. The work of developing definitions for cultural competence as well as effective solutions for improving providers' knowledge and training in the health needs of people with disabilities should involve people with disabilities. While community-based participatory research with racial and ethnic groups has a fairly strong track record, much could be done to bring the perspective of people with disabilities into the research process. Future research on disability-related health care disparities and interventions to address them should target dimensions most important to people with disabilities and include more patient-centered outcomes. Including people with disabilities in research conceptualization and design is critical to identifying more effective solutions and producing evidence that could be understood and used by various stakeholders including people with disabilities.

Many disability groups and subgroups are not represented in this literature. Many subgroups exist within the disability populations with multiple perspectives, interests, and challenges. These differences can be further complicated by factors not directly attributable to disability, such as rural or urban location, poverty status, or racial and ethnic differences. Interventions targeting the intersection of populations of interest (such as race and disability) were also not well researched for this population. Researchers have begun to document health disparities at the intersection of disability and race/ethnicity.<sup>52-56</sup> There is also movement to align disparities research across race/ethnic and disability populations.<sup>7,55,57</sup> However there is not a sufficient evidence base to conclude whether interventions used to promote racial and ethnic provider cultural competence will produce reductions in disparities when used to promote provider cultural competence for people with disabilities in health care contexts. Carefully designed studies conducted for

race/ethnic and disability populations, as well as their intersection, are needed. Intervention types appear to be tied to disability types in the literature. Work is needed to conceptualize cultural competence to address inclusion of the many populations and interventions under the diverse disability umbrella.

## **Limitations**

This review is limited by the difficulty of locating literature using either MeSH® terms or natural language keywords. This difficulty is exacerbated by the new extension of the concept of cultural competence to disability cultures. This, in turn, may be influenced by a lack of consensus among disability communities about whether disability is a “culture.”

While care and attention was dedicated to defining the scope boundaries for this review, they are necessarily arbitrary; no clear lines of demarcation can be easily drawn to separate patient-centered care, health literacy, or other quality improvements from cultural competence. Interventions that focused solely on changing the patient (e.g., patient education and health promotion) were excluded because while they targeted a reduction in a health disparity experienced, they did not require change on the part of the physician or the health care system. We also excluded wellness and secondary disease prevention trials that did not target the formal health care delivery system or its providers. Those studies are, however, relevant to the larger discussion of reducing health disparities in this population.<sup>58-74</sup>

Only eight of the 25 included studies were conducted in the United States. This raises questions regarding transferability of the included studies to the U.S. health care system.

## **Conclusions**

The results of the search show a patchy literature set that highlights the intrapopulation diversity subsumed under the disability umbrella. The literature also fails to recognize the intersections of disability populations with other populations experiencing healthcare disparities. The broader concept of diversity competence may be more appropriate for many people at these intersections. Further discussion of population intersectionality and alternative constructions of cultural competence that address structural inequities can be found in Chapter 5. None of the included studies measured the effect of cultural competence interventions on health care disparities. The medium or high risk of bias of the included studies, the heterogeneity of populations, and the lack of measurement consensus prohibited pooling estimates or commenting about efficacy in a meaningful or responsible way.

# Chapter 3. Lesbian, Gay, Bisexual, and Transgender Populations

## Introduction

Cultural competence refers to efforts to reduce the cultural and linguistic barriers between patients and medical personnel that interfere with effective health care delivery.<sup>75</sup> In the early 1990s, cultural competency programs and trainings expanded their areas of focus from immigrant and English language learner populations to all racial and ethnic minority populations experiencing health care disparities.<sup>75</sup> The tenets of cultural competence may help reduce health disparities in lesbian, gay, bisexual, and transgender (LGBT) populations as well.<sup>76</sup>

Estimates of the size of the LGBT populations are hindered by the lack of sexual orientation, sexual behavior, and gender identity items in national surveys.<sup>77,78</sup> The few nationally representative surveys that have collected LGBT data highlight how different ways of defining sexual orientation for research affect prevalence statistics. For example, some estimates include only people who self-identify as lesbian, gay, or bisexual, while others include people who report same-sex sexual behavior but identify as heterosexual. Bauer and Jairam, using data from the U.S. National Survey of Family Growth, found: 2.5 percent of female respondents between the ages of 20 and 44 identified as bisexual, and 1.4 percent identified as homosexual.<sup>79</sup> However, among women who ever had sex, approximately 12 percent had at least one female sex partner in their lifetime and 4 percent had one female sexual partner in the last year.<sup>79</sup> A similar pattern was found among men. Pethela et al. used data from the New York Community Health Survey and found: 3.7 percent of male respondents identified as gay, and 1.2 percent identified as bisexual.<sup>80</sup> National estimates of the proportion of men who have sex with men range from 2.9 percent in the past year to 6.9 percent ever.<sup>80</sup>

Available estimates suggest that almost nine million people in the United States identify as something other than heterosexual (e.g., gay, lesbian, bisexual, queer, pansexual, etc.) and an additional 10 million people who identify as heterosexual report engaging in sexual behavior with someone of the same sex.<sup>81</sup> Overall, approximately a quarter of Americans report some level of same-sex attraction.<sup>81</sup> For many people, the dimensions of sexual orientation – i.e., identity, attraction, and behavior – do not completely overlap. This discordance has implications beyond prevalence estimates; observed health disparities, and the interventions to address these disparities, differ based on whether or not the population is defined by identity or behavior.<sup>82-84</sup>

Transgender and gender nonconforming people, i.e., people whose gender identity or expression are different from those typically associated with their assigned sex at birth, likely constitute less than 1 percent of the population; however, demographic data for this population are sorely lacking.<sup>85</sup>

## Terminology

This review was commissioned by the Agency for Healthcare Research and Quality (AHRQ). To be consistent with other national reports, AHRQ recommends use of the terms lesbian, gay, bisexual, and transgender throughout this report. While LGBT is probably the most widely used acronym, consensus on terminology for this population is lacking. LGBT may exclude people who do not identify as lesbian, gay, bisexual, or transgender but who are sexually or romantically involved with people of the same or multiple genders or sexes. However, behavior-based terminology, including men who have sex with men (MSM), men who have sex

with men and women (MSMW), women who have sex with women (WSW), and women who have sex with women and men (WSWM), may also be problematic. These terms can divide the LGBT community socioeconomically and fail to recognize the important role of identification and community membership.<sup>86</sup> The American Association of Medical Colleges (AAMC) has recently advocated the form of person-first language; instead of gay patient, patient who may be gay.<sup>87</sup> This construction is also not yet widely used or accepted.

Although gender and sexual minority populations are often (and in this report) grouped together under the LGBT acronym, sexual orientation and gender identity are distinct concepts and capture different populations with distinct health and health care needs, concerns, and disparities. The following definitions were adapted from the 2011 Institute of Medicine Report on the Health of LGBT People:<sup>77</sup>

- Gender identity—One’s basic sense of being a man, woman, or other gender, such as transgender. Non-cisgender may be used to describe individuals and populations whose gender identity differs from the gender typically associated with their sex assigned at birth.
- Sexual orientation—Encompasses attraction (i.e., sexual or romantic feelings for people of the same gender/sex, another gender/sex, or multiple genders/sexes), behavior (i.e., sexual or romantic activity with people of the same gender/sex, another gender/sex, or multiple genders/sexes), personal identity (i.e., one’s conception of self as gay, bisexual, straight, etc.) and social identity (i.e., a sense of membership in a social group). “Sexual minority” may be used to describe individuals and populations whose sexual attraction, behavior, and/or identity are not exclusively heterosexual.

The purpose of this report is not to resolve language disputes. For studies included in this report, terminology used to refer to LGBT people is consistent with the source publication whenever possible. However, we have chosen not to use the term homosexual to describe identity in this report, because that term is associated with recent periods in U.S. history when being gay was considered pathological and criminal.

## Health Disparities

The most well-studied health disparity in the LGBT population is HIV/AIDS incidence and prevalence. Men who have sex with men are 44 times more likely than heterosexual men to be newly diagnosed with HIV and differences in all-cause mortality rates between gay and heterosexual men are largely attributable to this disparity.<sup>88</sup> A large proportion of the research on LGBT health has been dedicated to the incidence, prevention, and treatment of HIV/AIDS among men who have sex with men.<sup>89,90</sup> Lumping transgender male-to-female individuals with men who have sex with men masks the higher rates of HIV infection in this subgroup, particularly among African Americans.<sup>77</sup>

However, recent evidence demonstrates that LGBT populations face numerous additional health risks requiring intervention. For example, gay, bisexual, and other men who have sex with men have been found to be at increased risk of sexually transmitted infections (STI) other than HIV, such as syphilis, gonorrhea, chlamydia, human papillomavirus, and hepatitis A and B;<sup>91</sup> lesbian and bisexual women are more likely to be obese and to use tobacco and alcohol than heterosexual women;<sup>82,84,92,93</sup> and gay, lesbian, and bisexual adolescents and young adults of all genders have higher rates of tobacco and alcohol use, unhealthy weight control, and risky sexual behaviors than their straight peers.<sup>94-96</sup> LGBT populations also experience a greater prevalence of mental disorders, such as anxiety and depression, have higher rates of suicidal ideation and

attempts, and are subject to significantly more emotional, physical, and sexual trauma than straight and cisgender people, or individuals whose experience of their own gender matches their assigned sex at birth.<sup>97-100</sup> Individuals who identify as bisexual may experience more psychological distress compared with those who identify as heterosexual, gay, or lesbian.<sup>97</sup> The LGBT population is diverse in terms of race, ethnicity, disability status, socioeconomic status, and immigration status, and risk factor disparities may be further intensified by intersecting identities and multi-minority statuses.<sup>101-103</sup>

Despite accumulating evidence of risk factor disparities between LGBT and heterosexual and/or non-cisgender populations, scant research connects these risk factor disparities to intermediate or long-term health outcomes, such as cancer or cardiovascular disease (CVD). For example, apart from research that has found a higher prevalence of virus-linked cancers among men who have sex with men,<sup>104</sup> little is known about cancer incidence or mortality among LGBT populations because sexual orientation or gender identity information is not routinely captured in cancer registries. This lack of surveillance data is particularly problematic, as cancer risk factors may cluster in LGBT populations. For example, lesbian and bisexual women have higher rates of a number of breast cancer risk factors, including increased alcohol use, higher rates of smoking, obesity, and nulliparity, and they may receive breast cancer screening less frequently than heterosexual women (though the evidence regarding cancer screening behaviors among lesbian and bisexual women is conflicting).<sup>105-107</sup> Sexual minority women have also been found to have a higher Framingham general CVD risk score than straight women, indicating that they may be at greater risk of developing CVD.<sup>108</sup>

Thomas et al. delineated four phases of disparities research: (1) documenting the disparities, (2) exploring rationales for the disparities, (3) providing evidence for solutions, and (4) moving towards structural, multi-level interventions.<sup>6</sup> LGBT health disparities research is largely still in the first generation, as it is difficult to document the disparities without data from national health surveys and registries on sexual orientation and gender identity.<sup>77</sup> This review uses the limited second generation evidence for the causes of health disparities in LGBT populations to discuss the interventions designed to address these barriers in the formal health care system. As the disparities in various LGBT subgroups become better defined, barriers can also be identified more precisely, and interventions can be more tailored to root causes.

## **Cultural Competence**

Cultural competence has been widely promoted as one approach to reduce health disparities. Since cultural competence remains variously defined and operationalized, the term has come to describe a broad range of system- or provider-level interventions. Specific recommendations to create culturally competent health care for LGBT people include: educating staff on specific health disparities experienced by the LGBT communities and how to collect sexual and social history, using gender-neutral language on forms and communication, refraining from making assumptions about a person's sexual orientation or gender identity by asking directly about identity and sexual behavior, displaying LGBT-friendly symbols, and registering with the Gay and Lesbian Medical Association's online directory.<sup>109,110</sup> For many physicians, like many people in society, examining strongly held beliefs and biases may be a necessary first step to creating a welcoming environment for LGBT patients. Inclusive and nondiscriminatory policies can support the work of cultural competence. However, political interventions are beyond the scope of this review.

## Scope and Key Questions

### Scope of the Review

This review examines the evidence for cultural competence interventions at the system- and provider-level designed to address known or suspected health disparities among LGBT persons. As such, the review does not address policy-level evaluations. Being clear about whether interventions are within or outside is important, but challenging. This review focuses mainly on whether cultural competency interventions change the clinicians' behaviors (such as communication and clinical decisionmaking), the patient-provider relationship, and/or clinical systems to result in better outcomes for the patient.

### Key Question

**KQ:** What is the effectiveness of interventions to improve culturally appropriate health care for LGBT adolescents (ages 13-17), young adult (18-25), and adults?

### PICOTS

Table 9 provides the populations, interventions, comparators, outcomes, timing, and settings (PICOTS) of interest. The analytic frameworks can be found in Chapter 1 and Appendix A.

**Table 9. Review PICOTS—LGBT populations**

| PICOT             | Criteria   |
|-------------------|--|
| Population        | LGBT adolescents (ages 13-17), young adults (ages 18-25) and adults<br>Overall gender disparities experienced by women (in relationship to men) were not considered in this review.<br>Biological sexual development and disorders of sexual development are not part of this review.  |
| Intervention      | Cultural competence/culturally appropriate care provider education and training<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to patients<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to providers   |
| Comparator groups | Usual care<br>Head-to-head trials of different strategies  |
| Outcomes          | Intermediate outcomes <ul style="list-style-type: none"> <li>• Provider training and motivation outcomes (competencies, knowledge, changes in attitudes)</li> <li>• Provider behavior, such as clinical decisionmaking, communication</li> <li>• Provider beliefs/cognitions about the priority population, reducing stereotyping, stigmatization</li> <li>• Improved access to health services</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> <li>• Patient health behaviors</li> <li>• Use of preventive services and other access to care measures</li> </ul> Final health or patient-centered outcomes – reduced disparities in terms of <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, substance use)</li> </ul> Adverse effects of intervention(s) <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> |
| Timing            | Variable – depends on the purpose of the intervention  |
| Setting           | Inpatient, outpatient, and community settings in which patients from priority populations are interacting with health care providers.  |

LGBT = lesbian, gay, bisexual, transgender.

## Methods

This review followed the methods suggested in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at [www.effectivehealthcare.ahrq.gov/methodsguide.cfm](http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm)); certain methods map to the PRISMA checklist.<sup>12</sup> We recruited a technical expert panel to provide high-level content and methodological expertise feedback on the review protocol. The protocol was posted on July 8, 2014, at [www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov). This section summarizes the methods used.

## Literature Search Strategy

We searched Ovid MEDLINE®, PsychInfo, and Cochrane EPOC from 1990, when the concept of cultural competence gained traction, to June 2015. Because cultural competence interventions in LGBT communities are not well defined, and the literature set was relatively small, all intervention studies for the population of interest were reviewed for inclusion (no cultural competence intervention filter was used). Searches and screening were performed iteratively to identify concept boundaries and tighten the working definitions and eligibility criteria. The final search algorithms are provided in Appendix B. We also manually searched reference lists from systematic reviews and employed back and forward searching of key articles recommended by experts.

## Study Selection

We reviewed bibliographic database search results for randomized controlled trials (RCTs) systematic reviews, nonrandomized controlled trials, before and after case reports with comparators, and interrupted time series studies published in English language relevant to our PICOTS framework. All studies identified at title and abstract as relevant by either of two independent investigator underwent full-text screening. Two investigators independently performed full-text screening to determine if inclusion criteria were met.

Eligible studies tested an intervention to provide culturally appropriate health care to LGBT adolescents, young adults, and adults.

Interventions that targeted providers, formal health care systems, or the ability of the patient to communicate or interact with the provider or formal health care system in support of culturally competent care were eligible. Such interventions could include remote (such as web- or phone-based) interventions to provide access to care in a manner sensitive to the needs of the LGBT population. Studies that tailored interventions to individuals (patient-centered) rather than the community (cultural competence) were excluded. Interventions that were merely disease-driven (such as HIV) rather than population-driven were not included.

Studies conducted in public-health or specialized LGBT clinics were excluded. While the authors acknowledge the historic and continued importance of public-health clinics and other parallel systems in providing much of the care to the MSM population, particularly gay men with human immunodeficiency virus (HIV), the point of this review is to identify strategies to make the average, nonspecialized provider and system more able to address the specific needs of LGBT populations.

This restriction on setting eliminated a large portion of the LGBT literature that is focused on changing sexual risk-taking behavior related to HIV/AIDS. For example, a 2013 systematic review identified 33 U.S.-based RCTs of behavioral interventions to reduce HIV transmission and infection that were specifically designed for the MSM population.<sup>111</sup> Nine studies were

deemed by the authors to meet the Center for Disease Control and Prevention's Prevention Research Synthesis criteria and thus evidence-based.<sup>112-119</sup> Only one of these studies is included in this review;<sup>118</sup> the other eight did not meet inclusion criteria.

We also expanded the criteria to include studies from other developed countries that tested interventions that could possibly transfer to U.S. health care.

Initial search results were vetted by the full team. Differences of opinion regarding eligibility were resolved through consensus. Articles excluded at full text are provided in Appendix C with reasons for exclusion.

## **Data Extraction, Synthesis, and Presentation**

We evaluated the risk of bias in included studies according to study design using criteria from the Cochrane risk-of-bias tool in interventional studies (Appendix D). Given the paucity of literature identified, the heterogeneity of the study populations and interventions, small study samples, the lack of details for complex interventions and comparators, and the high risk of bias assessment for most of the included studies, we determined the strength of evidence for cultural competence interventions, in general, to be insufficient and thus we were unable to draw meaningful conclusions from the literature. Therefore, we focused on summarizing the results into evidence tables and conducted a qualitative synthesis, grouping synthesis results using emergent patterns from identified interventions, and evaluating the challenges of the literature that present barriers to forming inferences from study results. One investigator abstracted the relevant data from eligible trials directly into evidence tables. A second investigator reviewed evidence tables and verified them for accuracy.

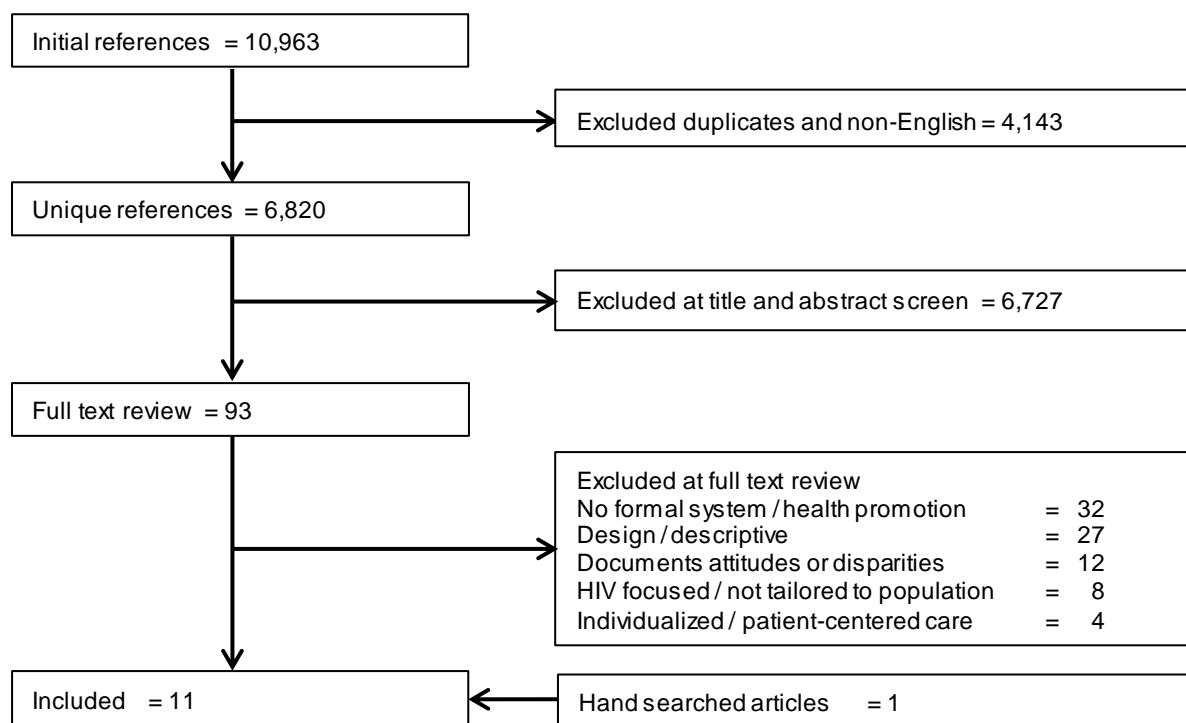
## **Results**

### **Literature Search Results**

We identified 6,820 unique English language citations (Figure 5) from 1990 to June 2015. After excluding articles based on title and abstract, full texts of 85 articles were reviewed to determine final inclusion.



**Figure 5. Literature flow diagram—LGBT populations**



LGBT = lesbian, gay, bisexual, transgender.

The 11 included studies (12 manuscripts) were not easily combined. The studies fell into five categories: interventions aimed at prompting patients to interact with the formal health care system for screening or testing (n=2); a clinic-based mental health and substance use intervention tailored to a LGBT population (n=1); a psychosocial intervention for a LGBT population with cancer (n=1), interventions aimed at behavioral risk reduction that involve formal health care providers (n=4), and interventions aimed at changing provider knowledge, attitudes, and beliefs through trainings or curricula (n=3). Studies were generally high risk of bias (Appendix D). Since the risk of bias and heterogeneity of the studies precluded any strength of evidence other than insufficient, we describe the studies by emergent patterns.

Table 10 describes the included studies by intervention type and LGBT population. Four studies focused on men who have sex with men,<sup>118,120-124</sup> two studies focused on gay and bisexual men,<sup>123,124</sup> three focused on lesbian and/or bisexual women,<sup>125-127</sup> and the three educational interventions focused more broadly on multiple LGBT populations.<sup>110,128,129</sup> We identified no studies specifically addressing the provision of culturally competent services for transgender people.

Four approaches to cultural competence were observed among the included studies: three included studies used a person to deliver the intervention that was also a member of the LGBT population;<sup>118,125,126</sup> two used a combination of provider training and prompts for the provider and patient during the clinical encounter;<sup>120,121</sup> three studies focused solely on provider education;<sup>110,128,129</sup> and three tailored an existing intervention to better reflect the target population.<sup>122-124,127</sup> Study sample sizes ranged from 20 to 1,396. Less than half of studies (5/11) were randomized trials.<sup>118,122-124,126,127</sup> Only one study (two manuscripts) used an attention control.<sup>123,124</sup>

**Table 10. Summary of included LGBT population studies**

| Type of Cultural Competence Interventions   | Number of Studies    | MSM   | WSW                                  | Lesbian Women              | Lesbian and Bisexual Women         | Gay and Bisexual Men  | LGBT   |
|---|----------------------|---|--------------------------------------|----------------------------|------------------------------------|---|--|
| Interventions aimed at prompting patients to interact with the formal health care system for screening or testing | 2                    | Blas et al., 2010 <sup>122</sup>  | NF                                   | NF                         | Bowen, et al., 2006 <sup>126</sup> | NF  | NF   |
| Clinic-based Mental Health and Substance Use Interventions Tailored to a LGBT Population                          | 1<br>(2 Manuscripts) | NF  | NF                                   | NF                         | NF                                 | Peck et al., 2005 <sup>123</sup><br>Shoptaw et al., 2005 <sup>124</sup> | NF   |
| Interventions Aimed at Behavioral Risk Reduction that Involve Formal Health care Providers                        | 4                    | Bachmann et al., 2013 <sup>120</sup><br>McKirman et al., 2010 <sup>118</sup><br>Patel et al., 2012 <sup>121</sup> | Marrazzo et al., 2011 <sup>127</sup> | NF                         | NF                                 | NF  | NF   |
| Interventions Aimed at Changing Provider Knowledge, Attitudes and Beliefs through Trainings or Curricula          | 3                    | NF  | NF                                   | NF                         | NF                                 | NF  | Beagan, 2003 <sup>128</sup><br>Kelley et al., 2008 <sup>129</sup><br>McGarry et al., 2002 <sup>110</sup> |
| Psychosocial intervention for a LGBT population with cancer   | 1                    | NF  | NF                                   | Fobair 2002 <sup>125</sup> | NF                                 | NF  | NF   |

LGBT = lesbian, gay, bisexual, transgender; MSM = men who have sex with men; NF = not found; WSW = women who have sex with women.

## Interventions Aimed at Prompting LGBT Patients To Interact With the Formal Health Care System for Screening or Testing

Table 11 summarizes the two studies in this category. One study was designed to address screening disparities as a potential modifiable pathway to early detection of breast cancer.<sup>126</sup> The RCT examined counseling to improve breast self-exam and mammography among women who self-identified as lesbian or bisexual.<sup>126</sup> The cultural competence approach used in this study was patient/provider sexual identity concordance; a key element of the program was making it clear to participants that all scientists, staff, and counselors involved in the studies were sexual minority women.<sup>126</sup> The authors reported significant increases in self-breast examination and mammography, and significant decreases in perceived risk, cancer worry, and mental health that were sustained over time compared to a waitlist/delayed control.<sup>126</sup> However, the study did not include an arm that compared the effectiveness of the counseling program delivered by providers who were not explicitly identified as sexual minority women. One of the more interesting findings of the trial is the differential effectiveness of the intervention by degree of “outness.” Among women in the intervention arm, after controlling for income, education, age, and sexual identity, women whose sexual orientation was known to coworkers and family members were three times more likely to have screening mammography.

Blas et al. tested the effect of an online intervention to encourage men who have sex with men, whether or not they identify as gay, to get tested for HIV on obtaining HIV testing.<sup>122</sup> The study randomized 142 gay-identified men to the video-based intervention group and 130 to the

text-based control intervention. Ninety-seven non-gay identified men (men who have sex with men but do not consider themselves to be gay) were randomly assigned to the video-based intervention and 90 to the text-based control intervention.<sup>122</sup> Even though this study was conducted outside of the United States (Lima, Peru), it is included because it prompts interaction with the health care system (going to get tested), documents whether testing occurred, and targets an underserved segment of the MSM population, men who have sex with men but do not identify as gay. The intervention itself is tailored to match the behavior and identity of the participant (non-gay or gay).<sup>122</sup> The 5-minute videos use the health belief model to transition through the stages of change and incorporated common reasons why MSM do not get tested.<sup>122</sup> Among the gay identified population, the intervention had no effect on intention to test (30 days or next 6 months), appointment making, or actual clinic attendance. However, among non-gay identified MSM, the video intervention significantly increased intention to test over the next 30 days and actual attendance at clinic.<sup>122</sup> These two studies highlight the importance of considering the multiple dimensions of sexual orientation (i.e., identity, attraction, behavior) when designing and tailoring interventions.

**Table 11. Interventions aimed at increasing interaction with the formal system for LGBT populations**

| <b>Study, Design, Setting</b>                    | <b>Aim</b>  | <b>Sample Size, Population</b>   | <b>Intervention, Comparators</b>  | <b>Reported General Findings</b>  |
|--|---|--|---|---|
| Blas, 2010 <sup>122</sup><br>RCT<br>Peru         | To test the effect of 5 minute videos customized based on self-identification as non-gay, gay, or trans on HIV testing. | 808 gay-identified and 588 non-gay adult MSM who had not been tested for HIV during the last year and were not HIV positive. | Customized (non-gay, gay, trans) 5 minute vs. public health text, both through a gay website  | The video was not more effective than text among the gay identified population on intention to get tested (30 days or 6 months), making an appointment online, or HIV testing. However, among the non-gay identified population, the video was more effective than text on intention to get tested (30 days) and HIV testing. |
| Bowen, 2006 <sup>126</sup><br>RCT<br>Seattle, WA | To test the effectiveness of a group counseling and educational program on breast and mammography screening.            | 150 lesbian and bisexual women aged 18-74 with no history of breast or ovarian cancer  | Four weekly 2-hour small group sessions led by a trained sexual minority woman health counselor versus a wait list control. Session themes included risk assessment, breast cancer screening, stress management and social support. | Significant increases in self-breast exam and mammography up to 24 months post-intervention and significant decreases in perceived risk, cancer worry, depression and anxiety. The intervention was more effective for women who were more "out."   |

HIV = human immunodeficiency virus; LGBT = lesbian, gay, bisexual, transgender; MSM = men who have sex with men; RCT = randomized controlled trial.

## **Clinic-Based Mental Health and Substance Use Interventions Tailored to an LGBT Population**

Increases in substance use and depression have been observed in the LGBT population.<sup>130-132</sup> We identified only one RCT tailoring a therapy or drug intervention to an LGBT population that met inclusion criteria for this review.<sup>123,124</sup> Self-identified gay and bisexual men (n=263) seeking outpatient behavioral drug abuse treatment for methamphetamine dependence, with a Structured Clinical Interview-verified diagnosed methamphetamine dependence, began a 2-week baseline period that took a similar format to the actual intervention (attendance three times per week, urine sample collection, and group therapy).<sup>124</sup> After this 2-week baseline period, 162 participants who had attended at least two of the four cognitive behavioral groups during baseline were randomized to one of four study conditions three times a week for 16 weeks: cognitive behavioral therapy (CBT) sessions, contingency management (CM), CBT and CM, or “gay-specific” CBT sessions.<sup>123,124</sup> The comparator, CBT, focused on teaching patients skills to achieve, maintain, and recover abstinence after relapse, including healthier coping strategies, recognition of triggers and cravings management, and stages of recovery.<sup>123,124</sup> Gay-specific CBT included the skills taught in the basic CBT with “referents to cultural norms and values of urban GBM [gay and bisexual men] and providers’ emphasis on reduction of HIV-related sexual behaviors.” (p. 126).<sup>123</sup> Gay-specific CBT was not differentially effective on treatment retention, number of days of methamphetamine abstinence, or depression outcomes when compared with standard CBT.<sup>123,124</sup> The gay-specific CBT condition significantly reduced unprotected receptive anal intercourse compared with standard CBT arm; however, those gains were not maintained over time.<sup>124</sup>

## **Interventions Aimed at Behavioral Risk Reduction That Involve Formal Health Care Providers**

We identified four studies for behavioral risk reduction interventions in the LGBT population that involved health care providers and were judged to be transferable to the nonspecialized health care system: three studies specific to MSM, and one specific to WSW. No studies were identified that were specific to transgender people. Table 12 provides a summary of the studies.

Two prospective cohort studies without comparators were included because they represent strong examples of sexual health cultural competence interventions.<sup>120,121</sup> In the Providers Advocating for Sexual Health Initiative (PASHIN), all primary care providers received a 5-hour training that emphasized enhancement of provider communication skills around sexual risk assessment and behavior change.<sup>120</sup> Similarly, the CDC-funded Partnership for Health intervention (part of the Study to Understand the Natural History of HIV/AIDS in the Era of Effective Therapy [SUN]) trained providers to conduct brief risk-reduction counseling during the clinical encounter. All clinic staff (including support staff) attended a 4-hour training that included lecture, videos, small group activities, and patient-provider simulations before study initiation, and a 1-month post-intervention booster session.<sup>121</sup> Pocket guides and videos also were used to support provider education.<sup>121</sup>

In the PASHIN study, participants completed a computerized assessment that generated a tailored, theory-based advice sheet with prioritized objectives for providers to use during the routine clinical encounters that occurred approximately every 3 months.<sup>120</sup> The intervention also included a prescription to recap the providers’ intervention messages that was given to each

patient to take home.<sup>120</sup> For SUN, patients received prevention messages in written form and then had the messages reinforced by providers.<sup>121</sup>

The RCT differed from the PASHIN and SUN studies because the counseling, scheduled around a routine primary care visit, was delivered by ethnically diverse, HIV positive members of the MSM community supervised by a clinical psychologist.<sup>118</sup> Treatment advocates received 40 hours of training on specific CBT techniques and motivational interviewing. Weekly supervision with doctoral- and masters-level licensed therapists, as well as recorded session audits, allowed for over 85 percent compliance with program protocol.<sup>118</sup> During the four-session intervention, a computer was used for the advocate and patient to complete each prescribed module and create a behavioral plan.<sup>118</sup>

**Table 12. Interventions aimed at behavioral risk reduction for LGBT populations**

| Study, Design, Setting   | Aim  | Sample Size, Population                 | Intervention, Comparators  | Reported General Findings   |
|--|--|---|--|---|
| Bachmann, 2013 <sup>120</sup><br><br>Longitudinal<br><br>Primary care, university-based HIV clinic   | To test the effect of computer-assisted (tailored per behavioral assessment), provider-delivered interventions on sexual risk behaviors. | 234 MSM                                 | Computer-assisted, provider-delivered interventions during routine primary care visits over 3 years vs. assessments prior to intervention; staff received 5 hours of training on change models and sexual risk assessment. | Significantly reduced the number of unprotected insertive oral and anal intercourse acts and number of sexual partners, but not number of unprotected receptive anal sex acts or HIV disclosure.  |
| Patel, 2012 <sup>121</sup><br><br>Prospective cohort, pre-post<br><br>7 specialty clinics in 4 cities  | To test the effect of computer-assisted, provider-delivered interventions on sexual behaviors and STIs.                                  | 216 HIV-infected MSM treated with HAART | Computer-assisted, provider-delivered interventions over 2 years vs. pre-intervention visit; staff received 5 hours of training  | STI incidence decreased and unprotected intercourse with HIV-positive partners increased but did not change with HIV-negative partners or partners of unknown status; no effect on disclosure of HIV-positive status.                         |
| McKirnan, 2010 <sup>118</sup><br><br>RCT<br><br>3 primary care clinics (gay/lesbian health center, public clinic, private medical center), Chicago | To test the effect of individual counseling sessions on sexual behaviors.  | 317 HIV-positive, MSM                   | 4 60-90 minute individual counseling sessions, 3-month call, 6- and 12-month followup sessions delivered by ethnically diverse, HIV-positive members of the MSM community vs. usual primary care                           | Transmission risk (unprotected sex with HIV-negative partners or partners of unknown status) decreased at 6 and 12 months; overall unprotected sex (with partners of any HIV status) decreased at 6 months but was not sustained at 12 months |
| Marrazzo, 2011 <sup>121</sup><br><br>RCT<br><br>University-based clinic  | To test the effect of individual counseling on persistent or recurrent BV  | 89 WSW aged 16-35 with BV               | Vaginal metronidazole (both groups) plus individual education to reduce misconceptions regarding BV vs. usual care (general STI education)   | Increased glove use during digital-vaginal sex at one-month followup, but no effect on persistent or recurrent BV based on survival curve analysis  |

BV = bacterial vaginosis; HAART = highly active antiretroviral treatment; HIV = human immunodeficiency virus; LGBT = lesbian, gay, bisexual, transgender; MSM = men who have sex with men; RCT = randomized controlled trial; STI = sexually transmitted infections; WSW = women who have sex with women.

Both prospective cohort studies reported to significantly reduce most unprotected sexual behaviors, but not HIV disclosure.<sup>120,121</sup> PASHIN also found reductions in STI incidence.<sup>121</sup> However, in addition to the lack of comparators, half the invited patients declined to participate, and 40 percent of enrolled patients in PASHIN did not receive all five provider-delivered interventions. The RCT intervention was effective in the short-term, but significant reductions in unprotected anal intercourse and transmission risk were not sustained at 12 months.<sup>118</sup> More rigorous evaluation is needed to evaluate the effectiveness of these components used individually and in combination.

One study addressed secondary prevention among WSW diagnosed with bacterial vaginosis (BV). Using focus groups, an informational intervention was developed to target misconceptions held by WSW, such as “women can’t get STDs by having sex with other women,” or “women who have sex with women don’t need pelvic exams.”<sup>127</sup> This randomized trial was part of a larger, clinic based study of BV treatment failure among women who have sex with women.<sup>127</sup>

In addition to addressing patient-specific misconceptions, the intervention targeted the use of gloves during digital vaginal sex, condom use for insertive toys, and use of water-based lubricant (gloves, condoms, and lubricant provided to intervention arm).<sup>127</sup> Participants in the intervention arm were significantly more likely to use gloves during digital-vaginal sex; there were no differences in frequency of other target behaviors including receptive digital-anal sex, sharing sex toys without cleaning them, and vaginal intercourse with men without condom use.<sup>127</sup> The intervention also had no effect on persistent or recurrent BV.<sup>127</sup>

## Interventions Aimed at Changing Provider Knowledge, Attitudes, and Beliefs Through Trainings or Curricula

Three provider training programs and curricula have been developed for providing care to LGBT populations,<sup>110,128,129</sup> but none have been rigorously evaluated. Two programs were short: a 2-hour program for second-year medical students<sup>129</sup> and a 3-hour seminar for post graduate year residents. One program ran 2 years as part of a medical curriculum.<sup>128</sup> To evaluate the impact of curricula, short programs used pre-/post-test designs while the undergraduate curriculum used the previous class cohort as a historical control. Table 13 gives summaries of the studies.

**Table 13. Summary of provider training interventions for LGBT populations**

| Study, Design, Setting  | Aim   | Sample Size, Population  | Intervention   | Reported General Findings  |
|---|---|--|--|--|
| Kelly, 2008 <sup>129</sup><br>Pre-post<br>University of California at San Francisco | To evaluate the effect of a short seminar on second year medical students' knowledge and attitudes toward treating members of the LGBT community.                     | 75 second year medical students  | A 2-hour seminar: LGBT patient panel and a scenario-based small group exercise led by faculty and physician members of the LGBT community  | Improved (4/16 survey items) knowledge, attitudes immediately following the intervention.  |
| McGarry, 2002 <sup>110</sup><br>Pre-post<br>Rhode Island Hospital, Brown University | To evaluate the effect of a short seminar on MD residents' preparedness and comfort with dealing with psychosocial and sexual issues of members of the LGBT community | 37 general internal medicine residents                                       | A 3-hour seminar: video, lecture, and case study on health care needs and barriers among LGBT people and physician attitudes   | Increased self-reported preparedness to address LGBT health care issues; no significant change in mean provider comfort with gay men or lesbians, although 9/11 residents who were uncomfortable at pre-test improved. |
| Beagan, 2003 <sup>128</sup><br>Prospective cohort, historical control<br>Canada     | To evaluate a course offered during the first and second years of the undergraduate medical curriculum  | 132 third-year medical students:<br>61 class cohort<br>71 historical control | Weekly seminars on social issues in medicine and socio-cultural differences, including gender, sexual orientation, race, and socio-economic status, affect the practice of medicine. | No significant differences in medical students' beliefs about how patient factors or their own backgrounds affect the care they provide.   |

LGBT = lesbian, gay, bisexual, transgender.

After the 2-hour seminar, four of the 16 items were significantly changed by the intervention (largest absolute change .57 on a 5-point scale).<sup>129</sup> Students more strongly disagreed with the following three statements after the intervention: “Access to health care is the same for LGBT people as for other members of the population;” “LGBT people are less likely than heterosexual people to be in long-term monogamous relationships;” and “I would prefer not to treat patients with gender identity issues.”(p.251)<sup>129</sup> Students more strongly agreed with the following statement after the intervention: “As a physician, I feel it is important for me to know about my patients’ sexual orientation, sexual practices, and gender identity.”(p.251)<sup>129</sup> This study had several methodological weaknesses, including absence of a control population, low response rate among eligible participants (52 percent), high baseline familiarity with the LGBT population, and no measure of effect of intervention over time.<sup>129</sup>

In another study, after attending the 3-hour seminar, residents felt more prepared to deal with lesbian and gay health care issues (absolute change .47 on a 5-point scale).<sup>110</sup> Mean changes in comfort summary scores were not significantly changed by the intervention, but trended in the direction of more comfort.<sup>110</sup> Limitations of this study include the lack of a control group, small study population, unclear instruments, absence of measurement of effects over time, and high baseline reported comfort and knowledge of the population.<sup>110</sup> It is not clear, however, whether either of these trainings actually produced changes in attitudes or merely elicited the socially desirable response from physicians, immediately post-training.

The 2-year intervention had no effect on medical students’ beliefs; students who received the intervention were as or more likely to believe social factors, including class, race, culture, religion, gender or sexual orientation, did not affect their education or practice.<sup>128</sup> Limitations of this study include: response rates of 50-60 percent of the eligible population participated and an unclear test of statistical significance on individual characteristics.

## **Psychosocial Interventions**

One study conducted a pre and post test of the effect of Supportive-Expressive group therapy on distress, anxiety and depression, self-efficacy, social support, physician satisfaction, and quality of life among 20 lesbian women who were recently diagnosed with primary breast cancer.<sup>125</sup> Outcome information was collected on all participants at baseline, 3, and 6 months; outcomes were collected for 17 of 20 participants at 12 months.<sup>125</sup> Participants met in groups of four or more, 12 times, for 90 minutes each session with 95 percent attendance at sessions.<sup>125</sup> Groups were led by lesbian clinical social workers; no other changes to the Supportive-Expressive therapy protocol were made.<sup>125</sup> The intervention reduced tension, pain, and anxiety, while improving mood, self-efficacy, and sleep. However, the intervention appeared to have a negative effect on perceived social support and no effect on patients’ rating of physicians or body image.<sup>125</sup> The ability to interpret these findings is limited by the absence of a control group.

## **Discussion**

### **Overview**

Our main finding is that the evidence on which to base culturally competent LGBT health care does not (yet) exist. Disparities in the LGBT population are not well documented,<sup>77</sup> and research testing interventions to reduce health disparities is even more rare. Over 6,800 articles were reviewed, resulting in 11 included studies, only five of which were RCTs.



Four approaches to cultural competence were observed: three studies used a person to deliver the intervention that was also a member of the LGBT population;<sup>118,125,126</sup> two used a combination of provider training and prompts for the provider and patient during the clinical encounter;<sup>120,121</sup> three studies focused solely on provider education,<sup>110,128,129</sup> and three tailored an existing intervention to better reflect the target population.<sup>122-124,127</sup> Sample sizes ranged from 20 to 1,396. Less than half of the studies (5/11) were RCTs.<sup>118,122-124,126,127</sup> Only one study (two manuscripts) used an attention control.<sup>123,124</sup>

While research on MSM remains under-resourced relative to HIV/AIDS disease burden,<sup>133</sup> a significant body of research has addressed how to deliver HIV prevention for this population using cultural competence approaches. This shows that the next step of conducting rigorous research addressing LGBT health disparities can be successfully undertaken if resources are made available.

This literature highlights the predominance of a parallel health care system for people with HIV/AIDS that grew out of mainstream fear at the height of the epidemic. AIDS service organizations (ASOs) in major urban areas (e.g., San Francisco AIDS Foundation, AIDS Project Los Angeles, and the New York Gay Men's Health Crisis), as well as smaller community health centers throughout the country, provided medical and psychosocial care to gay, bisexual, and other MSM.<sup>77</sup> These centers became affiliated with universities and received funding from multiple sources, including the government. In the subsequent decades, with the advent of life-changing drugs (highly active antiretroviral therapy, or HAART), these centers continue to provide care and comprehensive services for people with HIV/AIDS, particularly newly diagnosed men of color who have sex with men. However, the infrastructure developed as a result of the AIDS epidemic is now also used to deliver a host of other services to members of the LGBT community (see Fenway Health, [fenwayhealth.org](http://fenwayhealth.org)). This parallel health care system may inadvertently mask the need for cultural competence in the mainstream or nonspecialized health care system. Although many of the ideas for treating the LGBT population will likely come from the well-developed specialty care, using a segregated or supplementary system of care should be a patient-elected decision, not one driven either by stigma or the mainstream systems' lack of skill. The past 5 years have seen significant attempts to end "AIDS exceptionalism," by mainstreaming HIV care from ASOs into the health care system.

The health care system plays a key role in eliminating health disparities among populations. However, the 2011 IOM report found that "LGBT individuals face barriers to equitable health care that can have a profound impact on their overall well-being" (p. 297).<sup>77</sup> LGBT patients report having to teach providers about their health care-related needs, experiencing provider discrimination, receiving inappropriate care recommendations, and even being denied care.<sup>134-136</sup> Past experiences and/or fear of such treatment reduces the likelihood that LGBT patients will disclose their sexual orientation or gender identity to providers.<sup>137,138</sup> Disclosure in a health care encounter is associated with receiving more appropriate health services and better doctor-patient communication.<sup>139-141</sup>

Interventions aimed at changing the knowledge and attitudes of providers are a hallmark of cultural competence in other populations (although their effectiveness is not clear),<sup>51</sup> but most providers have little to no training in LGBT health.<sup>142,143</sup> Some protocols and recommendations have been published.<sup>144-147</sup> However, many physicians are not familiar with existing recommendations, hold misconceptions, and about LGBT patients, hold explicit and implicit biases against LGBT people, and are hesitant to inquire about support systems. In addition, many

are uncomfortable managing sexually transmitted infections (STIs) in LGBT populations.<sup>148,149</sup> Training programs and curricula have been developed to overcome some of these barriers in knowledge, attitude, and skill,<sup>110,129</sup> but none have been rigorously evaluated. The Fenway Institute is one of the sources of provider LGBT health education and training.<sup>150</sup> The American Association of Medical Colleges (AAMC) has also recently published a guideline including LGBT-based competencies for medical education curricula.<sup>87</sup>

## Research Directions

Research into other areas of health across the LGBT population remains extremely thin.<sup>77</sup> Our understanding of where important additional disparities might exist as well as interventions to address them has not been explored in full. As a result, health professionals may over-identify MSM and transgender populations with one disease (HIV/AIDS). Simultaneously, they may under appreciate or ignore the high rates of physical, mental, chemical, other sexual and relational health challenges facing LGBT patients and communities. Until this disparity is addressed, challenges such as the high rate of suicide in LGBT adolescents may continue to be largely ignored in the health system. Similarly, the lack of studies in transgender health care may contribute to it being viewed more as a specialty than part of competent comprehensive care.

Likewise, across the LGBT population, we observed disparities within the disparity. Although an emerging body of research addresses culturally competent HIV-related services for men who have sex with men, few studies have examined culturally competent services for other LGBT populations. In particular, more research is needed on the provision of culturally competent services to sexual minority women, transgender people, and LGBT youth as well as on the provision of culturally competent services to gay and bisexual men beyond those related to HIV. Dual and multiple minority status also warrant attention and research. For example, LGBT people of color or LGBT people with disabilities may face intersecting and potentially synergistic challenges in health disparities and access to culturally competent care. More research is needed into the inter-relationship between health disparities and how multiple minority status influences risk and resiliency.

The empirical evidence has not kept up with the social and political movements that are rapidly changing societal acceptance and insurance access for LGBT people. A number of individuals and organizations have made recommendations about how to reduce barriers to care for LGBT individuals. Appendix E summarizes some other published recommendations. These suggestions form the basis for future research that assesses the effectiveness of their content.

## Limitations

One of the major limitations of this review is the difficulty of distinguishing between cultural competence and the related concept of patient-centered care. For example, individual tailored interventions, such as an individualized cancer risk assessment, were deemed to be patient-centered care rather than cultural competence and were excluded on the basis of this distinction.<sup>75</sup> Significant trials excluded based on these criteria are Project Enhance and the Healthy Living Project.<sup>151,152</sup> Project Enhance involved an individualized HIV prevention intervention delivered by medical social workers in concert with primary care visits at Fenway Health.<sup>151</sup> A movement toward individualized, patient-centered care is underway. Interventions that are adapted individually rather than culturally may prove to be as or more effective. However, this review is focused on cultural tailoring of interventions.

## **Conclusions**

The results of the search show a patchy literature set that highlights the intrapopulation diversity subsumed under the LGBT umbrella terminology. The literature also fails to recognize the intersections of LGBT populations with other populations experiencing health care disparities. The broader concept of diversity competence may be more appropriate for many people at these intersections. Further discussion of population intersectionality and alternative constructions of cultural competence that address structural inequities can be found in Chapter 5. None of the included studies measured the effect of cultural competence interventions on health care disparities. The medium or high risk of bias of the included studies, the heterogeneity of populations, and the lack of measurement consensus prohibited pooling estimates or commenting about efficacy in a meaningful or responsible way.

# Chapter 4. Racial/Ethnic Populations

## Introduction

In the late 1970s and 1980s, the concept of cross-cultural medicine emerged from recognition and advocacy surrounding cultural and linguistic barriers to health care.<sup>75</sup> In the early 1990s, increased emphasis on health care disparities expanded the focus of cultural competency programs and trainings beyond immigrant populations and interpersonal aspects of cross-cultural health care. New focal areas included health care systems and all racial and ethnic minority populations experiencing health care disparities. With the aim of improving access and reducing health care disparities,<sup>153</sup> cultural appropriateness was framed as addressing cultural barriers to care and dimensions of provider quality.<sup>154</sup> Views of cultural competence (CC) have continued to evolve along with understanding of the structural sources of health disparities. New terms such as “structural competence” have been proposed for provider training to emphasize structural aspects of health inequalities.<sup>155</sup> On the other hand, interventions to improve cultural competence of the health care system may reflect nuanced conceptualization of the multilevel sources of disparities, transcending the origins of the term “cultural competence” in cross-cultural medical encounters.

Past systematic reviews have found an association between self-reported racism and illness among people of minority groups.<sup>156,157</sup> Perceptions of discrimination based on race/ethnicity are also associated with worse patient-reported experiences of care.<sup>158</sup> Past reviews have also found evidence of racism by health care providers toward minorities, although little is known about the extent of provider racism or how to measure it.<sup>159,160</sup> Personally mediated racism includes underlying (often unacknowledged) prejudices among clinicians that cause them to treat others differently, with clinical consequences, according to race/ethnicity.<sup>161</sup> Individual level racism can also manifest as omissions such as lack of services or failure to convey a welcoming environment.

In many instances, discrimination against minorities is exacerbated by and rooted in socioeconomic issues. Minorities are more likely to lack health insurance coverage and they are disproportionately covered by public programs like Medicaid, where reports of insurance-based discrimination (being treated unfairly by health care providers based on enrollment in public insurance or a lack of insurance) are higher.<sup>162-164</sup> Those who report insurance-based discrimination also report restricted and delayed access to care.<sup>165</sup>

## Health Disparities

The Institute of Medicine defines health care disparities among population groups as the difference in treatment or access not justified by the differences in health status or preferences of the groups.<sup>162</sup> Disparities in health outcomes for minority groups defined by race and/or ethnicity are an enduring challenge within the health care system.<sup>166</sup> For example, compared with whites, both African Americans and Latino Americans encounter higher rates of preventable hospitalizations and complications from chronic diseases.<sup>166</sup> Difficulties in documenting health care disparities include the presence of multiple racial/ethnic subpopulations and ways of defining these subpopulations.<sup>162</sup>

## **Cultural Competence**

Cultural competence has been variously defined and does not have a consensus definition. A foundational definition for racial and ethnic cultural competence was developed in 1989 through the Georgetown University Child Development Center: “Cultural and linguistic competence is 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. ‘Culture’ refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. ‘Competence’ implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.”<sup>167</sup>

An updated model of cultural competence produced by the National Center for Cultural Competence at the Georgetown University Center for Child and Human Development more explicitly posits cultural competence as an organizational or system capacity which requires understanding of the social, cultural, political, and economic contexts of health care organizations.<sup>168</sup> In this model, improved cultural competence leads to reduction in health care disparities as well as decreased bias and discrimination.

## **Scope and Key Questions**

### **Scope of the Review**

This review examines the evidence for cultural competence interventions at the system and provider level designed to address known or suspected health disparities in people from race/ethnic groups. We do not address policy-level evaluations.

Clarity about which interventions are within the scope of cultural competence versus those outside is important, but challenging. This review’s main focus is on whether cultural competency interventions change health care providers’ behaviors (such as communication and clinical decisionmaking), the patient-provider relationship, and/or clinical systems to ultimately result in better outcomes. The review focuses on interventions within the formal health system (such as located at clinic, led by a nurse, or treatment of a specific health condition that could be delivered within the formal health care system) rather than on public health outreach programs and other parallel systems outside the formal system. Within the clinical context, interventions aimed at improving care for all patients (such as patient-centered care or collaborative care) were excluded unless the intervention specifically addressed a cultural competence component and was compared with care without that component. Similarly, treatment interventions for health conditions were not in scope unless the intervention was specifically adapted to people from a particular racial/ethnic group and tested against a nonadapted and otherwise comparable intervention. The primary outcomes of interest were reductions in disparities among populations for a given health outcome measure. Since no studies directly evaluated disparity reduction, we focused on health outcomes and other patient-centered outcomes such as patient perceptions of cultural competence.

## Key Questions

**KQ:** What is the effectiveness of interventions to improve culturally appropriate health care for racial/ethnic minority children and adults?

## PICOTS

Table 14 provides the populations, interventions, comparators, outcomes, timing, and settings (PICOTS) of interest. The analytic frameworks can be found in Chapter 1 and Appendix A.

**Table 14. Review PICOTS—racial/ethnic populations**

| PICOTS            | Criteria  |
|-------------------|---|
| Population        | Racial/ethnic children and adults   |
| Intervention      | Cultural competence/culturally appropriate care provider education and training<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to patients<br>Cultural competence/culturally appropriate care clinic-based interventions targeted to providers  |
| Comparator groups | Usual care<br>Head-to-head trials of different strategies   |
| Outcomes          | Intermediate outcomes <ul style="list-style-type: none"> <li>• Provider knowledge, attitudes, and competencies (skills) in providing culturally competent health care</li> <li>• Provider behavior, such as clinical decisionmaking, communication</li> <li>• Provider beliefs/cognitions about the priority population, reduction in stereotyping, stigmatization</li> <li>• Patient beliefs/cognitions such as improved trust, perceived racism</li> <li>• Improved access to health services</li> <li>• Utilization of health services</li> <li>• Patient experience/satisfaction</li> <li>• Patient health behaviors</li> <li>• Use of preventive services and other access to care measures</li> </ul> Final health or patient-centered outcomes – reduced disparities in terms of: <ul style="list-style-type: none"> <li>• Patient medical care outcomes</li> <li>• Patient mental health care outcomes (depression, substance use)</li> </ul> Adverse effects of intervention(s) <ul style="list-style-type: none"> <li>• Unintended negative consequences of intervention</li> </ul> |
| Timing            | Variable – depends on the purpose of the intervention   |
| Setting           | U.S. inpatient, outpatient, and community settings in which patients from priority populations are interacting with health care providers   |

PICOTS = population, intervention, comparator, outcomes, timing, and setting.

## Methods

This review followed the methods suggested in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (available at [www.effectivehealthcare.ahrq.gov/methodsguide.cfm](http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm)); certain methods map to the PRISMA checklist.<sup>12</sup> We recruited a technical expert panel to provide high-level content and methodological expertise feedback on the review protocol. The protocol was posted on July 8, 2014, at [www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov). This section summarizes the methods used.

## Literature Search Strategy

We searched Ovid MEDLINE®, PsychInfo, and Cochrane EPOC from 1990 to June 2015. Keywords and MeSH terms to capture racial, ethnic, and immigrant population, cultural competence, and disparities were used. Searches and screening were performed iteratively to

identify concept boundaries and tighten the working definitions and eligibility criteria. The final search algorithms are provided in Appendix B. We also manually searched reference lists from systematic reviews and employed back and forward searching of key articles recommended by experts.

## Study Selection

We reviewed bibliographic database search results for RCTs, systematic reviews, nonrandomized controlled trials, before and after case reports with comparators, and interrupted time series studies published in English language relevant to our PICOTS framework. All studies identified at title and abstract as relevant by either of two independent investigators underwent full-text screening. Two investigators independently performed full-text screening to determine if inclusion criteria were met. Initial search results were vetted by the full team, and decision rules, discussed below, to identify studies that met inclusion criteria were established for second and subsequent rounds of screening. The decision rules were designed to capture the distinction between how to make the health care system more culturally competent, not whether there is culturally competent care. Differences of opinion regarding eligibility were resolved through consensus adjudication. Articles excluded at full text are provided in Appendix C with reasons for exclusion.

Eligible studies tested an intervention to provide culturally appropriate health care to children and adults from race/ethnic minority groups. We excluded interventions in which cultural tailoring was limited to language translation, patient-provider concordance, or culturally-tailored media (e.g., brochures, videos). The intervention had to be designed to improve cultural competence of the health care system. Only translating or adding a multicultural feature to patient materials was not sufficient. Patient-provider matching alone (based on race/ethnicity) was also not sufficient for inclusion. We excluded studies that examined racial or ethnic patient-provider matching as a sub-analysis of a larger study.<sup>169,170</sup>

We also excluded studies that lacked an appropriate comparator to test the cultural competence component(s) of the intervention. Because cultural competence was initially conceived for race/ethnic populations, we were stricter in our requirement of an appropriate comparator. Thus we excluded studies designed to compare variation in intensity rather than exposure to the cultural competence component(s) (e.g., authors described the comparator as low-dose, low-intensity, or minimal); studies of interventions that were educational or elective in nature that compared a number of classes or visits in the intervention group versus waitlist, media (such as a brochure), one class only, or the control was otherwise not comparable; multisession, multicomponent educational interventions for chronic disease (such as diabetes lifestyle education with some degree of cultural tailoring) versus usual care; and studies otherwise designed without manipulation of cultural competence variables (such as comparing the delivery format of two culturally tailored interventions). A common design is to compare individual or group visits or calls over weeks, months, or years versus usual care (no outreach). This design may be appropriate to test the effectiveness of increased treatment intensity on disease management outcomes, but this type of study does not contribute to the evidence base regarding the effectiveness of cultural competence. At the strongest level, we identified a smaller set of included studies that examined interventions to improve cultural competence with an experimental design.

Eligible settings were U.S. inpatient, outpatient, and community settings in which patients are interacting with health care providers.

We first assessed the relevance of systematic reviews that met inclusion criteria. If we determined that certain Key Questions or comparisons addressed in the previous systematic review were relevant to our review, we assessed the quality of the methodology using modified AMSTAR criteria.<sup>171</sup>

## **Data Extraction, Synthesis, and Presentation**

We evaluated the risk of bias in included studies according to study design using criteria from the Cochrane risk-of-bias tool in interventional studies (Appendix D). Given the paucity of literature identified, the heterogeneity of the study populations and interventions, small study samples, the lack of details for complex interventions and comparators, and the high risk of bias assessment for most of the included studies, we determined the strength of evidence for cultural competence interventions, in general, to be insufficient and thus we were unable to draw meaningful conclusions from the literature. Therefore, we focused on summarizing the results into evidence tables and conducted a qualitative synthesis, grouping synthesis results using emergent patterns from identified interventions, and evaluating the challenges of the literature that present barriers to forming inferences from study results. Where we were able to use previously published systematic reviews that evaluated strength of evidence, we report that review's strength of evidence finding. One investigator abstracted the relevant data from eligible trials directly into evidence tables. A second investigator reviewed evidence tables and verified them for accuracy.

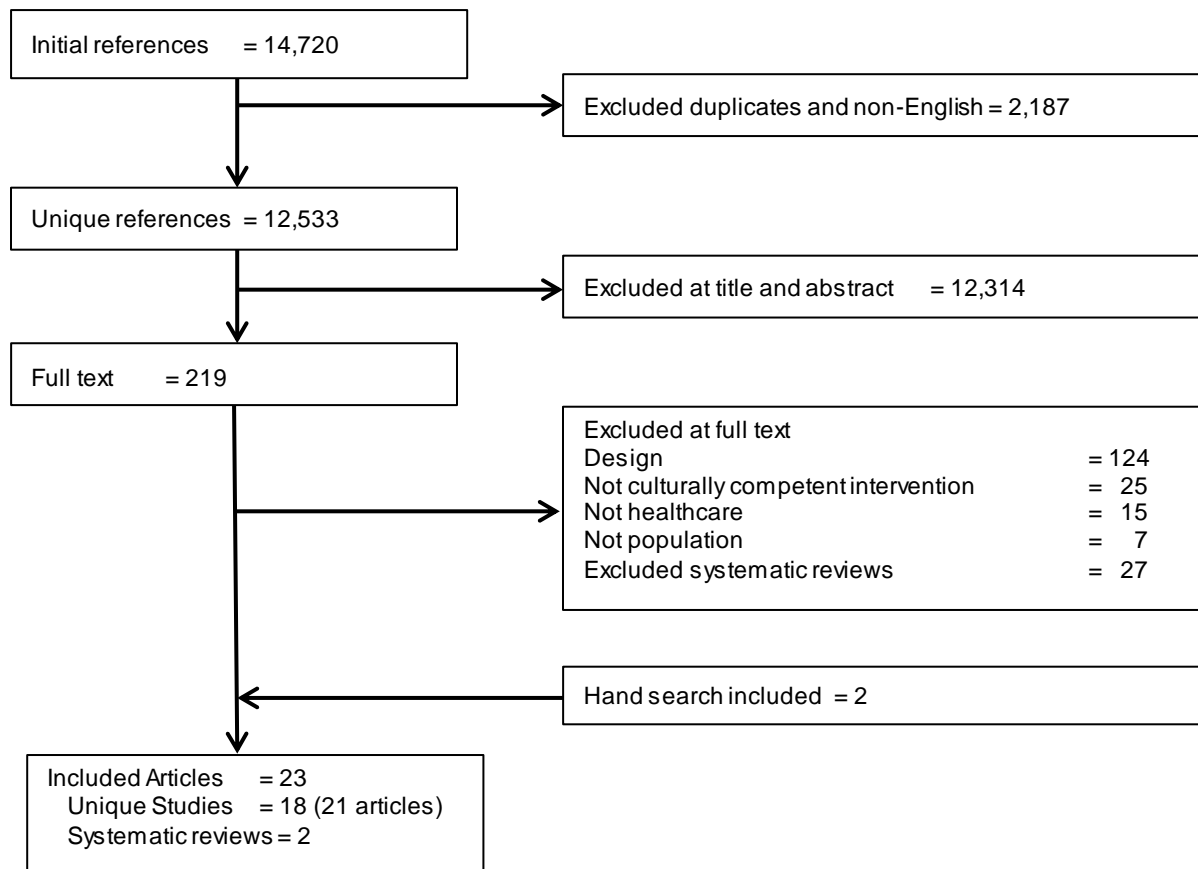
## **Results**

### **Literature Search Results**

We identified 12,533 unique English language citations (Figure 6) from 1990 to June 2015. After excluding articles at title and abstract, full texts of 223 articles were reviewed to determine final inclusion. Twenty-one articles representing 18 unique studies met eligibility criteria. Additionally, one systematic review and one overview of systematic reviews addressed provider education.<sup>51,172</sup> We report the strength of evidence assessed by the previously published systematic review of provider training. Six studies examined interventions to improve cultural competence in patient-provider interactions: two randomized trials at the physician level,<sup>173,174</sup> one cluster-randomized trial,<sup>175</sup> one randomized trial at the patient level,<sup>176</sup> and two controlled trials.<sup>177,178</sup> Ten randomized trials and two controlled observational studies examined interventions to improve cultural competence/cultural appropriateness of clinical treatment.<sup>179-187</sup> Individual studies were generally high risk of bias (Appendix D). Since the risk of bias and heterogeneity of the studies precluded any strength of evidence other than insufficient, we describe the studies by emergent patterns.



**Figure 6. Literature flow diagram—racial/ethnic populations**



The two reviews and 18 individual studies fell into three categories: interventions of provider training to improve cultural competence (n=1 overview of systematic reviews, n=1 systematic review); interventions to improve provider/patient contact (n=6); and culturally tailored interventions (n=12).

Patient populations represented in the 18 individual studies included African American, Hispanic/Latino American, Asian American (East Asian or Korean ethnicity), and American Indian and Alaska Native (AI/AN). Among the six studies that examined interventions to improve cultural competence in patient/provider interaction, three studies sampled African American patient populations and three focused on Hispanic/Latino Americans. Of the 12 studies that examined culturally tailored interventions for treatment of specific health conditions, three studies included African Americans, three included Asian Americans, one included AI/ANs, and six included Hispanic/Latino Americans, one of which included both African American and Latino men (Table 15).<sup>188</sup> No studies addressed culturally competent care specifically for children or older adults.

**Table 15. Cultural competence intervention type by race/ethnicity and health condition**

| Type of Cultural Competence Interventions | Number of Studies                              | African American  | Hispanic/Latino American  | Asian American   | AI/AN   |
|---|--|---|---|--|---|
| Provider education                        | 2 (1 review of 5 RCTs, 1 review of 19 reviews) | Various   | Various   | Various  | NF  |
| Patient/provider interaction              | 6  | 2 medical visits<br>Michalopoulou, 2010 <sup>178</sup><br>Penner, 2013 <sup>174</sup><br>1 mental health<br>Cooper, 2013 <sup>175</sup>     | 1 cancer screening<br>Aragones, 2010 <sup>173</sup><br>2 mental health<br>Alegria, 2008 <sup>177</sup><br>Alegria, 2014 <sup>176</sup>  | NF   | NF  |
| Culturally tailored interventions         | 12   | 1 diabetes<br>D'Eramo, 2010 <sup>182</sup><br>1 substance abuse<br>Calsyn, 2013 <sup>188</sup><br>1 depression<br>Kohn, 2002 <sup>184</sup> | 1 cancer screening<br>Breitkopf, 2012 <sup>179</sup><br>1 diabetes and depression<br>Eil, 2011 <sup>189</sup><br>1 pregnancy<br>Marsiglia, 2010 <sup>186</sup><br>3 substance abuse<br>Burrow-Sanchez, 2012 <sup>180</sup><br>Calsyn, 2013 <sup>188</sup><br>Lee, 2013 <sup>185</sup> | 1 diabetes <sup>190</sup><br>1 phobia<br>Pan, 2011 <sup>187</sup><br>1 smoking<br>Kim, 2015 <sup>183</sup> | 1 smoking cessation<br>Smith, 2014 <sup>191</sup> |

AI/AN = American Indian and Alaska Native; NF = not found; RCT = randomized controlled trial.

## Interventions for Provider Education

We identified two high quality systematic reviews that addressed provider education interventions. (See Appendix D for review quality assessment.) A recent Cochrane systematic review by Horvat et al.<sup>51</sup> included five RCTs that evaluated the effect of provider training on patient outcomes for culturally and linguistically diverse (CALD) populations and found low-strength evidence that cultural competence training had mixed effects for intermediate outcomes and no effect on treatment outcomes. Table 16 presents the reported findings in detail.

**Table 16. RCTs of cultural competence provider training for CALD patients compared with no training in primary care setting in high-income countries**

| Outcomes  | Impact  | Number of Participants (Studies)                   | Reported Quality of the Evidence |
|---|---|--|----------------------------------|
| Treatment outcomes (different measures) <sup>a</sup>    | No evidence of effect on treatment outcomes in two studies; the proportion who achieved cholesterol control target over 12 months and weight loss over 6 months were assessed.  | 2767<br>2 studies (1 international) <sup>e</sup>   | Low                              |
| Health behaviors  | Client concordance with attendance significantly improved for the intervention group across three counselling sessions. Women in intervention group were 1.5 times more likely to attend the third counselling session (RR 1.53, 95% CI 1.03 - 2.27)                                      | 28<br>(1 study)                                    | Low                              |
| Involvement in care (mutual understanding) <sup>b</sup> | One study in the Netherlands reported improved mutual understanding between one in five patients (described as "mainly Turkish, Moroccan, Cape Verdean, and Surinamese patients") and their largely "Western" GPs (mostly Dutch) (SMD 0.21, 95% CI 0.00 - 0.42)                           | 109<br>1 study<br>(international) <sup>e</sup>     | Low                              |
| Evaluations of care (different measures) <sup>c</sup>   | Three studies showed mixed outcomes. No evidence of effect on evaluations of care between intervention and control group participants in two studies; a third study showed significant improvements in client perceptions of their health professional after cultural competence training | 195<br>3 studies<br>(2 international) <sup>e</sup> | Low                              |

| Outcomes   | Impact   | Number of Participants (Studies) | Reported Quality of the Evidence |
|--|--|----------------------------------|----------------------------------|
| Health professionals' knowledge and understanding (awareness of racial differences) <sup>d</sup> | No evidence of effect on clinician awareness of racial differences in the quality of diabetes care for black clients was found in one study among the proportion of clinicians acknowledging racial disparities in care occurred "very often" or "somewhat often" (RR 1.37, 95% CI 0.97-1.94), with no adjustment for clustering | 87<br>(1 study)                  | Low                              |
| Adverse events   | None of the included studies measured adverse outcomes.  | 0                                |                                  |

Source: Horvat 2014 Cochrane systematic review<sup>51</sup>

CALD = culturally and linguistically diverse; CI = confidence interval; GP = general practitioner; RCT = randomized controlled trial; RR = relative risk; SMD = standardized mean difference.

<sup>a</sup> Rate of achieving control target of LDL cholesterol <2.59mmol/L (<100mg/dL) in previous 12 months and change in patient weight (pounds). Data in both studies collected from patient records.

<sup>b</sup> Validated scale to measure mutual understanding by comparing GP and patient assessments of consultation. Responses could range from -1 (total misunderstanding) to +1 (complete mutual understanding). GPs completed the questionnaire immediately after the consultation and patient interviews were conducted 3 to 8 days after a consultation.

<sup>c</sup> Measures include dichotomous measure of patient satisfaction with consultation, which was measured in patient interviews at home 3-8 days after GP consultation. There were two continuous measures: Patient reported physician cultural competency, which asks patients about 13 physician behaviors using 5-point scale with score transformed to a 0 to 100 scale, a single dimension (attractiveness) from validated scale with 12 7-point bipolar items, Client perception of counselors ('attractiveness').

<sup>d</sup> Clinician awareness of racial differences in care measured with a 5-point Likert scale (very often to very rarely).

<sup>e</sup> Outside of scope of main review due to limited generalizability.

The second review was a recent overview of systematic reviews by Truong et al. that included 19 individual reviews.<sup>172</sup> We synthesized the provider training results of studies included by Truong et al. in relation to Horvat et al. (see Appendix Table D3). (Since many of the studies in the reviews included by Truong et al. were not limited to provider training, we also screened these studies for possible inclusion based the criteria of this review.) We cross-walked the included sets of studies and treated additional studies identified in the Truong et al. overview as a sensitivity analysis of the Horvat et al. results.<sup>51</sup>

Of the 19 systematic reviews included by Truong et al., six focused on patients only and 13 had provider training within the review scope, with 5/13 reporting additional observational data on provider training outcomes broadly within the scope of Horvat et al. and our review.<sup>192-196</sup> Other topics explored by the reviewed literature include provider training specific to Australia<sup>197</sup> and international experiences in nursing education.<sup>198,199</sup> One review that aimed to study structures and processes in the development of a culturally competent workforce included primarily descriptive articles,<sup>200</sup> and a contextual review included articles that normally would not be included in a systematic review of interventions. Two reviews included studies of provider training that fully overlapped with those included by Horvat et al.<sup>201,202</sup> and one review included one provider training study that did not add data to the outcomes reviewed by Horvat et al.<sup>203</sup>

Truong et al. included an earlier influential review by Beach et al.<sup>192</sup> describing the weak study designs overall and lack of uniformity in specifying interventions and measuring outcomes. Much of the literature on health care provider training relies on self-reported provider outcomes.<sup>193,199,204</sup> Beach et al. reported positive evidence for the effect of cultural competence training on provider knowledge and attitudes, some evidence that training improves patient satisfaction, and no studies that tested patient treatment outcomes.

The additional evidence contributed by observational studies of provider training within the Truong et al. overview of reviews aligned with the results found by Beach et al.

Observational studies, often with a pre/post design, consistently reported improvement in provider knowledge and attitudes, and patient evaluations of care. However, RCTs have found low strength evidence of no effect on provider knowledge or treatment outcomes, mixed evidence for patient evaluations of care, and low strength evidence of effect on health behaviors and mutual understanding based on single studies.<sup>51</sup>

The eight observational studies from across the five systematic reviews included by Truong that were not included by Horvat or Beach did not add data to three of the five outcomes assessed by Horvat et al.: patient treatment outcomes, health behaviors, and involvement in care. Study designs were primarily pre/post, which precludes strong conclusions. Six observational studies reported improvement in provider knowledge/attitudes after cultural competence training, similar to the findings of Beach et al.<sup>193-196</sup> In contrast, one RCT reviewed by Horvat et al. found no evidence for the effectiveness of provider training on provider knowledge.<sup>205</sup> This study examined clinician awareness of racial differences in the quality of diabetes. Two observational studies reported improved evaluations of care: patient family satisfaction, perceived environmental changes favoring patients' interests and 'ethnic affinity' toward staff.<sup>196</sup> However for this outcomes domain, Horvat et al. reported mixed results. Two RCTs conducted outside of the United States indicated no effect,<sup>206,207</sup> while one RCT showed improvements in patient perceptions of their health care providers after cultural competence training.<sup>208</sup>

## **Interventions To Improve Patient/Provider Interactions**

Diverse interventions were used in the six studies that addressed cultural competence in patient/provider interactions (Table 17). Two studies broadly addressed cultural competence in medical visits by African American patients through the use of a "common identity" treatment (to enhance their sense of commonality) with racially discordant patients and physicians<sup>174</sup> or administration of a pamphlet prior to a medical visit.<sup>178</sup> Although we generally excluded culturally tailored pamphlets, we included the Ask Me 3 pamphlet intervention because it was designed specifically to promote patient-provider interaction rather than to communicate specific health information.<sup>178</sup> Two studies examined educational interventions to promote decisionmaking skills and patient empowerment among Latino mental health patients.<sup>176,177</sup> One study examined a culturally tailored collaborative care intervention for physicians aimed at improving the care of African American mental health care patients.<sup>175</sup> Lastly, one study examined a culturally sensitive, multi-level intervention (an educational video and brochure for patients along with a patient-delivered paper-based reminder for the physician) designed to improve colorectal cancer screening rates among Latino immigrant primary care patients.<sup>173</sup>

Whereas most studies tended to compare the intervention with usual care, one study compared patient-centered, culturally tailored collaborative care (clinician training to enhance participatory decisionmaking and care management focused on explanatory models, socio-cultural barriers, and patient preferences) versus a carefully-reported intervention defined as standard collaborative care.<sup>175</sup>

**Table 17. Interventions to improve patient/provider interactions for racial/ethnic minorities**

| Study, Design, Setting   | Aim  | Sample Size, Population  | Intervention, Comparators  | Reported General Findings  |
|--|--|--|--|--|
| Alegria, 2014 <sup>170</sup><br><br>Randomized trial<br><br>13 community outpatient mental health clinics in Massachusetts                               | To determine whether an educational strategy that teaches patients to ask questions and make collaborative decisions with their provider improves patient activation, self-management, engagement, and retention | (n=647)<br>Mental health patients with predominantly low educational attainment and non-employment, 66% Latino, 16% white, 11% black             | 3-session DECIDE educational intervention vs. giving patients a brochure on management of behavioral health  | Patients assigned to DECIDE reported significant increased activation and self-management, but no effect on engagement or retention in care.   |
| Cooper, 2013 <sup>173</sup><br><br>Cluster randomized trial with patient-level ITT analyses<br><br>Urban community-based practices in MD and DE          | To compare the effectiveness of patient-centered, culturally tailored collaborative care vs. standard collaborative care for African-American patients with depression   | (n=27 primary care clinicians and 132 patients)<br>African-American patients with major depressive disorder, range of socioeconomic backgrounds  | Patient-centered, culturally tailored collaborative care (clinician training to enhance participatory decisionmaking and care management including socio-cultural barriers, preferences) vs. standard collaborative care | Both groups showed similar improvements in clinical outcomes; the control group had higher treatment rates; the intervention group had higher odds of patients rating their clinician as participatory and rating their care manager as helpful. |
| Penner, 2013 <sup>174</sup><br><br>Randomized trial (at physician level)<br><br>Family medicine residency training clinic in Detroit, MI                 | To determine whether an intervention based on the common in-group identity model would change physician and patient responses in racially discordant medical interactions and improve adherence                  | Nonblack physicians (n=14; 11 Asian or South Asian, 3 white) and low-income Black patients (n=72)  | Common identity treatment (to enhance their sense of commonality) vs. control (standard health information)  | Four and 16 weeks after interactions, patient trust of their physician and physicians in general was significantly greater in the treatment condition. At 16 weeks, adherence was also significantly greater.                                    |
| Aragones, 2010 <sup>175</sup><br><br>Randomized trial (at physician level)<br><br>Primary care, urban teaching hospital, diverse, underserved population | To assess the effectiveness of a multilevel intervention in increasing the rate of colorectal cancer screening (CRC) screening among Latino immigrants   | (n=65)<br>Pairs of primary care physicians and Latino immigrant patients, age 50 and older   | Culturally sensitive, multi-level intervention to promote CRC (educational material for the patient and a patient-delivered paper-based reminder for their physician) vs. usual care                                     | The intervention was successful in increasing rates of completed CRC screening primarily through increasing adherence after screening was recommended.   |
| Michalopoulou, 2010 <sup>178</sup><br><br>Controlled trial<br><br>Clinic in Detroit, MI  | To evaluate the effect of receipt of the Ask Me 3 pamphlet prior to a medical visit on African American patient satisfaction and perceptions of physician cultural competency                                    | (n=64)<br>African Americans with low income and low educational attainment   | Receipt of the Ask Me 3 pamphlet, which encourages patients to ask questions of physicians, prior to physician visit vs. not receiving pamphlet  | Intervention participants who saw their regular physician reported higher satisfaction. All found the questions to be helpful.   |
| Alegria, 2008 <sup>177</sup><br><br>Controlled trial<br><br>2 community mental health clinics serving primarily Latino and other minority patients       | To evaluate the effect of the Right Question Project-Mental Health (RQP-MH) training on patient self-reported activation and empowerment   | (n=231; 141 intervention, 90 comparison)<br>Mental health patients, 80% Latino, with predominantly low educational attainment and low employment | Receipt of a 3-session intervention to teach patients effective questioning, decisionmaking skills, and empowerment in relation to their care vs. not receiving the intervention   | Participants showed increased retention, scheduled visits, attendance at scheduled visits, and self-reported patient activation, but not self-reported patient empowerment.  |

ITT = intention-to-treat; DECIDE = Decide the problem, Explore the questions, Closed or open-ended questions, Identify the who, why, or how of the problem, Direct questions to your health care professional, Enjoy a shared solution; CRC = colorectal cancer screening.

Only one of the six studies assessed clinical outcomes (Table 18).<sup>175</sup> This cluster-randomized trial of patient-centered, culturally tailored collaborative care versus standard collaborative care reported a full spectrum of outcomes ranging from depressive symptom reduction and treatment rates to patient ratings of clinicians' participatory decisionmaking and ratings of care managers' helpfulness in identifying concerns, identifying barriers, providing support, and improving treatment adherence. Five of the six studies included patient perceptions as outcomes. Five included outcomes related to health care utilization or adherence, and one of these reported only adherence.<sup>173</sup> Two studies evaluated patient-reported activation and empowerment<sup>177</sup> or self-management.<sup>176</sup> One study of a common identity treatment for racially discordant patients and physicians evaluated both patient and provider perceptions of being on the same team, patient trust of their physician and physicians in general, patient perception of patient-centeredness, and patients' adherence to physician recommendations.<sup>174</sup> One study reported the Perceived Cultural Competency Measure, as well as patient satisfaction and perception of participation and fair procedures.<sup>178</sup> No studies examined adverse effects or unintended negative consequences of the interventions.

All six studies of cultural competence in patient/provider interaction reported that their study outcomes support the effectiveness of the intervention.<sup>173-178,184</sup> One study of an educational intervention for patients reported effectiveness in self-reported patient activation and self-management but no effect on treatment retention.<sup>176</sup> One study reported no overall differences among groups, but in a post hoc subanalysis, people who were seeing their usual provider were more satisfied if they used the pamphlet.<sup>178</sup>

**Table 18. Outcomes for interventions to improve provider/patient interactions among racial and ethnic minority populations**

| Study                              | Provider Attitudes or Perceptions | Patient Perceptions | Patient Satisfaction | Health Care Utilization or Adherence | Clinical Outcomes |
|------------------------------------|-----------------------------------|---------------------|----------------------|--------------------------------------|-------------------|
| Alegria, 2014 <sup>176</sup>       | NM                                | ↑                   | NM                   | ↔                                    | NM                |
| Cooper, 2013 <sup>175</sup>        | NM                                | ↑                   | ↑                    | ↓                                    | ↔ <sup>a</sup>    |
| Penner, 2013 <sup>174</sup>        | ↔                                 | ↑                   | NM                   | ↑                                    | NM                |
| Aragones, 2010 <sup>173</sup>      | NM                                | NM                  | NM                   | ↑                                    | NM                |
| Michalopoulou, 2010 <sup>178</sup> | NM                                | ↔                   | mixed: ↑ / ↔         | NM                                   | NM                |
| Alegria, 2008 <sup>177</sup>       | NM                                | mixed: ↑ / ↔        | NM                   | ↑                                    | NM                |

↑ Significant findings in support of intervention; ↔ No significant findings; <sup>a</sup>both groups improved with no significant difference among groups; ↓ Significant findings in support of control group; NM = not measured.

## Culturally Tailored Interventions

The 12 studies of culturally tailored health care interventions focused primarily on treatment of chronic physical or mental health conditions (e.g., diabetes, depression, substance abuse) (Table 19). Studies including African American patients examined interventions for diabetes,<sup>182</sup> depression,<sup>184</sup> and substance abuse;<sup>188</sup> those including Hispanic/Latino Americans examined interventions for cancer screening,<sup>179</sup> diabetes and depression,<sup>189</sup> pregnancy,<sup>186</sup> and substance abuse;<sup>180,185,188</sup> those including Asian Americans examined interventions for diabetes,<sup>190</sup> phobia<sup>187</sup> and smoking cessation,<sup>183</sup> and the study including AI/ANs examined an intervention for smoking cessation.<sup>191</sup>

Eight of the 12 studies of culturally tailored health care interventions directly compared a culturally tailored version with a standard version of the same intervention.<sup>179,180,184,185,187,188,190,191</sup> Three of these studies involved a single session of psychological treatment<sup>185,187</sup> or a single phone call from a nurse.<sup>179</sup> One study compared four sessions of culturally tailored versus standard individual counseling for smoking cessation, with

both groups also receiving 12 weeks of varenicline.<sup>191</sup> The counseling sessions were designed to be the same except for the addition of culturally tailored components to address tobacco-related issues among Menominee and other AI/AN smokers. Another study compared 12 weeks of culturally accommodated versus standard cognitive-behavioral substance abuse treatment (S-CBT).<sup>180</sup> Cultural accommodation involved modifying cultural variables for relevance to Latino adolescents, resulting in a culturally tailored treatment manual. Similarly, one observational study compared 16 weeks of culturally accommodated versus standard cognitive behavioral therapy (manualized) for depression among African American women with multiple psychosocial stressors.<sup>184</sup> One study examined a culturally adapted version of Real Men Are Safe (REMAS-CA), an HIV prevention intervention for Hispanic or African American men in substance abuse treatment.<sup>188</sup> Results of the pilot test of REMAS-CA were compared with results of the original REMAS trial among minority participants. One observational study compared a culturally specific program for Asian Americans with type 2 diabetes with white patients with diabetes.<sup>190</sup> Both groups received care within the same diabetes center and time period.

The other four studies involved less direct comparisons. In a study of diabetes education for black women, the experimental group received slightly more sessions (11 weeks versus 10 weeks) and the intervention had a stronger cognitive behavioral focus than the control group, in addition to being cultural tailored versus nontailored.<sup>182</sup> In one study of a culturally tailored intervention for smoking cessation among Korean Americans, the experimental group received a 40-minute intervention while the nontailored group received a 10-minute intervention, but the duration was 8 weeks for both groups.<sup>183</sup> One study that included predominantly Hispanic diabetes patients with major depression symptoms compared socio-culturally tailored collaborative care with enhanced usual care.<sup>189</sup> Lastly, one study that included pregnant, immigrant Latinas compared Prenatal Partners (cultural brokers who showed participants how to navigate the health system, self-advocate, and communicate with providers) with usual care.<sup>186</sup>

**Table 19. Culturally tailored interventions among racial and ethnic minority populations**

| Study, Design, Setting  | Aim   | Sample Size, Population, Setting   | Intervention, Comparators   | Reported General Findings   |
|---|---|--|---|---|
| Breitkopf, 2014 <sup>179</sup><br>Randomized trial<br>6 Regional and Maternal Child Health clinics in southeast Texas | To evaluate the effect of a culturally targeted intervention on adherence to followup among low-income and minority women who experience an abnormal Pap test | (n=341)<br>Minority and low-income women at risk of cervical cancer, age 18-55, 63% Hispanic | 3 versions of nurse telephone script (to notify patients of abnormal results): culturally targeted vs. nontargeted patient activation vs. standard care | A theory-based, culturally targeted message was not more effective than a nontargeted message or standard care in improving behavior. |
| Kim, 2015 <sup>163</sup><br>Randomized trial<br>Delivered by trained therapists in NY and NJ                          | To evaluate a culturally adapted smoking cessation intervention for Korean Americans  | (n=109)<br>Korean American smokers   | 8 weekly culturally tailored (40 minute) vs. nontailored (10 minute) individual counseling sessions; both groups received nicotine patch                | The rate of biochemically verified 12-month abstinence was higher for the experimental group.   |
| Smith, 2014 <sup>191</sup><br>Randomized trial  | To evaluate the effect of culturally adapted treatment for AI/AN smokers in the Menominee tribal community.   | (n=103)<br>Menominee and other AI/AN smokers, mean age 40, 58% high school or less           | 4 sessions of culturally tailored vs. standard individual counseling sessions; both groups received 12 weeks of varenicline                             | No significant difference in 7-day, biochemically confirmed abstinence at 6 months.   |

| Study, Design, Setting  | Aim  | Sample Size, Population, Setting  | Intervention, Comparators  | Reported General Findings   |
|---|--|---|--|---|
| Calsyn, 2013 <sup>185</sup><br><br>Pilot vs. subgroup of randomized trial<br><br>4 community treatment program clinics                                  | To determine the acceptability and effectiveness of a culturally adapted version of REMAS-CA, an HIV prevention intervention for men in substance abuse treatment                                      | (n=54 REMAS-CA, n=63 REMAS)<br>Men in substance abuse treatment; subanalysis of African American or Hispanic men                      | REMAS-CA pilot study results vs. REMAS original trial results  | Intervention completion was not significantly different between REMAS-CA participants and minority men in the REMAS study. For men with casual partners, the number of unprotected sexual occasions had higher odds of decrease for REMAS-CA, but for regular partners there was no difference.                 |
| Le, 2013 <sup>186</sup><br><br>Cohort study<br><br>Diabetes clinic, Boston, MA  | To examine the effectiveness of a culturally specific pilot clinic for Asian Americans (AA) in reaching glycemic target in comparison with white counterparts after 12 months of care                  | (n= 109 AA, n=218 white)<br>AA and white adults with type 2 diabetes, mean age 62, 34% high school or less, 98% with health insurance | Culturally specific clinic vs. standard care within the same diabetes center; comparable mean MN/NP visits (2.7 AA, 3.1 white) and mean education visits (2.8 AA, 3.3 white) | No significant differences at baseline and after 12 months in the proportion of patients with A1C $\geq 7\%$ and rate of A1C decline; factors associated with lack of success in AA but not whites: older age, less education, less likelihood of having health insurance, need for more educational visits.    |
| Lee, 2013 <sup>185</sup><br><br>Randomized trial<br><br>Delivered by trained therapists in Providence, RI   | To evaluate a culturally adapted version of motivational interviewing versus a standard version for heavy drinking Latinos   | (n=57)<br>Latino heavy drinkers, English-speaking, mean age 35, mean education 12 years, mostly low-income                            | Single 1.5 hour session of culturally adapted motivational interviewing vs. standard motivational interviewing   | Significant declines across both groups were found in heavy drinking days/month and drinking consequences, with greater reductions for drinking consequences for culturally adapted treatment at 2 and 6 months.  |
| Burrow-Sanchez, 2012 <sup>180</sup><br><br>Randomized trial<br><br>Delivered by therapists in a Mountain West state                                     | To compare the feasibility and relative efficacy of a culturally accommodated version of cognitive-behavioral substance abuse treatment (A-CBT) to a standard version (S-CBT) among Latino adolescents | (n=35)<br>Latino adolescents with substance abuse referred via the juvenile justice system (95%) or parents (5%), 94% male            | Culturally accommodated version of cognitive-behavioral substance abuse treatment (A-CBT) for 12 weeks vs. standard version (S-CBT)  | Participants in both conditions demonstrated similar retention and satisfaction rates, and significant decreases in substance use, with slight increases at 3 months. Substance use outcomes were moderated by two cultural variables: ethnic identity and familialism.   |
| Ell, 2011 <sup>189</sup><br><br>Randomized trial<br><br>2 community safety net clinics operated by the Los Angeles County Department of Health Services | To determine sustained effectiveness of socioculturally adapted collaborative care in reducing depression symptoms and improving treatment 1 year following intervention completion                    | (n=387)<br>Low-income, predominantly Hispanic diabetes patients with major depression symptoms  | 12-month socioculturally adapted collaborative care (psychotherapy and/or antidepressants, telephone symptom monitoring/relapse prevention) vs. enhanced usual care          | At 2 years, more intervention patients received ongoing antidepressants and had sustained depression symptom improvement. For functional impairment, diabetes symptoms, anxiety and socioeconomic stressors, group by time interaction favored the intervention group but was no longer significant at 2 years. |



| Study, Design, Setting   | Aim   | Sample Size, Population, Setting  | Intervention, Comparators  | Reported General Findings  |
|--|---|---|--|--|
| Pan, 2011 <sup>187</sup><br>Randomized trial<br>University on the West coast   | To evaluate a culturally adapted OST (OST-CA) versus a standard one-session treatment (OST-S) among phobic Asian Americans  | (n=30)<br>Adults of East Asian ethnicity with phobia, mean age 22   | Culturally adapted vs. standard one-session treatment vs. self-help  | Both OST-S and OST-CA were effective at reducing phobic symptoms compared with self-help control.  |
| D'Eramo Melkus, 2010 <sup>182</sup><br>Randomized trial<br>Nurse-led intervention and nurse practitioner-delivered visits within primary care in urban, southern New England | To compare the effect of a culturally relevant group diabetes intervention with a usual diabetes education intervention on physiological and psychosocial outcomes in Black women | (n=109)<br>Black, predominantly low-income women with type 2 diabetes   | 11-week culturally relevant, cognitive behavioral group diabetes self-management training (DSMT) vs. 10-week usual diabetes group education with discussion sessions                             | Both groups improved in metabolic control, quality of life, and perceptions of provider care. The DSMT group had better outcomes in mental health domains at 24 months.  |
| Marsiglia, 2010 <sup>186</sup><br>Randomized trial<br>Women's Health Clinic in Phoenix, AZ   | To evaluate the effectiveness of a culturally tailored intervention on rates of return of Latinas to a postpartum visit   | Pregnant, low-income, immigrant Latina women (n=440)  | Prenatal Partners, (cultural brokers who showed participants how to navigate the health system, self-advocate, communicate with providers), one-on-one visits over about 4 months vs. usual care | Initial findings show a significant effect of the intervention, with participants in the experimental group returning for their postpartum clinic visit at a higher rate in comparison with the control group. |
| Kohn, 2002 <sup>184</sup><br>Cohort study<br>Outpatient Depression Clinic at San Francisco General Hospital  | To evaluate cultural adaptation of a CBT intervention among depressed low-income African American women with multiple stressors (e.g., economic strain, family-related problems)  | African American women with major depression and multiple stressors (poor, mostly unemployed and with comorbid health conditions) | Culturally adapted, manualized CBT vs. demographically-matched women who had been previously treated by CBT; 16 weekly sessions of 90-minute group therapy                                       | Women in the adapted group exhibited a larger drop in depression symptom scores; statistical significance not evaluated.   |

A-CBT = accommodated version of cognitive-behavioral treatment; AI/AN = American Indian and Alaska Native; CBT = cognitive behavioral therapy; OST-CA = one session treatment—culturally adapted; OST-S = one session treatment—standard; REMAS-CA = Real Men are Safe—culturally adapted version; S-CBT = standard cognitive-behavioral substance abuse treatment.

Most studies of culturally tailored interventions reported clinical outcomes and the majority also reported health care utilization or adherence (Table 20). One study reported therapeutic working alliance as perceived by the patient and therapist,<sup>187</sup> one study reported perceived provider support for diet and exercise,<sup>182</sup> and one reported patient satisfaction.<sup>180</sup> One study examined adverse effects and reported no serious adverse effects.<sup>191</sup>

Three studies reported no results in support of cultural tailoring,<sup>179,190,191</sup> with one of these studies reporting improvement in both groups and different factors contributing to lack of success among people receiving care at the culturally specific clinic.<sup>190</sup> One study reported no overall results favoring tailoring but supportive results mediated by cultural variables.<sup>180</sup> The other eight studies reported positive findings for culturally tailored interventions. For two studies, both culturally tailored and nontailored interventions were effective with some evidence of additional benefit for the culturally tailored intervention.<sup>182,187</sup> There was some selective emphasis in outcome reporting,<sup>183</sup> and one study did not test outcomes for statistical significance.

**Table 20. Outcomes for culturally tailored interventions among racial and ethnic minority populations**

| Study                               | Provider Attitudes or Perceptions | Patient Perceptions | Patient Satisfaction | Health Care Utilization or Adherence | Clinical Outcomes         |
|-------------------------------------|-----------------------------------|---------------------|----------------------|--------------------------------------|---------------------------|
| Breitkopf, 2014 <sup>179</sup>      | NM                                | NM                  | NM                   | ↔                                    | NM                        |
| Kim, 2015 <sup>183</sup>            | NM                                | NM                  | NM                   | ↑                                    | ↑                         |
| Smith, 2014 <sup>191</sup>          | NM                                | NM                  | NM                   | ↓                                    | ↔                         |
| Calsyn, 2013 <sup>185</sup>         | NM                                | NM                  | NM                   | ↑                                    | mixed: ↑ / ↔              |
| Le, 2014 <sup>190</sup>             | NM                                | NM                  | NM                   | ↔                                    | ↔                         |
| Lee, 2013 <sup>185</sup>            | NM                                | NM                  | NM                   | NM                                   | ↑                         |
| Burrow-Sanchez, 2012 <sup>180</sup> | NM                                | NM                  | ↔                    | ↔                                    | ↔ <sup>a</sup>            |
| Ell, 2011 <sup>189</sup>            | NM                                | NM                  | NM                   | ↑                                    | mixed: ↑ / ↔ <sup>a</sup> |
| Pan, 2011 <sup>187</sup>            | NM                                | ↔                   | NM                   | NM                                   | ↔                         |
| D'Eramo Melkus, 2010 <sup>182</sup> | NM                                | ↔                   | NM                   | NM                                   | mixed: ↑ / ↔ <sup>a</sup> |
| Marsiglia, 2010 <sup>186</sup>      | NM                                | NM                  | NM                   | ↑                                    | NM                        |
| Kohn, 2002 <sup>184</sup>           | NM                                | NM                  | NM                   | NM                                   | NM <sup>a</sup>           |

↑ Significant findings in support of intervention; ↔ No significant findings; <sup>a</sup>both groups improved with no significant difference among groups; ↓ Significant findings in support of control group; NM= not reported; <sup>a</sup> treatment group reported larger clinical improvement but statistical significance not assessed.

Note: Pan study, conducted as hypothesis-testing, reported some findings in support of the culturally tailored intervention, but if the authors had corrected the significance level for multiple outcomes, the results would not have been significant.

## Discussion

### Overview

Overall, the cultural competence intervention literature for racial/ethnic groups is still sparse and patchy. While several studies assessed changes in clinical outcomes, studies that directly address whether culturally competent interventions reduce the disparities gaps among race/ethnic groups and whites are not present in the literature. A few larger minority populations were represented in the literature, but many were absent, such as South Asian, or minimally represented, such as AAI/AN. None of the included studies specifically addressed people of multiracial or mixed ethnic background. While reviews were available on provider education interventions, only one individual study was targeted at the level of the health system.<sup>173</sup>

To move beyond provider education, we evaluate both studies clearly labeled as cultural competence and studies of diverse interventions aimed to improve the care and/or reduce health care disparities for minority patients at the provider and system level which were grounded in a variety of conceptual or theoretical models perhaps contributing to cultural competence. Of those studies that rose to the level of experimentally testing cultural competence interventions, we found a heterogeneous mix of studies that loosely fit into two intervention categories: (1) interventions to improve patient/provider interactions and (2) culturally tailored interventions targeted to specific racial or ethnic groups.

The interventions to improve patient/provider interactions are heterogeneous across target populations and interventions designs, and very few studies in the set included outcomes to assess changes in patient-centered outcomes. Cultural competence interventions targeting patient/provider relationships are important. Interventions based on theories or frameworks focused on improving communication skills or shared decisionmaking may change the patient/provider relationships. The limited results in this area coincide with the status of disparities research generally. A prior systematic review of disparities interventions (1979 –

2011) found that most interventions target patients (50 percent) and community members (32 percent), whereas 7 percent target providers, 9 percent target the care team, 3 percent target the organization, and 0.1 percent target policy.<sup>209</sup>

Cultural tailoring of health care interventions was the largest set of newly identified studies. This heterogeneous set had several challenges. It often lacked transparency regarding what constitutes the cultural accommodation, providing little to no detail regarding the specific features that constitute cultural tailoring of the intervention. A minority of articles publish detailed reports of the process of culturally tailoring interventions.<sup>175,191,209,210,211</sup> Cultural tailoring was often a small component of a multicomponent intervention focused on patient education and self-management. This type of intervention may be suitable for clinical, practical, and ethical reasons, but it does not lend itself to isolating and testing the effectiveness of cultural competence as a specific component of the intervention. Further, few studies of culturally tailored health care interventions measured patient perceptions, and none assessed factors (such as attitudes and perceptions) that are shared among underserved minorities, such as medical mistrust, experiences of discrimination, immigrant status, or problems communicating with their providers. The inclusion of these factors would help our understanding of how and why interventions might transfer to other groups.

Understanding the extent to which certain interventions could successfully transfer across groups would help leverage the current research. Whether an intervention delivered to and/or tailored based on a sample population can be generalized to others within the same race or ethnic group, such as Hispanic Americans living in different geographic regions or with different levels of acculturation, or across mixed backgrounds remains unknown. This is of particular concern considering the predominance of single studies of interventions that were culturally adapted to a specific racial/ethnic population. Definitions of racial or ethnic minorities cannot necessarily be cleanly applied within clear boundaries. On the other hand, studies of interventions designed to improve patient/provider interactions were relatively more universal in their approaches to cultural competence through coaching patients, facilitating patient-physician shared decisionmaking, or the use of reminders in the context of a multi-level intervention.

Our review excluded many types of intervention studies described as culturally competent but lacking a study design that would test cultural competence. Many studies did not use a comparison group that received a nonculturally tailored version of the intervention received by the experimental group. This design issue is exemplified by research on patient education for people in racial or ethnic minority groups with type 2 diabetes. In a recent Cochrane systematic review of culturally appropriate health education for people in ethnic minority groups with type 2 diabetes mellitus,<sup>2112</sup> only one of 33 studies<sup>182</sup> compared a culturally tailored intervention group with a nontailored active control group. One additional study included by Attridge et al. used an active control group but did not test cultural competence; culturally tailored symptom management was compared with culturally tailored diet and weight management.<sup>212</sup> Half of the included studies compared diabetes education with usual care (waitlist or no outreach), and in other cases the control group received a token intervention such as brochures, newsletters, or occasional phone calls.

Patient navigation is an area of active research that overlaps with cultural competence. Interventions in this realm are often described as culturally competent but are generally not studied with a design that could test the effectiveness of cultural competence. We found no studies that directly compared culturally tailored versus nontailored patient navigation. Cultural tailoring may be one aspect of patient navigation, but such interventions aim to address barriers

to care broadly. Similarly, collaborative care is occasionally described as culturally competent. However, this language may reflect different contextual settings for collaborative care interventions rather than evaluation of the effectiveness of cultural competence. For example, one excluded study compared a safety net clinic serving a minority population with collaborative care versus general clinics (without collaborative care, a safety net function, or a focus on minority populations).<sup>213</sup> This design does not provide evidence regarding the effectiveness of cultural competence.

Community health workers are another area of active research where the language of cultural competence is often used, but where interventions are generally not studied with a design to evaluate the effectiveness of cultural competence. Interventions using community health workers range from advocacy and patient education to disease management (see <http://mnchwalliance.org/explore-the-field/evidence-2/>). Some studies framed as addressing disparities through community health workers hired a person from the target racial or ethnic group to deliver the intervention, but were designed to test the effects of two levels of treatment intensity<sup>214</sup> or 2 years of asthma coaching versus usual care.<sup>215</sup> Thus, such studies were not designed to test the effects of a culturally tailored versus nontailored intervention, as were the studies of interventions included in this review.

Although prior systematic reviews concluded that evidence supports the use of community health workers who are culturally competent,<sup>195,203</sup> the interventions included in these reviews were heterogeneous. Fisher et al. concluded that community health workers “are among the most successful strategies that emerged from our literature review” despite noting that conditions and interventions were heterogeneous, no studies were designed to examine the effectiveness of the intervention in reducing health disparities, and “none of the studies actually addressed the extent to which the cultural aspects of these interventions brought about the improvements in care, apart from the general mechanisms of quality improvement or public health strategies inherent in the interventions” (p 276S-277S).<sup>203</sup> The studies included by Henderson et al. had similar weaknesses.<sup>195</sup> We found no studies that compared culturally tailored versus nontailored interventions delivered by community health workers.

Racial/ethnic characteristics often overlap with sociodemographic characteristics that increase the likelihood of disparities, such as socioeconomic status and immigration status. Often, interventions aim to address multiple types of barriers to health care and health outcomes, rather than isolating cultural competence factors. This may be appropriate depending on study goals, but in this case the effectiveness of cultural competence factors is assumed rather than tested. Additionally, the language of “cultural tailoring” may be used in multiple contexts that may be distinct from cultural adaptations based on race and ethnicity. For example, one excluded study described the cultural tailoring of the intervention as “culturally relevant to socioeconomically disadvantaged women,”<sup>216</sup> exemplifying the issue that approaches used to address health disparities for racial or ethnic minorities may also serve populations of low socioeconomic status. Of the studies included in this review, over half of the sample populations were described as low income and/or low education.

Lack of uniformity in cultural competence definitions and frameworks has already been noted.<sup>172</sup> This lack of consensus in defining and evaluating cultural competence may contribute to the heterogeneity of interventions and lack of reported detail on cultural competence components, especially for cultural tailoring interventions, although word count limitations may also constrain reporting cultural adaptation in detail. One of the most thoroughly described

interventions was reported in an article with a much higher word count than typical for this literature.<sup>191</sup>

## Research Directions

As noted above, interventions often aim to address multiple types of barriers to health care and health outcomes for racial and ethnic minorities. While this is understandable, given the correlation of racial and ethnic minorities and low socioeconomic status, research designed to isolate the effectiveness of cultural competence factors is needed if and when the specific goal of the research is to examine the effectiveness of interventions to improve cultural competence, as opposed to increasing the reach of care for vulnerable populations. However, we emphasize that both effectiveness and reach are essential for increasing the impact of cultural competence interventions. Such effectiveness research should specifically test components seen as directly related to cultural competence. For example, patient/provider concordance may jumpstart trust and facilitate communication, but other social factors may interfere with the assumed benefits. Likewise, culturally matching community health workers may help address language barriers and facilitate more open communication than one would see with a concordant physician because of the more similar shared status between the patient and the community health worker. Our understanding could be advanced by testing the role played by the community health worker and feeding back to the health system what is learned from the patient rather than merely conveying the health promotion or disease management information the health system deems important.

Research that aims to clarify which cultural competence components are relatively universal and easily generalizable and which are truly group or sub-group specific would also make a contribution. One obvious place to extend the research would be in examining what works for people of multiracial or mixed ethnic backgrounds.

Most of the included studies measured only clinical outcomes (such as change in symptoms) or intermediate outcomes (such as health care utilization or adherence). These studies did not provide direct evidence that improved cultural competence leads eventually to reduced disparities. Studies that examine only clinical outcomes and/or utilization/adherence may point the way towards interventions that may reduce disparities via improved cultural competence, but the last step is still inference rather than direct demonstration. A more explicit link between cultural competence interventions and clinical outcomes could be made by combining clinical outcomes with intermediate measures of improved cultural competence, such as patient perceptions of cultural competence. Directly connecting observed changes in outcomes and improved cultural competence is important considering the challenges in clearly isolating cultural competence as a concept.

The included studies primarily focused on comparing interventions within race/ethnic groups, not among groups, thus inferences about reducing disparity gaps would need to be based on indirect comparisons. One cohort study directly compared Asian American and white people with type 2 diabetes. Although this study did not find differences between groups at baseline and therefore did not directly examine disparities, this study exemplified the type of design that could provide direct evidence regarding culturally adapted interventions that aim to reduce disparities.<sup>190</sup>

Further, nearly all of the included studies evaluated outcomes of a single group, rather than examining whether the intervention reduced health disparities via improved cultural competence. Comparing clinical outcomes by race/ethnicity could indicate a reduction in disparities in those outcomes (such as if/whether the intervention benefitted a nondominant group more than the

dominant group). Studies that assess improvement in cultural competence and show differential results in clinical outcomes among racial/ethnic groups would provide more direct evidence that cultural competence is a pathway to reduced disparities in health outcomes.

## **Limitations**

The major limitation of this review is the difficulty drawing boundaries between patient-centered care and cultural competence, particularly regarding interventions designed to improve patient/provider interactions. Individually tailored interventions, such as individualized cancer risk assessment in cancer screening education,<sup>217,218</sup> were excluded to distinguish cultural competence interventions from a related concept, patient-centered care.<sup>75</sup> Individually versus culturally adapted interventions may prove to be as or more effective. However, of the two, this review is focused on cultural tailoring of interventions and interventions to improve cultural competence of patient/provider interactions. The latter were operationalized as studies that intervened at the level of the patient's relationship to the health care system, as opposed to disease treatment/management.

Another limitation is that a number of studies of interventions to improve cultural competence in patient/provider interactions are based on conceptual frameworks drawn from social science literature from various disciplines. While the interventions may indeed have been consistent with cultural competency models, study authors may or may not have intended the interventions be evaluated as cultural competence.

## **Conclusions**

The results of the search show a patchy literature set that highlights the intrapopulation diversity subsumed under the racial and ethnic minority umbrella terminology. The literature also fails to recognize the intersections of racial and ethnic minority populations with other populations experiencing health care disparities. The broader concept of diversity competence may be more appropriate for many people at these intersections. Further discussion of population intersectionality and alternative constructions of cultural competence that address structural inequities can be found in Chapter 5. None of the included studies measured the effect of cultural competence interventions on health care disparities. The medium or high risk of bias of the included studies, the heterogeneity of populations, and the lack of measurement consensus prohibited pooling estimates or commenting about efficacy in a meaningful or responsible way.

# Chapter 5. Models and Cross-Cutting Themes

## Introduction

This report addresses cultural competence as a construct that can be applied to diverse subgroups. Each subgroup has its own culture. Elements such as alienation and prejudice are likely common to all; but other elements, such as language and physical access, may affect some groups more or differently than others. This chapter provides an overview of models that have been used to conceptualize cultural competence and culturally appropriate care in health contexts. The discussion section examines overarching themes that transcend the three populations of interest: people with disabilities; lesbian, gay, bisexual, and transgender (LGBT) people; and racial and ethnic minority groups.

## Cultural Competence Models

To help inform the review process, we undertook a review of cultural competence conceptual models. Specific methods pertinent to this review process are in Appendix A, along with the search algorithm used. We identified 857 unique English language citations from 1990 to February 2014. After excluding articles at title and abstract, full texts of 89 articles were considered as possible sources of models. After checking full text, references, and consolidating models identified, 24 models were identified for examination.

We expected the models to map with the included intervention literature in a useful way and provide an overarching framework for mapping the literature. Instead, the models connected very little with the intervention literature, and the literature was so sparse that a mapping exercise would interfere with the overarching key messages drawn from each priority population group. Here we present the models briefly for informational purposes, while drawing a few high level themes of interest.

All models but one were developed in response to racial and ethnic group concerns (the groups to which cultural competence was first applied) (Table 21). The Inequalities Imagination model intends to cover a much broader set of populations that may be disadvantaged in a formal health care system.<sup>219</sup> The model explicitly includes people with disabilities. Because it uses broad definitions of disadvantaged people who have experienced prejudice or discrimination, the model can also be viewed as covering people from the race/ethnic and LGBT groups. Models other than the Inequalities Imagination model would include disability and LGBT groups only implicitly. The Inequalities Imagination model also goes further than the populations included in this report by explicitly naming people from impoverished situations, although there can be considerable overlap of poverty and people from any of the three priority populations.

**Table 21. Cultural competence models**

| Model   | Focus                | Description   | Use                                  |
|---|----------------------|---|--------------------------------------|
| <b>Disadvantaged populations</b>  |                      |   |                                      |
| Inequalities Imagination model<br>Hart, 2003 <sup>219</sup>                 | Provider             | 7 factors: equalities analysis, equalities awareness, equalities skill, equalities action, cultural knowledge, cultural encounter.<br><br>Disadvantaged populations: Mental or physical impairment, historical prejudice and discrimination; current prejudice or discrimination, poverty   | Training for providers               |
| <b>Models motivated by race/ethnic populations</b>                          |                      |   |                                      |
| QIAN model for cultural humility<br>Chang, 2012 <sup>220</sup>              | Provider             | 4 principles: self-questioning and critique; bi-directional cultural immersion; mutually active-listening; flexible negotiation. Affects patient-provider dyad, and elicit support of family, health care system, and community at large  | Training for providers               |
| Disability disparities model<br>Lewis, 2009 <sup>221</sup>                  | Patient              | Includes hypothesized view of what accounts for disparities, macrolevel concepts (5 domains), and microlevel aspects. Incorporates cultural competence aspects, such as disability group's culturally driven help seeking tradition, the extent to which the provider is viewed as culturally competent, patient/provider trust, extent outcomes align with culture                   | Training for providers               |
| Cultural Empowerment model<br>Garrett, 2008 <sup>222</sup>                  | Patient              | 6 domains: facilitating language (removing language barriers); negotiating family involvement; understanding patient beliefs, expectations, experiences, and constructions; being compassionate and respecting patient and human rights; negotiating a care partnership; providing systems so services and providers can be competent<br><br>Empirically developed from patient views | Training for providers               |
| 3-D Puzzle Model of culturally congruent care<br>Schim, 2007 <sup>223</sup> | Patient              | Extends Leininger's Sunrise Model (see below) to include patients as part of the system and how the interaction of patients and providers contribute to culturally congruent care.  | Training for providers               |
| CRASH model<br>Rust, 2006 <sup>224</sup>                                    | Patient/<br>provider | 7 elements: Importance of culture; respect; assess within-group differences, affirm the positive values behind behaviors seen as different, sensitivity, self-awareness, humility in practicing but not achieving mastery of cultural competence  | Training for providers               |
| Explanatory models approach<br>Kleinman, 2006 <sup>225</sup>                | Patient              | 6-step mini-ethnography: ethnic identity; what is at stake; illness narrative; psychosocial stresses; influence of culture on clinical relationships; problems of cultural competency approach  | Practice tool for clinical encounter |
| BESAFE model<br>McNeil, 2003 <sup>226</sup>                                 | Patient              | 6 core elements: barriers to health care, ethics in cultural competency, sensitivity of the provider, assessment appropriate to a cultural determination, facts related to ethnocentric physiologic differences, encounters   | Practice tool for clinical encounter |
| GREET model<br>Chong, 2002 <sup>227</sup>                                   | Patient              | Specific to non-native patients: generation (how acculturated is patient), reason (for immigration), extended family, ethnic behavior, time living in U.S.  | Practice tool for clinical encounter |
| Model for Cultural Competence<br>Purnell, 2002 <sup>228</sup>               | Patient/provider     | Systems approach to 12 domains from person through family and community to global society. Domains: communication; overview/heritage; family roles and organization; workforce issues; bio-cultural ecology; high-risk behaviors, nutrition, pregnancy and childbearing practices; death rituals; spirituality; health care practices; health care practitioner concepts              | Practice tool for clinical encounter |



| <b>Model</b>  | <b>Focus</b>     | <b>Description</b>   | <b>Use</b>                           |
|---|------------------|--|--------------------------------------|
| ETHNIC model<br>Levin, 2000 <sup>229</sup>  | Patient          | Facilitate communication by asking questions in 6 areas of process: explanation, treatment, healers, negotiation, intervention, collaboration  | Practice tool for clinical encounter |
| 9 cultural competence techniques/reducing disparities<br>Brach, 2000 <sup>230</sup>                   | Patient          | 9 cultural competence techniques that facilitate changes in clinician and patient behavior, which lead to provision of appropriate services, which lead to good outcomes (Model focused on provider side. Other contributors to health disparities not included) | Framework: providers and systems     |
| Model of Cultural Competency<br>Campinha-Bacote, 1999 <sup>231</sup>                                  | Patient/provider | 5 constructs of cultural competence: cultural awareness (including self-awareness), skills, knowledge, encounters (applying knowledge and skills to specific patient care), and desire to understand cultural issues   | Training for providers               |
| Taxonomy for Culturally Competent Care<br>Lister, 1999 <sup>232</sup>                                 | Patient          | Five elements: Awareness, knowledge, understanding, sensitivity, and competence  | Training for providers               |
| Model of Culturally Competent Health Care Practice<br>Papadopoulos, 1998 <sup>233</sup>               | Patient          | 4 stages moving through cultural awareness, cultural knowledge, cultural sensitivity (where patients are considered true partners), to cultural competence   | Training for providers               |
| ACCESS model<br>Narayanasamy, 1999 <sup>234</sup>   | Patient          | 6 domains: assessment, communication, cultural negotiation and compromise, establishing respect and rapport, sensitivity, safety   | Training for providers               |
| Cultural Competence Model<br>Culhane-Pera, 1997 <sup>235</sup>  | Provider/patient | 5 stages of development from no insight, through minimal emphasis, acceptance, incorporation, and integration of attention to culture in all areas of professional life  | Training for providers               |
| Transcultural Model Giger and Davidhizar, 1995 <sup>236</sup>   | Patient          | 5 domains: communication, space, social organization, time, environmental factors, and biological variations   | Practice tool for clinical encounter |
| BATHE model<br>Stuart, 1993 <sup>237</sup>  | Patient          | Focus on providing culturally competent environment: background, affect, trouble, handling, empathy  | Practice tool for clinical encounter |
| Developmental Model of Ethnosensitivity<br>Borkan, 1991 <sup>238</sup>                                | Provider         | 7 stages of developmental from ethnocentric to ethnosensitive: fear, denial, superiority, minimization, relativism, empathy, integration   | Training for providers               |
| Four-step Approach to Providing Culturally Sensitive Patient Teaching<br>Kittler, 1990 <sup>239</sup> | Patient/provider | Four-step process of self-evaluation, pre-interview research, in-depth interviewing, and unbiased data analysis  | Practice tool for clinical encounter |
| Cultural competence continuum model<br>Cross, 1989 <sup>240</sup>                                     | System           | System development through 6 stages: cultural destructiveness, cultural incapacity, cultural blindness, cultural precompetence, cultural competence, cultural proficiency  | Training for providers               |
| Sunrise Model<br>Leininger, 1988 <sup>241</sup>   | Patient          | Holistic view of sociocultural and worldview factors that influence care patterns, which in turn influence well-being; incorporates nursing subsystem. Focuses on views of patient   | Practice tool for clinical encounter |
| LEARN model<br>Berlin, 1983 <sup>242</sup>  | Patient          | Facilitate communication regarding health belief systems: Listen, explain, acknowledge, recommend, negotiate   | Practice tool for clinical encounter |

The majority of models, whether created for training purposes or to provide a practice tool for clinical encounters, focused on patient factors. That is, the model describes what patients bring to the clinical encounter, often based on attributes believed to be associated with cultural groups. A much smaller set focuses more on what the provider brings to the encounter. With the provider-focused models, providers are encouraged to self-reflectively examine their own biases and habits of thought. However, the distinctions between patient-focused and provider-focused categories should not be overemphasized. All models necessarily incorporated both views and differed primarily in their degree of emphasis.

Of the provider-focused models, the Inequalities Imagination model is unique in its main focus on encouraging the provider to move beyond “politically correct” thinking and develop true empathy by imagining experiences from the perspective of the patient.<sup>219</sup> The imagination process is explicated as a specific learning technique. First, a provider must bring to mind the experiences of others and consider how previous behaviors could be changed. The provider is further challenged to bring to light cognitive processes from the subconscious levels.

Another model is noteworthy for its development process. The Cultural Empowerment model was developed by gathering information from focus groups about the factors that non-English speaking patients view as constructing culturally competent care.<sup>222</sup> This patient-centered process to construct a culturally competent care model is concordant with the models generated through academic expert-based or theoretically driven models.

The trend over time is that newer models are more provider-focused. They reflect developments in the conceptualization of cultural competence, particularly cultural empowerment and cultural humility, which encourage providers to consider their own place of privilege. These models emphasize that providers do not have to know everything, and patients can have expertise in their own experience and an active role in sharing information. Newer models also focus on external factors, such as structural and individual discrimination (present and historical), that priority populations face in the health care system.

Two other reviews of the cultural competence literature are notable. A 2010 review by Williamson and Harrison categorized cultural competence models related to midwifery and nursing into two groups.<sup>243</sup> One group of models used approaches that were patient-focused, attending to the characteristics of the group itself, explaining health status using individual behaviors and beliefs. The other group focused on the larger social structure within which the patient-group lives, including the impact of colonial processes on patient/provider relationships. These frameworks concentrated on social position rather than individual beliefs and values as health determinants.

In the second paper, Saha and colleagues conducted a review of cultural competence models in order to derive a measure for provider cultural competence.<sup>75</sup> The final measure used 20 items that mapped to six domains: concept of culture; relevance of sociocultural context; disparities in health and health care; diverse beliefs and behaviors; cross-cultural care; and patient-centered communication.

## **Overview of Cross-Cutting Themes**

Overall, the literature on interventions to improve cultural competence in the health care system is very sparse. Not surprisingly, the largest blocks of literature addressed provider training. However, although the cultural competence training is intended to improve quality of care and downstream health disparities, no studies included outcomes that demonstrated whether a health disparity gap had been reduced. This holds true for interventions aimed at improving

provider/patient communication, or attempts to culturally tailor interventions to better meet specific priority population group’s needs. Further, large segments of vulnerable or disadvantaged populations remain essentially invisible in the cultural competence literature, including children with disabilities, people who may be gender nonconforming or transgender, or numerous racial or ethnic groups including Native Americans or Alaskan Natives. This is compounded for people who are members of more than one priority population.

While many advocacy, professional, and government organizations (as well as individual researchers) have published recommendations on ways to create more culturally competent health care environments,<sup>77,244-248</sup> peer reviewed published evidence for the effectiveness of interventions at the system level are also rare. We found only five studies, two each in disabilities<sup>38,39</sup> and LGBT populations<sup>120,121</sup> and one in the race/ethnic groups,<sup>173</sup> which tested interventions aiming to integrate cultural competence into the health care system itself by intervening structurally at the point of care of patient/provider interaction using formal system documents, not a one-time training or a brochure picked up in the lobby. The strategies involved prompting clinicians to provide culturally competent care, regardless of any individual clinician’s placement on a cultural competence developmental continuum. The published literature was also silent on system-level concerns such as designing welcoming environments or physically accessible spaces into conventional health care system spaces.

The challenges with the methodological rigor of the studies are pervasive across the priority populations. A 2005 review noted that the lack of rigor limited the ability to assess the impact of provider training on racial and ethnic minorities.<sup>249</sup> We found essentially the same challenges after we extended the scope of groups covered to include disability and LGBT populations and broadened the potential range for cultural competence interventions. One of the most common reasons for excluding an article was lack of study design rigor.

## Differences Among Populations

All three priority populations, race/ethnicity, disability, and LGBT, face historical and current stigma and discrimination in society and the medical community. This fosters social distance, mistrust, differential treatment, and downstream disparities. However, cultural competence interventions need to recognize the differences in underlying constructs and social formulations used by each priority population. Interventions must also recognize within-population differences as well. Table 22 provides examples of population differences in what may be salient aspects of cultural competence.

**Table 22. Examples of different aspects of cultural competence by subgroup**

| Aspect               | Race/Ethnicity  | Disability  | LGBT   |
|----------------------|---|---|--|
| Physical Environment | (Not as applicable)   | Access to clinic, examining table, remote access  | Accessible restrooms   |
| Social Environment   | Sense of being welcomed, absence of prejudice                               | Sense of being welcomed, absence of prejudice   | Sense of being welcomed, absence of prejudice  |
| Cultural Mores       | Talking to elder; not discussing death                                      | (Not as applicable)   | (Not as applicable)  |
| Language             | Need for translation; assuring you are understood                           | Need for translation (deaf community); assuring understanding   | Misusing terms   |
| Clinical             | Recognizing disease presentation; assuming most probable cause of a problem | Managing a common clinical problem in the context of the disability; managing complications of the disability | Knowing what problems may be associated with sexual behaviors and/or gender transition |

LGBT = lesbian, gay, transsexual, transgender.

The IoM 2002 report carefully noted that health disparities for racial and ethnic minorities arise from both biologic/genomic differences and larger ecological/environmental sources of health determinants outside the health care systems.<sup>250</sup> The report also clearly laid out the challenges to addressing health disparities, especially discrimination and implicit bias at the individual and clinical encounter level, and institutional stigma and discrimination at the system level.<sup>250</sup>

Efforts to improve cultural competence for the care of people of different racial and ethnic backgrounds must go beyond weaker types of interventions such as language translation, tailoring existing media such as health promotion videos or patient education brochures, or the assumption that hiring a bilingual or bicultural worker is sufficient for cultural competence. Interventions must simultaneously address fundamental beliefs people hold about the nature of disease, what are causal mechanisms, and expectations of treatment. Another key piece to address is the impact of discrimination within and outside of health care, which are experienced by these groups and affect many aspects of health and health care (such as adherence, utilization, and substance use).<sup>157</sup> Other issues that affect racial/ethnic minorities include the enduring effects of residential segregation,<sup>251-253</sup> which also affects the clustering of racial/ethnic minorities into certain health care facilities, which have been shown to have fewer resources than facilities where nonminorities get care.<sup>252,254</sup>

Another confounder is the frequent association between racial/ethnic minority status and poverty. Medicaid disproportionate coverage may pose limitations to access to care or restrictions in options. Medicaid coverage also adds another layer of stigma to populations experiencing discrimination within the health care system.

For disability groups, the underlying political and social culture is based on achieving equity of access to all of life's opportunities. Major advances such as the Americans with Disabilities Act have been based on a civil rights platform. Many people with disabilities do not view their disability as a medical problem, although it may complicate the receipt of medical care for clinical problems unrelated to the disability. For this subgroup of people, the goals of disability specific health care may be less curative and more focused on maximizing function and optimizing potential opportunities. Other people may frame their disability within a medical model. Therefore, treatment goals, as captured by outcomes of care, can differ based on disability definitions, disability models, and the professional perspectives of the care being provided in support of different service goals.<sup>255</sup> While the goals of the care need to be individualized, there are some common barriers people with disabilities face to accessing competent medical care, including: getting care in the context of their disability (many medical providers have limited experience treating a traditional medical problem experienced by someone whose underlying disability that may affect treatment and prognosis); getting physical access to medical facilities (e.g., transportation, entrance, examining tables, etc.), and the general discomfort some clinicians may feel caring for patients with disabilities. For some people with disabilities, cognition may pose a problem in understanding of treatment options. However, this same problem applies to older people with cognitive impairment, except for the risk of stereotyping and premature judgment about cognitive abilities. Many people with disabilities may be covered by Medicaid and face the same limitations to access to care or restrictions in options faced by racial/ethnic minorities.

Cultural competence interventions in the LGBT population need to be sensitive to the invisibility of the population. While the race and disability populations likely produce an implicit bias or social distance on sight, LGBT people may elicit a straight bias from clinicians who do not consider sexual orientation status. People with disabilities that are not immediately apparent (such

as mental health disabilities and autism spectrum disorders) may experience disparities associated with their hidden disabilities. Similar to the visible disability populations, LGBT people may not feel welcomed by clinicians and staff and may face clinical ignorance about how to address (or even raise) salient health-related issues. Internal and external stigma may interfere with disclosure and the ability to receive effective care. LGBT people are more educated, on average, than the general population but may have less access to insurance than their straight counterparts.<sup>256</sup>

## **Conceptualization of Cultural Competence for Various Populations**

Much has been written deconstructing and/or constructing the concepts and common uses of cultural competence. The cultural competence construct is not an entirely comfortable fit for disability populations, because identification with disability is not always viewed as a positive in-group dynamic. Concerns have also been raised about cultural competence programs that use a group-specific approach to teach providers about the attitudes, values, and beliefs of a specific cultural group. Such approaches can lead to stereotyping and oversimplifying the diversity within a particular priority group.<sup>257</sup> Indeed, our review identified one study that resulted in this adverse consequence for the disability population.<sup>23</sup> As long as cultural competence models focus on tailoring interventions for specific populations, outcomes will depend on the degree to which a person identifies as part of the target “culture.”

The broader concept of diversity competence may be more appropriate in regard to the full range of populations that experience health disparities. The recent shift towards cultural empowerment and cultural humility is encouraging and also consistent with the recommended shift toward structural equity-focused interventions.

A large body of literature has shown how discrimination and inequality harms the health of socially disadvantaged groups through multiple pathways, resulting in disparities.<sup>157,258,259</sup> Repeated discrimination is a source of chronic stress, resulting in damage to the immune system, inflammatory disorders, and cardiovascular disease, as well as mental health disorders and cognitive impairment (see Mays et al., 2007,<sup>260</sup> for a review). Discrimination is also associated with lower levels of adherence and health care use, greater mistrust in health care, and poorer communication with providers.<sup>258,260,261</sup> Unconscious bias can lead to poorer communication on the part of health care providers and biased clinical decisionmaking. Many of the cultural competency interventions we reviewed addressed these barriers by seeking to reduce stigma among health care professionals or improving health care providers’ skills at communicating with members of racial minority groups. Given this, it seems problematic to use the cultural competency label to describe interventions designed to reduce disparities. Cultural competency focuses too much attention on the internal characteristics of groups (i.e., their culture) while drawing attention away from the external factors (discrimination, exclusion) that contribute to disparities. Instead, we might call such interventions “equity interventions” to more accurately emphasize their goal.

## **Research Directions**

We need an evidence-base for cultural competence interventions. Two other reviews found that, similar to our findings, the research was not connected to disparities-related outcomes, the disparities addressed were minimally defined, and little concrete detail was provided on the cultural competence strategies used.<sup>230,262</sup> However, the sheer number of studies that would be

needed to address every possible subset of disability, LGBT, and racial/ethnic groups is daunting. A key direction for future research requires shifting models. Rather than attributional models that focus on the internal characteristics (or “culture”) of groups, research can use relational models that focus on the devaluation and exclusion of these groups within the broader society. This approach may also help to mitigate unintended consequences that could develop if research based on attributional models is generalized to a population for whom that particular approach is not a good fit.

Cultural competence research for the wider priority populations will require interdisciplinary approaches. These interdisciplinary teams will need to draw from the same skill pool as they reach across different academic, policy, and layperson cultures. As a simple example, team members for this project were drawn from diverse fields, disciplines, and research interests. The research process required synching language, since terms used in one academic culture did not automatically transfer to other academic cultures. While the process was complicated by the multiple perspectives brought to the task, those variations facilitated broader examinations of the constructs, and produced a more nuanced examination of cultural competence.

A call has been made to employ cultural sensitivity within the general health services research process.<sup>263</sup> This call is similar to exhortations to incorporate the concept of universal design into health services research that reaches beyond disability-specific research.<sup>264</sup> Research teams that include inside and outside perspectives (of study populations and researchers) can better capture both nuance and missed opportunities. Interdisciplinary and culturally sensitive research teams would weigh the trade-offs between generic instruments (that maximize what is common across groups) and culturally sensitive instruments (that narrow in on the issues most salient to a specific cultural group, or what works for whom). As the common wisdom says, we pay attention to what we measure.

Patients should be seen as active participants in the complex patient/provider/health care system. The relational models are better suited to working with patients who are not just members of a singular culture but rather a mosaic of cultural influences.<sup>265</sup> Ultimately, the ability to provide culturally appropriate care may rely on some capable patients to act as an active part of the system by providing meaningful feedback so the system can learn. Involving patients in a participatory research process to help determine the concerns and outcomes of most interest to each group is common across all the priority populations.

All of this research would benefit from designs that follow downstream effects to capture whether the interventions closed the disparities gap. Interventions that raise the quality of care for all patients regardless of group membership is certainly welcome, but does not necessarily help reduce the difference.

## Conclusion

The HHS Office of Minority Health has dedicated an initiative to supporting cultural competence and has set cultural and linguistic standards for organizations to meet. Organizations also feel the pressure of legislative mandates and the need to be competitive in serving diverse groups and populations.<sup>266</sup> These efforts are aimed at worthy social goals of reduced disparities and health equity.

Despite the effort dedicated to cultural competence, evidenced by the numerous models that have been published, the empiric work testing interventions identified in this review in support of cultural competence is sparse. There is not a consensus definition for cultural competence, particularly in the LGBT and disability populations. It is often conflated with patient-centered, or

individualized care. None of the included studies measured the effect of cultural competence interventions on health care disparities. Interventions that altered existing protocols, empowered patients to interact with the formal health care system, or prompted provider behavior at the point of care were more likely to measure patient-centered outcomes. Actual tests of intervention effectiveness and harms or unintended consequences, whether model-based or empiric-based, would be of benefit.

The most prevalent type of cultural competence intervention is provider training. Yet, little evidence supports the effectiveness of provider trainings. Long-term effects of such programs on provider behavior in the clinical setting and subsequent patient health outcomes have not been evaluated. Further, traditional provider cultural competence trainings based on attributions of a culture have the potential for unintended consequences, such as reinforcing stereotypes or increasing stigma.

For each population, we identified interventions at the individual level to improve patient/provider interactions, often with cultural tailoring. These studies met inclusion criteria if they targeted a population of interest and were conducted by a medical professional in a formal health care system. Frequently, these interventions placed responsibility on patients more than providers or systems, without requiring either the provider or the system to become more competent. These programs tended to weigh heavily on common identity and cultural attributions and, in some cases, were less effective in subpopulations that were less tied to the community.

Five system-level interventions were identified that address disparities in one of the target populations, but do not necessarily require a provider to be competent. The most prominent example of such an intervention was patient-held medical records that prompt providers to evaluate areas of known disparity for a specific population. These point-of-care interventions were seen in all three population groups.

We need better understanding of how cultural competence differs between and within groups. For example, people with a physical disability experience more screening disparities because of limitations of the physical plant, whereas people with intellectual disabilities are more likely to not have secondary conditions diagnosed and treated. The interventions to address these disparities must also be different. There is also significant between- and within-group variation in population visibility that affects interventions to reduce disparities. For members of sexual minority populations, which are more invisible, cultural competence interventions may focus on reducing heterosexual bias among providers; for example, providers may not know that the patient is an LGBT person. In contrast, provider bias to racial and ethnic minority populations is immediate and based on characteristics perceived by the provider.

The “cultural competency” label itself may be outdated, because it emphasizes the “internal culture” of groups. A more useful term might be “equity interventions,” which emphasizes equity as the desired outcome. More important than labels is that interventions address structural barriers faced by priority populations in order to attain health equity. Future research with greater methodological rigor and greater attention to relational rather than attributional dimensions to meet the heterogeneity of these populations is needed.

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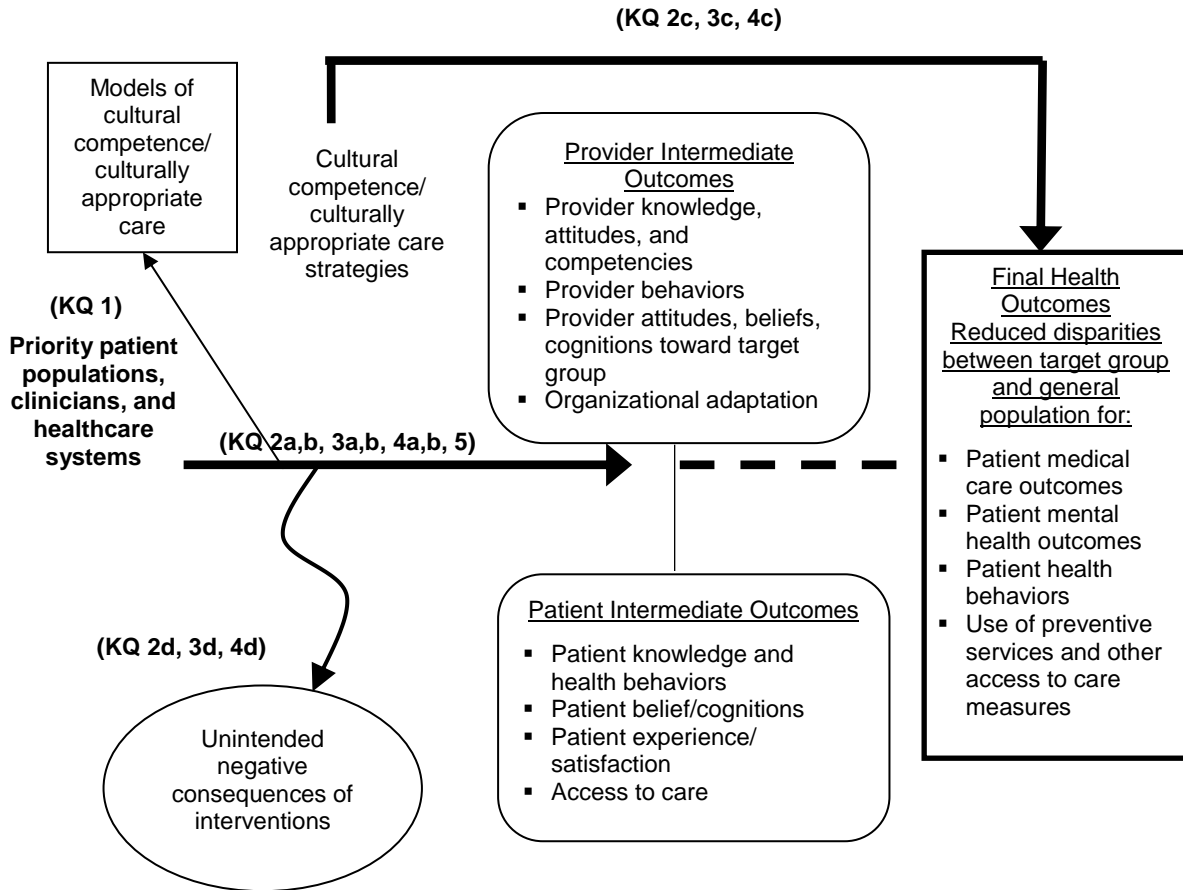
## Abbreviations

|             |   |
|-------------|---|
| AAMC        | American Association of Medical Colleges                            |
| A-CBT       | Accommodated version of cognitive-behavioral treatment              |
| ACS         | American Community Survey   |
| AHRQ        | Agency for Healthcare Research and Quality                          |
| AI/AN       | American Indian and Alaska Native                                   |
| AIMS2       | Arthritis Self-Efficacy Scale                                       |
| AQ-9        | Attribution Questionnaire   |
| ASES        | Arthritis Self-Efficacy Scale                                       |
| ASO         | AIDS service organization   |
| AwQ         | Awareness Questionnaire   |
| BV          | Bacterial vaginosis   |
| CALD        | Culturally and linguistically diverse                               |
| CAMI        | Community Attitudes towards the Mentally Ill                        |
| CBT         | Cognitive behavioral therapy  |
| CC          | Cultural competency   |
| CES-D       | Center for Epidemiological Studies Depression Scale                 |
| CHAP        | Comprehensive Health Assessment Program                             |
| CLAS        | Culturally and linguistically appropriate services                  |
| CM          | Contingency management  |
| CMPPQ       | Comorbidity Problems Perceptions Questionnaire                      |
| CVD         | Cardiovascular disease  |
| DSMT        | Diabetes self-management training                                   |
| ERMIS       | Emotional Reactions to Mental Illness Scale                         |
| ESL         | English as a second language  |
| FIS         | Fatigue Impact Scale  |
| FSS         | Fatigue Severity Scale  |
| GBM         | Gay and bisexual men  |
| HAART       | Highly active antiretroviral treatment                              |
| HAN-D       | Hamilton Depression Rating Scale                                    |
| HIV         | Human immunodeficiency virus  |
| ICF         | International Classification of Functioning, Disability, and Health |
| IDs         | Intellectual disabilities   |
| IES-Revised | Impact of Event Scale-Revised                                       |
| KQ          | Key Question  |
| LGBT        | Lesbian, gay, bisexual, and transgender                             |
| MAKS        | Mental Health Knowledge Schedule                                    |
| MHFA        | Mental Health First Aid   |
| MICA        | Mental Illness: Clinicians Attitudes Scale                          |
| MSM         | Men who have sex with men   |
| MSMW        | Men who have sex with men and women                                 |
| OMS-HC      | Opening Minds Scale for Health Care Providers                       |
| PASHIN      | Providers Advocating for Sexual Health Initiative                   |
| PHP         | Personal health profile   |
| PICOTS      | Population, Interventions, Comparators, Outcomes, Timing, Settings  |
| PTSD        | Post-traumatic stress disorder                                      |

|          |   |
|----------|---|
| QLS      | Quality of Life Scale   |
| RA       | Rheumatoid arthritis  |
| RAPID    | Rapid Assessment of Disease Activity in Rheumatology                                |
| RCT      | Randomized controlled trial   |
| REMAS-CA | Real Men Are Safe—culturally adapted version  |
| RIBS     | Reported and Intended Behaviour Scale   |
| S-CBT    | Standard cognitive-behavioral substance abuse treatment                             |
| SDS      | Self-Determination Scale  |
| SMW      | Sexual minority women   |
| SPS      | Social Provisions Scale   |
| STI      | Sexually transmitted infection  |
| SUN      | Study to Understand the Natural History of HIV/AIDS in the Era of Effective Therapy |
| WAI      | Working Alliance Inventory  |
| WSW      | Women who have sex with women   |
| WSWM     | Women who have sex with women and men   |

# Appendix A. Analytic Framework

Figure A1. Analytic framework for improving cultural competence to reduce disparities in priority populations





## Appendix B. Search Strings

### Disability Search String

| #  | Searches  |
|----|---|
| 1  | meta analysis as topic/   |
| 2  | meta-analy\$.tw.  |
| 3  | metaanaly\$.tw.   |
| 4  | meta-analysis/  |
| 5  | (systematic adj (review\$1 or overview\$1)).tw.                           |
| 6  | exp Review Literature as Topic/   |
| 7  | or/1-6  |
| 8  | cochrane.ab.  |
| 9  | embase.ab.  |
| 10 | (psychlit or psyclit).ab.   |
| 11 | (psychinfo or psycinfo).ab.   |
| 12 | or/8-11   |
| 13 | reference list\$.ab.  |
| 14 | bibliograph\$.ab.   |
| 15 | hand search.ab.   |
| 16 | relevant journals.ab.   |
| 17 | manual search\$.ab.   |
| 18 | or/13-17  |
| 19 | selection criteria.ab.  |
| 20 | (data adj2 (extract* or abstract*)).ab.                                   |
| 21 | 19 or 20  |
| 22 | review/   |
| 23 | 21 and 22   |
| 24 | Comment/  |
| 25 | Letter/   |
| 26 | editorial/  |
| 27 | animal/   |
| 28 | human/  |
| 29 | 27 not (28 and 27)  |
| 30 | or/24-26,29   |
| 31 | 7 or 12 or 18 or 23   |
| 32 | 31 not 30   |
| 33 | randomized controlled trials as topic/                                    |
| 34 | randomized controlled trial/  |
| 35 | random allocation/  |
| 36 | double blind method/  |
| 37 | single blind method/  |
| 38 | clinical trial/   |
| 39 | clinical trial, phase i.pt.   |
| 40 | clinical trial, phase ii.pt.  |
| 41 | clinical trial, phase iii.pt.   |
| 42 | clinical trial, phase iv.pt.  |
| 43 | controlled clinical trial.pt.   |
| 44 | randomized controlled trial.pt.   |
| 45 | multicenter study.pt.   |
| 46 | clinical trial.pt.  |
| 47 | exp clinical trials as topic/   |
| 48 | or/33-47  |
| 49 | (clinical adj trial\$).tw.  |
| 50 | ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw. |
| 51 | placebos/   |
| 52 | placebo\$.tw.   |
| 53 | randomly allocated.tw.  |
| 54 | (allocated adj2 random\$).tw.   |
| 55 | or/49-54  |

|     |   |
|-----|---|
| 56  | 48 or 55  |
| 57  | case report.tw.   |
| 58  | letter/   |
| 59  | historical article/   |
| 60  | or/57-59  |
| 61  | 56 not 60   |
| 62  | exp cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.   |
| 63  | cohort\$.tw.  |
| 64  | controlled clinical trial.pt.   |
| 65  | epidemiological methods/  |
| 66  | limit 65 to yr=1971-1983  |
| 67  | or/62-64,66   |
| 68  | exp disabled person/ or (amputee\$ or disabled person\$ or disabled child\$ or disab\$ or disabled people or mentally disabled person\$ or mentally disabled people or mentally ill person\$ or mentally ill people or visually impaired person\$ or visually impaired people or hearing impaired person\$ or hearing impaired people).mp.  |
| 69  | exp mental disorders diagnosed in childhood/ or (Asperger Syndrome or Aperger\$ or Autism or Autistic or Autistic Disorde\$ or learning disabil\$ or learning disorder\$ or developmental disability\$ or Attention Deficit Disorder\$ or Attention Deficit Disorder with Hyperactivity or behavior\$ disorder\$ or conduct disorder\$ or dyslexia or affective Disorder\$ or mood disorder\$ or depress\$ or depress\$ disorder\$ or personality disorder\$).mp. |
| 70  | exp cognition disorders/ or (cognit\$ disord\$ or cognit\$ disabil\$ or Mild Cognitive Impairment\$ or Huntington\$ or cognitive\$ impair\$).mp.  |
| 71  | exp intellectual disability/ or (intellectual disab\$ or Down Syndrome or mental\$ retard\$ or Fragile X or Rett Syndrome or Prader-Willi Syndrome or Williams Syndrome).mp.  |
| 72  | exp "Activities of Daily Living"/ or (activit\$ of daily living or functional limitation\$ or activity limitation\$ or participation limitation\$).mp.  |
| 73  | Mobility limitation/ or (mobility limitation\$ or mobility impairment\$).mp.  |
| 74  | Dependent ambulation/ or dependent ambulation.mp.   |
| 75  | Paraplegia/ or paraplegia.mp.   |
| 76  | Quadriplegia/ or quadriplegia.mp.   |
| 77  | Hearing loss/ or (hearing loss or hearing impair\$ or deaf\$).mp.   |
| 78  | Vision disorders/ or (blind\$ or vis\$ impair\$).mp.  |
| 79  | exp self-help devices/ or (assist\$ techn\$ or Commun\$ Aid\$ or commun\$ device\$ or Wheelchair\$).mp.   |
| 80  | Mental disorders/ or (mental disorder\$ or psychiatric disabilit\$ or mental health disabilit\$ or mental health impairment\$).mp.  |
| 81  | or/68-80  |
| 82  | minority groups/ or minority Health/  |
| 83  | exp health personnel/ed   |
| 84  | health services accessibility/ or healthcare disparities/   |
| 85  | "Attitude of Health Personnel"/   |
| 86  | Health Communication/   |
| 87  | (divers* adj3 (competenc* or understanding or knowledg* or expertise or skill* or sensitiv* or aware* or appropriate* or acceptab* or safe* or humility or service* or communicat* or barrier* or divers* or comparison* or identity or specific or background* or value* or belief*).tw.   |
| 88  | stigma.tw.  |
| 89  | Comprehensive Health Care/mt [Methods]  |
| 90  | "Delivery of Health Care"/mt [Methods]  |
| 91  | Health Promotion/mt [Methods]   |
| 92  | or/82-91  |
| 93  | 61 and 81 and 92  |
| 94  | limit 93 to yr="1990-Current"   |
| 95  | 32 and 81 and 92  |
| 96  | 95 not 94   |
| 97  | limit 96 to yr="1990-Current"   |
| 98  | 67 and 81 and 92  |
| 99  | intervention*.ti,ab.  |
| 100 | program*.ti,ab.   |
| 101 | 99 or 100   |
| 102 | 98 and 101  |
| 103 | 102 not (94 or 97)  |
| 104 | limit 103 to yr="1990-Current"  |

## Gender and Sexual Minority Search String

| #  | Searches  |
|----|---|
| 1  | meta analysis as topic/   |
| 2  | meta-analy\$.tw.  |
| 3  | metaanaly\$.tw.   |
| 4  | meta-analysis/  |
| 5  | (systematic adj (review\$1 or overview\$1)).tw.                           |
| 6  | exp Review Literature as Topic/   |
| 7  | or/1-6  |
| 8  | cochrane.ab.  |
| 9  | embase.ab.  |
| 10 | (psychlit or psyclit).ab.   |
| 11 | (psychinfo or psycinfo).ab.   |
| 12 | or/8-11   |
| 13 | reference list\$.ab.  |
| 14 | bibliograph\$.ab.   |
| 15 | hand search.ab.   |
| 16 | relevant journals.ab.   |
| 17 | manual search\$.ab.   |
| 18 | or/13-17  |
| 19 | selection criteria.ab.  |
| 20 | (data adj2 (extract* or abstract*)).ab.                                   |
| 21 | 19 or 20  |
| 22 | review/   |
| 23 | 21 and 22   |
| 24 | Comment/  |
| 25 | Letter/   |
| 26 | editorial/  |
| 27 | animal/   |
| 28 | human/  |
| 29 | 27 not (28 and 27)  |
| 30 | or/24-26,29   |
| 31 | 7 or 12 or 18 or 23   |
| 32 | 31 not 30   |
| 33 | randomized controlled trials as topic/                                    |
| 34 | randomized controlled trial/  |
| 35 | random allocation/  |
| 36 | double blind method/  |
| 37 | single blind method/  |
| 38 | clinical trial/   |
| 39 | clinical trial, phase i.pt.   |
| 40 | clinical trial, phase ii.pt.  |
| 41 | clinical trial, phase iii.pt.   |
| 42 | clinical trial, phase iv.pt.  |
| 43 | controlled clinical trial.pt.   |
| 44 | randomized controlled trial.pt.   |
| 45 | multicenter study.pt.   |
| 46 | clinical trial.pt.  |
| 47 | exp clinical trials as topic/   |
| 48 | or/33-47  |
| 49 | (clinical adj trial\$).tw.  |
| 50 | ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw. |
| 51 | placebos/   |
| 52 | placebo\$.tw.   |
| 53 | randomly allocated.tw.  |
| 54 | (allocated adj2 random\$).tw.   |
| 55 | or/49-54  |
| 56 | 48 or 55  |
| 57 | case report.tw.   |
| 58 | letter/   |

|     |   |
|-----|---|
| 59  | historical article/   |
| 60  | or/57-59  |
| 61  | 56 not 60   |
| 62  | exp cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.   |
| 63  | cohort\$.tw.  |
| 64  | controlled clinical trial.pt.   |
| 65  | exp teaching/   |
| 66  | exp health personnel/ed   |
| 67  | exp teaching materials/   |
| 68  | exp education/  |
| 69  | ((education* or teaching or learning or elearning or instruction* or training or skills or didactic or pedagogic* or online or online or web* or internet or cd-rom* or dvd or multimedia or multi-media or computer*) adj2 (intervention* or session* or course* or program* or activit* or presentation* or round* or material* or package* or module* or demonstration* or method* or process*)).tw. |
| 70  | (inservice or in service or workshop* or (discussion adj1 group*) or lectur* or seminar* or (short adj2 course*) or role play* or immersion or mentor* or lifelong learning or life long learning).tw.  |
| 71  | ((staff or professional or workforce or work force) adj (development or training)).tw.  |
| 72  | ((medical or continuing or residency or distance) adj2 education).tw.   |
| 73  | ((cultural* or transcultural* or multicultural* or intercultural* or bicultural*) adj2 (education or train* or teach* or learn* or instruct* or coach* or skills or content*)).tw.  |
| 74  | (curriculum or curricul* intervent*).tw.  |
| 75  | or/62-74  |
| 76  | exp Bisexuality/ or bisexual*.mp.   |
| 77  | exp Transsexualism/ or transsexual*.mp.   |
| 78  | exp Homosexuality/ or homosexual*.mp.   |
| 79  | exp Transgendered Persons/ or transgender*.mp.  |
| 80  | (lgbt* or glbt*).mp.  |
| 81  | (gay or lesbian).mp.  |
| 82  | ("men who have sex with men" or msm or "women who have sex with women" or wsw).mp.  |
| 83  | (WSMW or WSWM or MSWM or MSMW).mp.  |
| 84  | sexual minority.mp.   |
| 85  | gender minority.mp.   |
| 86  | gender expression.mp.   |
| 87  | (gender identit* or sexual orientation or sexual identit*).mp.  |
| 88  | or/76-87  |
| 89  | 32 and 88   |
| 90  | 61 and 88   |
| 91  | 75 and 88   |
| 92  | limit 89 to yr="1990-Current"   |
| 93  | limit 90 to yr="1990-Current"   |
| 94  | limit 91 to yr="1990-Current"   |
| 95  | intervention*.ti,ab.  |
| 96  | program*.ti,ab.   |
| 97  | curriculum.ti,ab.   |
| 98  | or/95-97  |
| 99  | 94 and 98   |
| 100 | 93  |
| 101 | 92 not 93   |
| 102 | 99 not (93 or 92)   |

## Racial/Ethnic Populations Search String

| #  | Searches  |
|----|---|
| 1  | meta analysis as topic/   |
| 2  | meta-analy\$.tw.  |
| 3  | metaanaly\$.tw.   |
| 4  | meta-analysis/  |
| 5  | (systematic adj (review\$1 or overview\$1)).tw.                           |
| 6  | exp Review Literature as Topic/   |
| 7  | or/1-6  |
| 8  | cochrane.ab.  |
| 9  | embase.ab.  |
| 10 | (psychlit or psyclit).ab.   |
| 11 | (psychinfo or psycinfo).ab.   |
| 12 | or/8-11   |
| 13 | reference list\$.ab.  |
| 14 | bibliograph\$.ab.   |
| 15 | hand search.ab.   |
| 16 | relevant journals.ab.   |
| 17 | manual search\$.ab.   |
| 18 | or/13-17  |
| 19 | selection criteria.ab.  |
| 20 | (data adj2 (extract* or abstract*)).ab.                                   |
| 21 | 19 or 20  |
| 22 | review/   |
| 23 | 21 and 22   |
| 24 | Comment/  |
| 25 | Letter/   |
| 26 | editorial/  |
| 27 | animal/   |
| 28 | human/  |
| 29 | 27 not (28 and 27)  |
| 30 | or/24-26,29   |
| 31 | 7 or 12 or 18 or 23   |
| 32 | 31 not 30   |
| 33 | randomized controlled trials as topic/                                    |
| 34 | randomized controlled trial/  |
| 35 | random allocation/  |
| 36 | double blind method/  |
| 37 | single blind method/  |
| 38 | clinical trial/   |
| 39 | clinical trial, phase i.pt.   |
| 40 | clinical trial, phase ii.pt.  |
| 41 | clinical trial, phase iii.pt.   |
| 42 | clinical trial, phase iv.pt.  |
| 43 | controlled clinical trial.pt.   |
| 44 | randomized controlled trial.pt.   |
| 45 | multicenter study.pt.   |
| 46 | clinical trial.pt.  |
| 47 | exp clinical trials as topic/   |
| 48 | or/33-47  |
| 49 | (clinical adj trial\$).tw.  |
| 50 | ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw. |
| 51 | placebos/   |
| 52 | placebo\$.tw.   |
| 53 | randomly allocated.tw.  |
| 54 | (allocated adj2 random\$).tw.   |
| 55 | or/49-54  |
| 56 | 48 or 55  |
| 57 | case report.tw.   |
| 58 | letter/   |

|    |  |
|----|--|
| 59 | historical article/  |
| 60 | or/57-59   |
| 61 | 56 not 60  |
| 62 | exp cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.  |
| 63 | cohort\$.tw.   |
| 64 | controlled clinical trial.pt.  |
| 65 | epidemiological methods/   |
| 66 | limit 65 to yr=1971-1983   |
| 67 | or/62-64,66  |
| 68 | population groups/ or african continental ancestry group/ or african americans/ or indians, north american/ or inuits/ or asian americans/ or oceanic ancestry group/ or ethnic groups/ or arabs/ or hispanic americans/ or mexican americans/   |
| 69 | "Emigration and Immigration"/ or "Emigrants and Immigrants"/ or "Transients and Migrants"/ or refugees/  |
| 70 | race relations/ or racism/   |
| 71 | (immigrant* or migrant* or refugee* or (displaced and (people or person*)) or ("foreign born" or "non us born" or "non-us born") or undocumented or second language* or ((language or english) and proficien*) or interpreter* or "minority group*" or "ethnic group*" or "urban health" or "urban population" or "inner city" or ethnic* or race or racial or minorit* or urban or inner-city or multiethnic).tw. |
| 72 | (non-english or hispanic* or latin* or ((african or black or asian or native or mexican) adj american*) or inuit* or islander*).tw.  |
| 73 | or/68-72   |
| 74 | culture/ or cross-cultural comparison/ or cultural characteristics/ or cultural competency/ or cultural diversity/   |
| 75 | multilingualism/ or language/  |
| 76 | ((cultur* or linguistic* or language*) adj3 (competenc* or understanding or knowledg* or expertise or skill* or sensitiv* or aware* or appropriate* or acceptab* or safe* or humility or service* or communicat* or barrier* or divers* or comparison* or identity or specific or background* or value* or belief*)).tw.   |
| 77 | (intercultural* or inter-cultural or transcultural* or trans-cultural or cross-cultural or crosscultural or multicultural* or multicultural* or bicultural or bi-cultural or multilingual* or multi-lingual* or bilingual or bi-lingual).tw.   |
| 78 | transcultural nursing/   |
| 79 | minority groups/ or minority Health/   |
| 80 | ((cultural* or transcultural* or multicultural* or intercultural* or bicultural*) adj2 (education or train* or teach* or learn* or instruct* or coach* or skills or content*)).tw.   |
| 81 | Healthcare Disparities/  |
| 82 | stigma.mp.   |
| 83 | or/74-82   |
| 84 | 61 and 73 and 83   |
| 85 | limit 84 to yr="1990-Current"  |
| 86 | 32 and 83  |
| 87 | 86 not 85  |
| 88 | limit 87 to yr="1990-Current"  |
| 89 | 67 and 73 and 83   |
| 90 | intervention*.ti,ab.   |
| 91 | program*.ti,ab.  |
| 92 | 90 or 91   |
| 93 | 89 and 92  |
| 94 | 93 not (85 or 88)  |
| 95 | limit 94 to yr="1990-Current"  |

## Cultural Competence Model Search String

| #  | Searches   |
|----|--|
| 1  | Culture/   |
| 2  | Cultural Competency/   |
| 3  | Anthropology, Cultural/  |
| 4  | Cultural Characteristics/  |
| 5  | Cultural Diversity/  |
| 6  | Cross-Cultural Comparison/   |
| 7  | (cultur* adj3 competenc*).tw.  |
| 8  | (cultur* adj3 understanding).tw.   |
| 9  | (cultur* adj3 knowledg*).tw.   |
| 10 | (cultur* adj3 skill*).tw.  |
| 11 | (cultur* adj3 sensitiv*).tw.   |
| 12 | (cultur* adj3 aware*).tw.  |
| 13 | (cultur* adj3 appropriate*).tw.  |
| 14 | (cultur* adj3 acceptab*).tw.   |
| 15 | (cultur* adj3 safe*).tw.   |
| 16 | (cultur* adj3 service*).tw.  |
| 17 | (cultur* adj3 communicat*).tw.   |
| 18 | (cultur* adj3 barrier*).tw.  |
| 19 | (cultur* adj3 divers*).tw.   |
| 20 | (cultur* adj3 comparison*).tw.   |
| 21 | (cultur* adj3 identity*).tw.   |
| 22 | (cultur* adj3 specific*).tw.   |
| 23 | (cultur* adj3 background*).tw.   |
| 24 | (cultur* adj3 value*).tw.  |
| 25 | (cultur* adj3 belief*).tw.   |
| 26 | Transcultural Nursing/   |
| 27 | (intercultural* or inter-cultural or transcultural* or trans-cultural or cross-cultural or crosscultural or multicultural* or multi-cultural* or multiethnic or bicultural or bi-cultural or multilingual* or multi-lingual* or bilingual or bi-lingual).tw. |
| 28 | "Emigration and Immigration"/  |
| 29 | "Emigrants and Immigrants"/  |
| 30 | "Transients and Migrants"/   |
| 31 | Refugees/  |
| 32 | exp Population Groups/   |
| 33 | Minority Groups/   |
| 34 | Minority Health/   |
| 35 | (immigrant* or migrant* or refugee* or ethnic* or racial or indigenous or aborigin*).tw.   |
| 36 | (non-english or hispanic* or latino* or ((african or black or asian or native or mexican) adj american*) or inuit* or maori or islander*).tw.  |
| 37 | exp Bisexuality/ or exp Transsexualism/ or exp Homosexuality/ or exp Homosexuality, Female/ or lgbt.mp. or exp Homosexuality, Male/ or exp Sexual Behavior/  |
| 38 | exp child development disorders/   |
| 39 | exp child development disorders, pervasive/  |
| 40 | exp communication disorders/   |
| 41 | exp developmental disabilities/  |
| 42 | exp learning disorders/  |
| 43 | exp intellectual disability/   |
| 44 | exp psychomotor disorders/   |
| 45 | exp Disabled Persons/  |
| 46 | exp Disabled Children/   |
| 47 | exp Models, Nursing/   |
| 48 | exp Models, Theoretical/   |
| 49 | model*.mp. or framework*.tw. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]                       |
| 50 | exp Models, Organizational/  |
| 51 | delivery of health care/   |

|    |  |
|----|--|
| 52 | patient-centered care/                                   |
| 53 | health knowledge attitudes practice/                     |
| 54 | exp Clinical Competence/ or exp Professional Competence/ |
| 55 | or/1-27  |
| 56 | or/28-46   |
| 57 | or/47-50   |
| 58 | or/51-54   |
| 59 | 55 and 56 and 57   |
| 60 | 55 and 56 and 57 and 58                                  |

This section briefly summarizes the methods used to search for the conceptual models. We searched Ovid MEDLINE® from 1990, when the concept of cultural competence gained traction, to February 2014. We used natural language key words and MeSH terms to capture the concepts of cultural competence, models, and the three included priority populations.

Two independent reviewers screened the references for articles that described the development of a cultural competence model, reviewed models of cultural competence, or appeared to have likely used a cultural competence model as the basis for research in order to identify likely models. Full texts of articles that might be a source for a model were then pulled and examined for likely descriptions of or references to cultural competence models. This process necessarily required backward citation searching to locate original source material for models. Identified models were included if they were intended for use by the formal healthcare system, were designed for or applicable to at least one of the three priority populations, and suggested possible point of interventions to improve cultural competence of providers or the healthcare system. Mid-level models that examined only one facet or factor of cultural competence, or only one type of patient behavior (such as help-seeking) were not included. Models were then collated and presented as unique models with one citation for the source from which it was eventually drawn. Each model was abstracted directly into an evidence table for whether the model focused primarily on the inner experience of the provider, externally on the person(s) the provider would be interacting with, or both; a brief description of the model; and the model characteristics. One investigator abstracted the model and a second investigator quality checked the abstraction.



# Appendix C. Excluded Studies

## Disability Populations

### Full Text—Care Coordination/Patient Centered Care (5)

1. Bauer MS, McBride L, Williford WO, et al. Collaborative care for bipolar disorder: Part II. Impact on clinical outcome, function, and costs. *Psychiatric Services* 2006 Jul; 57(7):937-45. PMID: 16816277.
2. Bickman L, Summerfelt WT, Noser K. Comparative outcomes of emotionally disturbed children and adolescents in a system of services and usual care. *Psychiatric Services* 1997 Dec; 48(12):1543-8. PMID: 9406261.
3. Crowley R, Wolfe I, Lock K, et al. Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood* 2011 Jun; 96(6):548-53. PMID: 21388969.
4. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics* 2008 Oct; 122(4):e922-37. PMID: 18829788.
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### Full Text—Descriptive/No Intervention (7)

1. Arvaniti A, Samakouri M, Kalamara E, et al. Health service staff's attitudes towards patients with mental illness. *Social Psychiatry and Psychiatric Epidemiology* 2009; 44(8):658-665. PMID: 19082905.
2. Berman BA, Jo A, Cumberland WG, et al. Breast cancer knowledge and practices among D/deaf women. *Disability and Health Journal* 2013; 6(4):303-316. PMID: 24060253.
3. Handler EG, Bhardwaj A, Jackson DS. Medical students' and allied health care professionals' perceptions toward the mentally retarded population. *Journal of Developmental and Physical Disabilities* 1994; 6(3):291-297.
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## Full Text—Design Methods (9)

1. Bell JS, Johns R, Chen TF. Pharmacy students' and graduates' attitudes towards people with schizophrenia and severe depression. *American Journal of Pharmaceutical Education* 2006; 70(4):7. PMID: 17136196
2. Brooks E, Novins DK, Noe T, et al. Reaching rural communities with culturally appropriate care: A model for adapting remote monitoring to American Indian veterans with posttraumatic stress disorder. *Telemedicine and e-Health* 2013; 19(4):272-277. PMID: 23451811.
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## Full Text—No Formal System/Health Promotion (20)

1. Baker-Ericzen MJ, Mueggenborg MG, Shea MM. Impact of trainings on child care providers' attitudes and perceived competence toward inclusion: What factors are associated with change? *Topics in Early Childhood Special Education* 2009; 28(4):196-208.
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## Full Text—Provider Education Only (4)

1. Catteau C, Faulks D, Mishellany-Dutour A, et al. Using e-learning to train dentists in the development of standardised oral health promotion interventions for persons with disability. *European Journal of Dental Education* 2013 Aug; 17(3):143-53. PMID: 23815691.
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## Full Text—Virtual Care/Not Access Focused (10)

1. Boisvert M, Lang R, Andrianopoulos M, et al. Telepractice in the assessment and treatment of individuals with autism spectrum disorders: A systematic review. *Developmental Neurorehabilitation* 2010; 13(6):423-432. PMID: 20887200.
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# Lesbian, Gay, Bisexual, and Transgender Populations

## Full Text—Design/Descriptive (27)

1. Beverly A. Transforming the nursing curriculum: integrating concepts of gender, race, class, and ethnicity. *Deans Notes* 1992 Mar; 13(4):1-3. PMID: 1563112.
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4. Brondani MA, Paterson R. Teaching lesbian, gay, bisexual, and transgender issues in dental education: a multipurpose method. *Journal of Dental Education* 2011 Oct; 75(10):1354-61. PMID: 22012779.
5. Celik H, Lagro-Janssen TALM, Widdershoven GGAM, et al. Bringing gender sensitivity into healthcare practice: a systematic review. *Patient Education & Counseling* 2011 Aug; 84(2):143-9. PMID: 20719461.
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## Full Text –Descriptive/No Intervention (12)

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### **Full Text—HIV Focused (8)**

1. Carrico AW, Nation A, Gomez W, et al. Pilot trial of an expressive writing intervention with HIV-positive methamphetamine-using men who have sex with men. *Psychology of Addictive Behaviors* 2015 Jun; 29(2):277-82. PMID: 25437153.
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### **Full Text—Individualized/Patient Centered Care (4)**

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## Full Text—No Formal System (32)

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## Appendix D. Description and Characteristics of Included Studies

**Appendix Table D1. Description and characteristics of included studies—disability populations**

| Reference                    | Target of Intervention | Disability Population        | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity   | Population   | Setting   | Primary Outcomes  |
|------------------------------|------------------------|------------------------------|---|---|---|--|---|---|
| Bannatyne, 2015 <sup>1</sup> | Medical students       | People with anorexia nervosa | “In relation to AN, research has indicated medical students and early career physicians, who have little to no experience in treating EDs, often report a lack of empathy and strongly endorse beliefs of self-infliction.” | RCT<br><br>To compare the effect of biogenic education versus traditional multi-factorial education versus no education on volitional stigma towards patients with anorexia nervosa.          | The two active interventions were one-time, 3 hour courses that were identical in all respects, except information regarding the etiology of anorexia nervosa: the biogenetic arm emphasized potential genetic underpinnings of the disease: the multifactorial arm emphasized interaction between psychological and social etiologies. | 40 fourth-year medicine students were randomized   | University, Australia   | Causal attribution, attitudes toward people with anorexia nervosa, and eating disorder stigma scales were used to collect pre- and post- and 8-week followup data.                |
| Clement, 2012 <sup>2</sup>   | Nursing students       | People with mental illness   | “Social contact interventions in which individuals affected by mental illness share their personal stories...are common components of mental health anti-stigma programmes, and are increasingly                            | RCT<br><br>To test the following hypotheses that: (a) there would be no difference in stigma between the filmed (indirect social contact) and live (direct social contact) interventions; and | Participants were randomized to DVD intervention, live intervention, or lecture control arms. The DVD and live intervention arms both had similar content: personal narratives from mental health consumers and a   | 360 student general nurses in their university foundation year following diploma, degree or accelerated diploma courses were randomized, 216 participated. | University, UK<br><br><i>Note: some association between researchers and DVD</i> | The following were measured immediately following intervention and 4 months later: stigmatizing attitudes, intended social proximity, knowledge, prosocial emotional reactions to |

| Reference                     | Target of Intervention | Disability Population              | Article Framing   | Study Design and Aim   | Intervention Duration and Intensity   | Population   | Setting              | Primary Outcomes  |
|-------------------------------|------------------------|------------------------------------|---|--|---|--|----------------------|---|
|                               |                        |                                    | being used in the training of health professionals as their attitudes and behaviour may also be stigmatising.”  | (b) the conditions with social contact, either direct or indirect (live or filmed) would be more effective in reducing stigma than a control condition with no social contact (lecture). | researcher facilitated discussion. The lecture was given by a nurse and contained no indirect or direct contact with consumers.   |  |                      | people with mental illness, cost effectiveness, participant satisfaction, and emotional response  |
| Cutler, 2012 <sup>3</sup>     | Medical students       | People with chronic mental illness | “Stigma toward psychiatric patients remains a challenge for our field despite efforts at reduction. In psychiatric education, stigma plays a significant role in shaping medical students’ views of individuals living with psychiatric disorders. Stigma also impedes recruitment of talented students to join our field.” | Randomized trial<br>To determine the effect of a one-time exposure to an art exhibit featuring art created by people with chronic mental illness on medical student attitudes.           | 64 students toured the art studio that was housed in state psychiatric facility, 44 of the 64 interacted with an artist (a person with a chronic mental health condition). The control group consisted of 110 students who had not visited the exhibit. | 174 pre-clinical medical students enrolled in a psychiatric medicine course  | University, New York | The following were measured one time using a waitlist control: positive feelings toward people mental illness, contentment of people with mental illness, positive personality traits of people with mental illness, discomfort of interactions with people with mental illness, and hopelessness of people with mental illness |
| Domenech, 2011 <sup>4</sup> . | PT students            |                                    | “Health care providers’ conceptualisations of LBP and disability may also influence the recommendations they provide to their patients.”  | RCT<br>The objectives of this study were to determine the effectiveness of 2 brief educational modules with different orientations (i.e., biomedical or                                  | Students were cluster randomized into 2 groups: The experimental group received a specific education module based on the bio-psychosocial model of back-  | A total of 170 second-year physical therapy students participated in the study. Before inclusion in the study, all participants received theoretical and | University, Spain    | To evaluate any changes in attitudes, 7 dependent variables were considered: FABQ–Work scores, FABQ–Physical Activity scores, HC-PAIRS scores, the  |

| Reference                    | Target of Intervention | Disability Population | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity  | Population   | Setting                                | Primary Outcomes  |
|------------------------------|------------------------|-----------------------|---|---|--|--|--|---|
|                              |                        |                       |   | biopsychosocial) on changing the beliefs and attitudes of students, and to verify whether there were also changes in the recommendations given to their patients.   | pain management, and the control group received lectures on the biomechanics of the spine. The intervention in the experimental group consisted of 2 sessions of 3 hours each, 1 week apart. The educational sessions in the control group also consisted of 2 sessions 3 hours each, 1 week apart.  | practical lessons on managing LBP, following the recommendations of the CPG, as part of their regular curriculum. The students had observed patients with back pain in clinical settings but had not directly managed or treated patients without supervision. |  | perceived severity of symptoms and pathology, and recommendations for work and activity levels.                           |
| Friedrich, 2013 <sup>5</sup> | Medical students       |                       | "People with mental illness die prematurely. One reason is that their physical healthcare is on average worse than that provided to people without mental health problems. A potential mechanism underlying these disparities is discrimination against people with mental illness by health professionals who share the general public's stigmatising views towards such | RCT<br>The aim of this study was to ascertain the effects of the training on medical students both immediately and after 6 months with respect to mental health-related knowledge, attitudes, intended behaviour and empathy. | The intervention consisted of a short lecture with key facts and figures about stigma and discrimination; testimonies about the experiences of mental health problems and stigma from people with direct experience of mental health problems, either personally or as carers; and role-plays in small groups, using professional role-players to act the parts of service | 1,452 third-year medical students randomized at baseline, 625 immediately after intervention, 137 at 6 month followup.   | Four participating medical schools, UK | Mental health related knowledge, mental health related attitudes, reported and intended behavior scale, physician empathy |



| Reference                  | Target of Intervention | Disability Population | Article Framing  | Study Design and Aim  | Intervention Duration and Intensity   | Population   | Setting           | Primary Outcomes   |
|----------------------------|------------------------|-----------------------|--|---|---|--|-------------------|--|
|                            |                        |                       | people.”   |   | users and carers. It is not clear what happened with the controls.  |  |                   |  |
| Goddard, 1998 <sup>b</sup> | Nursing students       |                       | The attitudes of nurses and other health care professionals are believed to influence their interactions with people who have disabilities   | RCT<br>To determine whether or not there are significant differences between the sensitivity lab and control groups on the Attitudes Toward Disabled Persons Scale immediately, 6 weeks and 6 months after lab. | The experimental group participated in the sensitivity lab and the control group did not. Sensitivity lab was an 8-hour clinical activity with 3 major parts: (1) a simulation activity in which students assumed various disabilities while carrying out normal activities in the community, (2) panel presentations by persons with a variety of disabilities and their caregivers, and (3) debriefing in small clinical groups | 67 nursing students enrolled in a chronic disease course received the intervention, 54 students enrolled in the same course served as the control                            | University, Texas | Attitudes Toward Persons with Disabilities Scale           |
| Kassam, 2011 <sup>f</sup>  | Medical students       |                       | “Like the general public, medical students often hold the stereotypical views that people with mental illness are unlikely to recover and people with severe mental illness are dangerous and violent” | RCT<br>To compare the effects of 3 different interventions, and directly assessed students’ mental illness related knowledge, attitudes and behaviour towards   | The study was a nonrandomised controlled trial with three conditions:<br>A. Control Condition (CC): none of the intervention elements below.<br>B. Experimental Condition 1 (EC1):  | Of the 188 students who completed baseline instruments 110 (59%) had both pre- and post-intervention instruments (Knowledge Quiz and MICA scale) completed and were used for | University, UK    | Knowledge quiz, clinician attitudes scale, role play score |

| Reference                | Target of Intervention         | Disability Population | Article Framing   | Study Design and Aim   | Intervention Duration and Intensity   | Population   | Setting            | Primary Outcomes   |
|--------------------------|--------------------------------|-----------------------|---|--|---|--|--------------------|--|
|                          |                                |                       |   | people with mental illness.  | A presentation on mental illness related stigma that included the social and personal impacts of stigma against people with mental illness together with personal testimonies from a mental health service user and a caregiver of a person with mental illness.<br>C. Experimental Condition 2 (EC2):<br>As B above plus a role-play training session in a classroom setting with mental health service user and caregiver feedback. | subsequent analyses. Of the 204 allocated to EC1, 154 attended the lecture and completed satisfaction questionnaires. Of the 65 of the 204 allocated to EC2, 33 attended the role-play training and completed satisfaction questionnaires. |                    |  |
| Kirby, 2011 <sup>8</sup> | Undergraduate Medical Students |                       | "Physicians too should be comfortable and knowledgeable about wheelchair use when caring for patients who use wheelchairs, to meet the patients' functional needs and to work effectively with other members of the healthcare team. However, many family | RCT<br><br>The primary objective of this study was to test the hypothesis that a workshop tailored for undergraduate medical students would be effective in improving wheelchair-related knowledge, skills, and attitudes. | The intervention group received the 4-hour educational experience 6-9 days later. All participants from both groups attended an evaluation session 6 days after the workshop. The 6-month questionnaire was emailed to the participants in the  | A total of 196 first- and second-year medical students were invited to participate, 26 participants were randomly allocated into two equal-sized groups (intervention and control)   | University, Canada | The main outcome measures were a written knowledge test, a practical examination, the Scale of Attitudes Toward Disabled Persons, and students' perceptions. |

| Reference                   | Target of Intervention | Disability Population | Article Framing  | Study Design and Aim | Intervention Duration and Intensity                        | Population  | Setting | Primary Outcomes |
|-----------------------------|------------------------|-----------------------|--|----------------------|--|---|---------|------------------|
|                             |                        |                       | physicians have reported discomfort when dealing with people who have physical disabilities”   |                      | intervention group, with follow-up reminders as necessary. |   |         |                  |
| Melville, 2006 <sup>9</sup> | Practice nurses        |                       | “Practice Nurses have been identified as a group of professionals who make an important contribution to primary health care teams. However, they have significant unmet training needs relevant to their work with people with IDs.” | RCT                  |  | Of the 201 practice nurses who completed the first questionnaire (69% response rate), 79 volunteered to participate in the training intervention. Practice nurses who volunteered were sent the training pack and instructions, and invited to attend a training event on one of two arranged dates. Sixty-three Practice Nurses participated in the intervention and completed the research outcome measures. Of the participants, 42 practice nurses (67%) received the training pack and attended the training event (Group 1), and 21 practice nurses (33%) received the training pack only (Group 2). Sixty of |         |                  |

| Reference                    | Target of Intervention          | Disability Population      | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity   | Population   | Setting  | Primary Outcomes   |
|------------------------------|---------------------------------|----------------------------|---|---|---|--|--|--|
|                              |                                 |                            |   |   |   | the practice nurses who had not participated in any aspect of the training initiative (Group 3) completed the questionnaire at Time 2. |  |  |
| Meurs, 2010 <sup>10</sup>    | Dentists                        |                            | “People who are intellectually disabled have poorer oral hygiene and a higher prevalence of oral health problems compared to the general population...it seems that the dentist’s attitude and experience with regard to patients who are intellectually disabled play a significant role, as dental treatment of this particular patient group demands extra time, and specific knowledge and skills.” | RCT<br><br>The purpose of the current study, therefore, was to investigate whether background information of a patient who is intellectually disabled would positively contribute to the level of cooperation during dental care. | In case of an unsealed envelope, the practicing dentist would read the completed questionnaire before starting the intake. In the case of a sealed envelope, the dentist was not allowed to see the questionnaire and received only limited information about the subject | 58 persons with ID were randomly allocated to treatment or control conditions  | The study was conducted from September 2007 to June 2008 at two centers of special dental care (CBT Fatima and CBT Nijmegen) in the Netherlands. | Cooperation scores   |
| Michaels, 2014 <sup>11</sup> | Mental health service providers | People with mental illness | “Hypothesized benefits for service providers included stigma reduction, increased stigma awareness, and improved beliefs  | RCT<br><br>To assess the effect of a workshop designed to reduce stigma   | The 3 hour Anti-Stigma Project workshop (ASP) includes: a facilitated small-group discussion in which   | 127 people with mental illness and 131 mental health service providers were randomized.  | Maryland mental health facilities  | Attribution questionnaire, awareness questionnaire, error choice test, recovery assessment test, |

| Reference                 | Target of Intervention | Disability Population | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity   | Population  | Setting   | Primary Outcomes  |
|---------------------------|------------------------|-----------------------|---|---|---|---|---|---|
|                           |                        |                       | about self-determination and recovery for people with mental illness.”  | surrounding mental illness for people with mental illness and providers of services to people with mental illness.  | participants share their own experience of stigma, a video on the impact of public stigma on mental health services, and a group discussion of ways to combat public stigma on both a personal and systemic level. The control arms watched 3-hour videos on unrelated topics.        |   |   | self-determination scale given pre- and post-intervention   |
| Munro, 2007 <sup>12</sup> | Mental health nurses   |                       | “Substance misuse can trigger or be causally associated with mental health problems. Therapeutic attitude is important in predicting effective engagement with people with alcohol and drug problems but health professionals’ attitudes towards this client group are often negative.” | The aim of the study was to assess the impact of a tailored training programme on the therapeutic attitudes and knowledge of mental health nursing staff with regard to working with people who have co-existing substance misuse and mental health problems. | Those who were allocated to the experimental group received 4 days of training. A range of teaching methods was employed, including small interactive group-work and lectures that were delivered over 4 full days, from 9.30 am–4.30 pm. The control group received no intervention. | 49 mental health nurses employed in adult generic mental health and addiction services were recruited to the study: 24 were randomly allocated to the experimental group (who received training) and 25 were allocated to the control group (who received no training). Random number generation from within the statistical package for the social sciences was used to allocate random samples from each strata into each group. Due to the | The study was conducted in an NHS mental health service in the West of Scotland. A venue was purpose-built for staff training | Therapeutic attitude was measured using the comorbidity problems perceptions questionnaire (CMPPQ). The knowledge questionnaire was designed specifically for the study to reflect the course content |

| Reference                    | Target of Intervention | Disability Population             | Article Framing  | Study Design and Aim   | Intervention Duration and Intensity  | Population   | Setting                         | Primary Outcomes  |
|------------------------------|------------------------|-----------------------------------|--|--|--|--|---------------------------------|---|
|                              |                        |                                   |  |  |  | nature of the intervention, no blinding of the participants was possible. Registered nurses who were employed in adult generic mental health and addiction services.   |                                 |   |
| Nguyen, 2012 <sup>13</sup>   | Pharmacy students      | People with mental health illness | “However, research has consistently found that the suboptimal attitudes towards mental illness held by pharmacists and students can act as a major barrier to professional practice.”  | Controlled trial<br>To compare the effect of direct versus indirect contact with mental health consumers on stigma       | The direct contact arm attended a 2 hour workshop led by 3-4 mental health consumer educators and 2 pharmacists where consumers shared their personal experiences of mental illness with students. The indirect arm was 90 minutes and featured videos of consumers being interviewed as well as videos of clinical scenarios. | 244 3rd and 4th year pharmacy students had complete, paired data for analysis  | University of Sydney, Australia | Scales measuring social distance, attribution questionnaire, stigmatization, comfort providing pharmaceutical services were delivered pre- and post- intervention   |
| O'Reilly, 2011 <sup>14</sup> | Pharmacy students      |                                   | “Mental illness is the leading cause of nonfatal disease burden in Australia...stigma remains the major barrier to receiving effective mental health care. Mental health stigma is not | RCT<br>The aim of this study was to assess the impact of delivering Mental Health First Aid (MHFA) training for pharmacy | Two MHFA courses (standard adult MHFA training program, first edition), of 12 hour duration were conducted in September 2009. MHFA teaches participants skills   | All pharmacy students in their third year of a four-year Bachelor of Pharmacy degree were invited to participate, 174 applied to attend the training, 60 students were | University of Sydney, Australia | Social distance scale, correct identification of mental disorder in vignette, beliefs about treatments for schizophrenia and depression, confidence with medication |

| Reference                  | Target of Intervention | Disability Population | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity  | Population  | Setting                       | Primary Outcomes   |
|----------------------------|------------------------|-----------------------|---|---|--|---|-------------------------------|--|
|                            |                        |                       | restricted to members of the public and can extend to health care professionals, including pharmacists.”                  | students on their mental health literacy and stigma towards mental illness.   | to recognize the early warning signs of mental illness and how to provide initial help to someone in a mental health crisis.   | randomly selected to attend the training. 212 students were in the control group.   |                               | counseling and dealing with drug related problems                            |
| Papish, 2013 <sup>15</sup> | Medical students       |                       | “The stigma of mental illness among medical students is a prevalent concern that has far reaching negative consequences.” | Cluster-randomized trial design<br><br>This study examined the impact of a one-time contact-based educational intervention on the stigma of mental illness among medical students and compared this with a multimodal undergraduate psychiatry course that integrates contact-based educational strategies. | A randomized control trial was designed to assess the impact of two different educational interventions on medical student attitudes towards mental illness: a one-time contact based educational intervention and a 4 week mandatory psychiatry course at the University of Calgary, in Calgary (U of C), Canada. The Psychiatry and Family Violence Course is part of the U of C Medical School’s 3-year, year-round program where clinical presentations are the foundation of the curriculum [44] and the majority of students have an undergraduate or graduate | Of the 179 students eligible to participate in the study, 111 completed a baseline survey (62% response rate). Of these, 81% (n=90) completed the second survey, 86.5% (n=96) completed the third survey and 52.1% (n=50) completed the 3 month followup survey. Although 96.1% (n=172) of the class responded to the third survey, only data from students who completed the baseline survey was used to assess the impact of the contact-based interventions. | University of Calgary, Canada | OMS-HC scores, attitudes towards mental illness vs. type 2 diabetes mellitus |

| Reference                  | Target of Intervention | Disability Population      | Article Framing   | Study Design and Aim  | Intervention Duration and Intensity   | Population  | Setting  | Primary Outcomes  |
|----------------------------|------------------------|----------------------------|---|---|---|---|--|---|
|                            |                        |                            |   |   | university degree prior to entering medical school. Students completed the course in their second year immediately prior to starting the clerkship component of their education.    |   |  |   |
| Patten, 2012 <sup>16</sup> | Pharmacy students      | People with mental illness | "A sparsely studied yet significant area of concern is stigma and discrimination against people with mental illness by health care providers. Attitudes held by health care providers can have a negative impact on patient quality of life."     | RCT<br>To examine the impact of a contact-based intervention on stigma toward persons with schizophrenia or bipolar disorder.   | One-time, contact-based intervention varied in length by participating university (60-120 minute discussion featuring 2-3 consumer speakers) compared with a wait list control.     | 74 third and fourth year pharmacy students from three Universities had data for all three time points (56.5%) of randomized population.   | University, Canada                                   | The Opening Minds Survey for Health Care Providers (OMS-HC), was the instrument used to assess attitudes of pharmacy students toward people with mental illness |
| Symons, 2014 <sup>17</sup> | Medical students       |                            | "People with disabilities have reported physician attitudes as a barrier to receiving health care services. There is evidence that when health care providers are placed in a situation where they need to care for people with disabilities they | The study design is a controlled non-randomized before and after trial<br><br>They developed and implemented a longitudinal curriculum to improve medical students' knowledge, attitudes, and skills pertaining to patient-centered | The curriculum is described in detail in a previous publication. In brief, the curriculum is integrated into existing course curricula in all 4 years of medical student education. | Participants in the intervention group consisted of medical students enrolled in a public medical school (the State University of New York at Buffalo, NY). They were specifically the first cohort of students to participate in the entire core curriculum. The | Medical students in two public medical schools in NY | Medical students' self-reported attitudes and comfort level toward people with disabilities   |



| Reference | Target of Intervention | Disability Population | Article Framing  | Study Design and Aim  | Intervention Duration and Intensity | Population  | Setting | Primary Outcomes |
|-----------|------------------------|-----------------------|--|---|-------------------------------------|---|---------|------------------|
|           |                        |                       | may develop negative attitudes about working with this population because they lack training.” | care of persons with disabilities. This paper examines the effect of this curriculum on medical students’ self-reported attitudes and comfort level in caring for people with disabilities. |                                     | entire class participated in all elements of the curriculum. Participants in the control group consisted of medical students at a comparable public medical school in the same region (the State University of New York at Syracuse, NY). |         |                  |

**Appendix Table D2. Risk of bias for cultural competence interventions targeting persons with disabilities**

| Study Country Funding   | Type of Study                                | Overall Risk of Bias Assessment | Rationale   |
|---|--|---------------------------------|---|
| <b><i>Interventions Aimed at Changing Health Professionals' Attitudes</i></b>   |  |                                 |   |
| Bannatyne, 2015 <sup>1</sup><br>Australia<br>Funding not reported   | Randomized Trial                             | Moderate                        | Blinding likely not possible, self-reported outcomes, Inadequate sample size (<25 per arm)  |
| Clement, 2012 <sup>2</sup><br>United Kingdom<br>Government<br>Primary researchers have investment in DVD tested by this trial | Randomized Trial                             | High                            | Blinding likely not possible, self-reported outcomes, differential duration of intervention arms, more a test of intervention modality than cultural components of intervention   |
| Cutler, 2012 <sup>3</sup><br>United States<br>Professional Association Funding  | Randomized Trial                             | High                            | Blinding likely not possible, self-reported outcomes, no attention control (wait-list control only), not randomized to direct interaction or no direct interaction but an analysis was done based on this difference  |
| Domenech, 2011 <sup>4</sup><br>Spain<br>Funding not reported  | Cluster-randomized trial                     | Moderate                        | Blinding likely not possible, self-reported outcomes.<br>Caveat – the biopsychosocial model may not be considered by all people to be a reasonable proxy for cultural competence, but we chose to include it because it was tailored to low back pain disability groups and was framed as addressing a disparity. |
| Friedrich, 2013 <sup>5</sup><br>United Kingdom<br>Government  | Randomized Trial or Cluster-randomized trial | High                            | Unclear randomization and allocation concealment blinding likely not possible, self-reported outcomes, no attention control, controls not available for all participating colleges  |
| Goddard, 1998 <sup>6</sup><br>United States<br>Funding not reported   | Pre-Post, historical control                 | High                            | No randomization, blinding likely not possible, self-reported outcomes  |
| Kassam, 2011 <sup>7</sup><br>United Kingdom<br>Industry, Government   | Clustered trial                              | High                            | Not true randomization, allocated concealment adequately described, blinding likely not possible, self-reported outcomes, lack of attention control   |
| Kirby, 2011 <sup>8</sup><br>Canada<br>No External Funding   | Randomized Trial                             | High                            | Allocation concealment not adequately described, blinding likely not possible, self-reported outcomes, no attention control, small Ns (12 per arm)  |
| Melville, 2006 <sup>9</sup><br>Scotland<br>Government   | Controlled Trial                             | High                            | No randomization, blinding likely not possible, self-reported outcomes  |
| Michaels, 2012 <sup>11</sup><br>United States<br>US Government  | Randomized Trial                             | Moderate                        | Blinding likely not possible, self-reported outcomes but with a measure intended to detect social desirability  |
| Munro, 2007 <sup>12</sup><br>Scotland<br>Government   | Randomized Trial                             | High                            | Allocation concealment and blinding not possible, 37% attrition, no attention control, self-reported outcomes   |
| Nguyen, 2012 <sup>13</sup>  | Controlled Trial                             | High                            | No randomization, no blinding, self-reported outcomes   |

| <b>Study<br/>Country<br/>Funding</b>  | <b>Type of Study</b>   | <b>Overall<br/>Risk of Bias<br/>Assessment</b> | <b>Rationale</b>  |
|---|--|--|---|
| Australia<br>University Funded  |  |  |   |
| O'Reilly, 2011 <sup>14</sup><br>Australia<br>University funded                    | Randomized Trial   | High   | Process for randomization and allocation concealment not adequately described, blinding likely not possible, no attention control, some self-reported outcomes  |
| Papish, 2013 <sup>15</sup><br>Canada<br>Government                                | Cluster-Randomized trial                                     | High   | Potential for contamination as those who received intervention early interacted with controls post-intervention (in the same course), significant differences in control and intervention clusters at baseline, only 52% of participants completed 3 month followup assessments |
| Patten, 2012 <sup>16</sup><br>Canada<br>Government                                | Randomized Trial   | High   | Process for randomization and allocation concealment not adequately described, blinding likely not possible, no attention control, self-reported outcomes, high attrition   |
| Symons, 2014 <sup>17</sup><br>United States<br>Government                         | Controlled Trial   | High   | No randomization, unclear if controls similar enough at baseline, no blinding, self-reported outcomes   |
| <b><i>Interventions Prompting Interaction Between Patients and Physicians</i></b> |  |  |   |
| Lennox, 2007 <sup>18</sup><br>Australia<br>Government                             | Clustered-randomized trial at the general practitioner level | Moderate                                       | Unblinded, no attention control   |
| Meurs, 2010 <sup>10</sup><br>Netherlands<br>Funding not reported                  | Randomized trial   | Moderate                                       | Inadequate sample size (<30 per arm)  |
| Peterson, 2012 <sup>19</sup><br>United States<br>Government                       | Randomized trial   | High   | Blinding not possible, process for randomization not adequately described – may be more systematic than random, 56% of women randomized to intervention had posttest data available   |
| Turk, 2010 <sup>20</sup><br>United Kingdom<br>Government                          | Cluster-randomized trial at practice level                   | High   | Blinding not possible, only 54% of adults with learning disabilities completed the research interview at baseline and 32% of adults with learning disabilities dropped out before followup  |
| Wolraich, 2005 <sup>21</sup><br>United States<br>Funding not reported             | Longitudinal   | High   | No randomization, low treatment uptake (only 34% of students randomized to the intervention arm had a parent receive the intervention, and only 19% had a PCP receive the intervention)   |
| <b><i>Interventions Improving Access to Care</i></b>                              |  |  |   |
| Bombardier, 2013 <sup>22</sup><br>United States<br>Government                     | RCT  | Moderate                                       | No attention control  |
| Finlayson, 2011 <sup>23</sup><br>United States<br>Government                      | Randomized Trial   | High   | No attention control  |
| Knaevelsrud, 2007 <sup>24</sup><br>Germany<br>NGO                                 | Randomized Trial   | High   | Randomization, allocation concealment and blinding not adequately described, self-reported outcomes, describe having a wait list control group but data not analyzed against control  |

| <b>Study<br/>Country<br/>Funding</b>                       | <b>Type of Study</b> | <b>Overall<br/>Risk of Bias<br/>Assessment</b> | <b>Rationale</b>   |
|--|----------------------|--|--|
| Shigaki, 2013 <sup>25</sup><br>United States<br>Government | Randomized Trial     | High   | Unclear randomization and allocation concealment, no blinding, 22% attrition in intervention arm, no attention control, self-reported outcomes |

**Appendix Table D3. Description and characteristics of included studies—LGBT**

|   | <b>Bowen et al., 2006<sup>26</sup></b>                                       | <b>Blas et al., 2010<sup>27</sup></b>   | <b>Peck et al., 2005<sup>28</sup><br/>Shoptaw et al., 2005<sup>29</sup></b>  | <b>McKirnan et al., 2010<sup>30</sup></b>  | <b>Marrazzo et al., 2011<sup>31</sup></b>   |
|---|--|---|--|--|---|
| Sequence generation                                       | The sequence generation process was not described.                           | Per study protocol, a computer randomly assigns the participant to one of the two arms of the intervention. The randomization will be automatically done by an algorithm that evaluates each case and uses a random number generator to make an independent assignment. | An urn randomization procedure was used that provided multivariate balance across conditions based on level of drug use (heavy versus light) and ethnicity (Caucasian, Hispanic, African American, other). | The sequence generation process was not described.   | "...randomization included a simple randomization scheme generated by a statistician." (p.400)  |
| Allocation concealment                                    | Allocation concealment was not described.                                    | Web-based allocation allowed for concealment.   | Allocation concealment was not described.  | The research assistant called a central research office to receive randomly assigned participant number. The assigned identification number coded the participant as intervention or comparison. | "After enrollment, the study coordinator obtained the randomization assignment from a sealed envelope that was generated in a sequence reflecting this scheme." (p.400) |
| Blinding of participants, personnel and outcome assessors | No evidence of blinding  | Investigators were blinded to condition assignments.  | No evidence of blinding  | No evidence of blinding  | No evidence of blinding   |
| Incomplete outcome data                                   | It is not clear whether or not intent to treat (ITT) analysis was conducted. | The authors describe using an ITT analysis.   | The authors describe using an ITT analysis.  | The authors described first using an ITT analysis (80% completion) followed by multiple imputation. It appears the analysis was conducted on only those who completed followup (Figure 1).       | The authors describe using an ITT analysis.   |
| Selective outcome reporting                               | Unable to determine selective outcome reporting.                             | No evidence of selective outcome reporting  | Missing values on outcome variables were not imputed for univariate or multivariate analyses. Missing data were handled using casewise deletion. No evidence of selective outcome reporting.               | No evidence of selective outcome reporting   | No evidence of selective outcome reporting  |

**Appendix Table D4. Risk of bias for cultural competence interventions targeting gender and sexual minorities**

| <b>Study<br/>Country<br/>Funding</b>  | <b>Type of Study</b>                      | <b>Overall<br/>Risk of Bias<br/>Assessment</b> | <b>Rationale</b>  |
|---|---|--|---|
| <b><i>Interventions Aimed at Prompting LGBT Patients to Interact With the Formal Healthcare System for Screening or Testing</i></b> |   |  |   |
| Blas, 2010 <sup>27</sup><br>Peru<br>Government/NGO  | Randomized trial                          | High   | Lack of equivalent control  |
| Bowen, 2006 <sup>26</sup><br>United States<br>Government  | Randomized trial                          | High   | Unclear randomization process and allocation concealment, unblinded, no attention control   |
| <b><i>Clinic-based Mental Health and Substance Use Interventions Tailored to an LGBT Population</i></b>                             |   |  |   |
| Peck, 2005 <sup>32</sup><br>United States<br>Government<br><br>Shoptaw, 2004 <sup>32</sup><br>United States<br>Government           | Randomized trial                          | High   | Unclear blinding of participants or assessors. Unclear attrition reporting and missing data analysis for sexual risk behavior outcomes. |
| <b><i>Interventions Aimed at Behavioral Risk Reduction That Involve Formal Healthcare Providers</i></b>                             |   |  |   |
| Bachmann, 2013 <sup>33</sup><br>United States<br>Government   | Longitudinal                              | High   | Nonrandomized longitudinal design, possible bias due to attrition   |
| Patel, 2012 <sup>34</sup><br>United States<br>Government  | Prospective cohort,<br>pre-post           | High   | Nonrandomized pre-post design   |
| McKirnan, 2010 <sup>30</sup><br>United States<br>Government   | Randomized trial                          | High   | Unclear randomization process and allocation concealment, unblinded, no attention control   |
| Marrazzo, 2011 <sup>31</sup><br>United States<br>Government   | Randomized trial                          | High   | Unclear blinding of participants or assessors, lack of clarity in describing intervention components                                    |
| <b><i>Interventions Testing Medical Training Curricula</i></b>  |   |  |   |
| Kelly, 2008 <sup>35</sup><br>United States<br>Government  | Pre-post                                  | High   | Nonrandomized pre-post survey design  |
| McGarry, 2002 <sup>36</sup><br>United States<br>Funding not reported  | Pre-post                                  | High   | Nonrandomized pre-post survey design  |
| Beagan, 2003 <sup>37</sup><br>Canada<br>Government  | Prospective cohort,<br>historical control | High   | Nonrandomized pre-post survey design  |
| <b>Psychosocial Interventions</b>   |   |  |   |

| <b>Study<br/>Country<br/>Funding</b>                       | <b>Type of Study</b> | <b>Overall<br/>Risk of Bias<br/>Assessment</b> | <b>Rationale</b>  |
|--|----------------------|--|---|
| Fobair, 2002 <sup>113</sup><br>Unites States<br>Government | Pre-post             | High   | Nonrandomized pre-post design, insufficient sample size |

**Appendix Table D5. Risk of bias for cultural competence interventions targeting racial/ethnic minorities**

| <b>Study Funding</b>   | <b>Type of Study</b>                                     | <b>Overall Risk of Bias Assessment</b> | <b>Rationale</b>   |
|--|--|--|--|
| <b><i>Interventions to improve provider/patient interactions</i></b> |  |  |  |
| Alegria, 2014 <sup>38</sup><br>Government                            | Randomized trial   | High                                   | Unblinded, no attention control  |
| Cooper, 2013 <sup>39</sup><br>Government, Foundation                 | Cluster randomized trial with patient-level ITT analyses | High                                   | Unblinded, possible confounding (cultural competence one component of multicomponent intervention)   |
| Penner, 2013 <sup>40</sup><br>Government                             | Randomized trial (at physician level)                    | High                                   | Unclear randomization process and allocation concealment, unblinded, inadequate sample size (n=14 physicians)  |
| Aragones, 2010 <sup>41</sup><br>Government                           | Randomized trial (at physician level)                    | High                                   | Unblinded, no attention control  |
| Michalopoulou, 2010 <sup>42</sup><br>Government                      | Controlled trial   | High                                   | Nonrandomized design, noattention control, possible reporting bias   |
| Alegria, 2008 <sup>43</sup><br>Government                            | Controlled trial   | High                                   | Nonrandomized design, no attention control   |
| <b><i>Culturally tailored interventions</i></b>                      |  |  |  |
| Breitkopf, 2014 <sup>32</sup><br>Government                          | Randomized trial   | Moderate                               | Possible bias due to attrition   |
| Kim, 2014 <sup>44</sup><br>Government                                | Randomized trial   | High                                   | Unblinded, lack of time equivalent control, possible bias due to attrition   |
| Smith, 2014 <sup>45</sup>  | Randomized trial   | Moderate                               | Unblinded, possible bias due to attrition, possible bias due to contamination (information shared among participants)  |
| Calsyn, 2013 <sup>46</sup><br>Government                             | Pilot vs. subgroup of randomized trial                   | High                                   | Nonrandomized design, possible bias due to attrition, possible reporting bias  |
| Le, 2013 <sup>47</sup><br>NR   | Cohort study   | High                                   | Nonrandomized design, limited description of intervention (perhaps constrained by wordcount)   |
| Lee, 2013 <sup>48</sup><br>Government                                | Randomized trial   | High                                   | Unclear randomization process and allocation concealment, unblinded  |
| Burrow-Sanchez, 2012 <sup>49</sup><br>Government                     | Randomized trial   | High                                   | Unclear randomization process and allocation concealment, unblinded, inadequate sample size  |
| Ell, 2011 <sup>50</sup><br>Government                                | Randomized trial   | High                                   | Unblinded, no attention control, possible bias due to attrition  |
| Pan, 2011 <sup>51</sup><br>Government                                | Randomized trial   | High                                   | Unclear randomization process and allocation concealment, unblinded, inadequate sample size, possible reporting bias   |
| D'Eramo Melkus, 2010 <sup>52</sup><br>Government                     | Randomized trial   | High                                   | Unclear randomization process, allocation concealment, unclear blinding, possible bias due to attrition, possible confounding (cultural competence one component of multicomponent intervention) |
| Marsiglia, 2010 <sup>53</sup><br>Government                          | Randomized trial   | High                                   | Unblinded, no attention control  |
| Kohn, 2002 <sup>54</sup><br>Funding not reported                     | Cohort study   | High                                   | Nonrandomized design, inadequate sample size   |



**Appendix Table D6. Map of studies included in Truong 2014 review of systematic reviews, with focus on provider training—racial/ethnic populations**

| Study                          | Aims  | Provider Training in Scope | Number of Included Studies | Map to Our Review: Inside or Outside Our Scope; Inclusion of Provider Training   | Results for Provider Training  |
|--------------------------------|---|----------------------------|----------------------------|--|--|
| Anderson, 2003 <sup>55</sup>   | To review interventions to improve cultural competence in healthcare systems (provider training, translation, tailored media, recruitment of diverse staff, and culturally specific settings) | Yes and broader            | 6                          | Outside: translation, health education material<br>Training – 1 study  | 1 RCT (Wade, 1991) in Horvat   |
| Beach, 2005 <sup>56</sup>      | To synthesize the findings of studies evaluating educational interventions to improve the cultural competence of health professionals   | Yes                        | 34                         | Training: 34 studies   | There is good evidence that cultural competence training improves staff knowledge, attitudes, and skill, and that the provision of training to staff improves patient satisfaction. Evidence to show improvements in patient adherence was poor and no studies reported patient health outcomes. |
| Bhui, 2007 <sup>57</sup>       | A systematic review that included evaluated models of cultural competence training or service delivery  | Yes and broader            | 9                          | Training: 3 with quantitative outcomes, 1/3 reporting prevalence of services<br>Inside: service delivery – 1 study, case series only | 2 pre-post studies with positive results for provider behavior and satisfaction, no patient outcomes   |
| Chippis, 2008 <sup>58</sup>    | To review studies evaluated cultural competence training in community-based rehabilitation settings   | Yes                        | 5                          | Training: 5 studies  | 3/5 studies overlap with Horvat (Wade, Thom, Majumdar)<br>2/5 studies overlap with Beach (Wade, Smith)   |
| Downing, 2011 <sup>59</sup>    | To review approaches to indigenous cultural training for health workers in Australia  | Yes, but outside our scope | 9                          | Outside: training within Australia   | N/A  |
| Fisher, 2007 <sup>60</sup>     | To review interventions (that modified patient behavior, access, or the health care system) using cultural leverage to narrow racial disparities in health care                               | Yes and broader            | 38 (35 unique studies)     | 34/35 lacked comparison to test CC<br>Training: 1 study  | 1 study (Briscoe, 1999), pre-post: 10-30% of participants implemented cultural strategies at 6 month followup  |
| Forsetlund, 2010 <sup>61</sup> | To review interventions to improve health care services for ethnic minorities   | Yes and broader            | 19 RCTs                    | Training: 8 studies, 5/8 not on CC<br>Outside: translation, matching, or not CC (reminders, care organization)                       | 3 CC training studies, all in Horvat (Wade, Thom, Harmsen)   |

| Study  | Aims   | Provider Training in Scope | Number of Included Studies | Map to Our Review: Inside or Outside Our Scope; Inclusion of Provider Training   | Results for Provider Training   |
|--|--|----------------------------|----------------------------|--|---|
| Harun, 2013 <sup>62</sup>  | To review interventions to improve 3 aspects of participation in cancer care among CALD groups: involvement in decisionmaking, communication with health providers and treatment adherence | No                         | 7                          | In scope/no comparison: patient navigation (3 studies)<br>Outside: culturally tailored video, individualized decision support software   | N/A   |
| Attridge, 2014 <sup>63</sup> (updated – Truong included earlier version) | To assess the effectiveness of culturally appropriate health education for people in ethnic minority groups with type 2 diabetes mellitus  | No                         | 33                         | In scope<br>32/33 lacked comparison to test CC<br>1/33 included: D'Eramo Melkus  | N/A   |
| Henderson, 2011 <sup>64</sup>  | To review the literature on the effectiveness of culturally appropriate interventions to manage or prevent chronic disease in CALD communities   | Yes and broader            | 24                         | Training:4 studies, 1/4 outside scope (translation)<br>Outside: translation, culturally tailored media, establishment of point-of-care testing<br>In scope: culturally tailored interventions (CHW, 16 studies)<br>16/16 no comparison | 1/4 studies in Horvat (Majumdar), 1 pre/post study (Chevannes et al. 2002) and 1 longitudinal study (Schim et al. 2006) reported improved provider knowledge/attitudes  |
| Kehoe, 2003 <sup>65</sup><br>good early discussion of intensity/duration | To review culturally relevant healthcare interventions, and their effect on health outcomes  | No                         | 14                         | In scope/no comparison: culturally tailored interventions (12 studies)<br>Outside: media only  | N/A   |
| Kokko, 2011 <sup>66</sup>  | To describe the learning experiences of nursing students studying abroad   | Yes, but outside our scope | 7                          | Training   | N/A   |
| Lie, 2011 <sup>67</sup>  | To review the effects of cultural competency training on patient-centered outcomes   | Yes                        | 7                          | Training: 7 studies  | 4/7 overlap with Horvat (Wade, Majumdar, Thom, Sequist)<br>2 pre/post studies reported improved evaluations of care (patient family satisfaction, perceived environmental changes favoring their interests and 'ethnic affinity' toward staff), 1 pre/post study reported improvement in provider perception of communication |
| Lu, 2012 <sup>68</sup>   | To synthesize knowledge about the effectiveness of cancer screening interventions targeting Asian women  | Yes, but outside our scope | 37                         | Cancer screening interventions, sometimes culturally tailored, lack of design to test CC   | N/A   |
| McQuilkin, 2012 <sup>69</sup>  | To evaluate the effectiveness of educational strategies for cultural   | Yes, but outside our       | 37 (16 interventions)      | Training   | N/A   |

| Study                          | Aims   | Provider Training in Scope | Number of Included Studies | Map to Our Review: Inside or Outside Our Scope; Inclusion of Provider Training                    | Results for Provider Training |
|--------------------------------|--|----------------------------|----------------------------|---|-------------------------------|
|                                | competence of undergraduate baccalaureate nursing students   | scope                      |                            |   |                               |
| Pearson, 2007 <sup>70</sup>    | To evaluate evidence on the structures and processes that support development of effective culturally competent practices and a healthy work environment | Yes                        | 19                         | Training: 2 quantitative studies (outside scope, matching), 4 qualitative, 13 textual             | N/A                           |
| Smith, 2006 <sup>71</sup>      | To examine the effectiveness of multicultural education in mental health care professions  | Yes                        | 37 on interventions        | Training: 37 studies, lack of detail on individual studies and outcomes                           | N/A                           |
| Sumlin, 2012 <sup>72</sup>     | To synthesize research that tested culturally competent food-related interventions designed for African American women with type 2 diabetes              | No                         | 15                         | In scope/no comparison (15 studies)<br>Culturally tailored interventions or targeted not tailored | N/A                           |
| Whittemore, 2007 <sup>73</sup> | To synthesize the research on culturally competent interventions for Hispanic adults with type 2 diabetes  | No                         | 11                         | In scope, culturally tailored interventions 10/11 no comparison, 1/11 not on CC                   | N/A                           |

CALD=culturally and linguistically diverse; CC=cultural competence; N/A=not applicable

**Appendix Table D7. Quality of previous systematic reviews—racial/ethnic populations**

| <b>Study</b>               | <b>A Priori Study Design</b> | <b>Dual Study Selection and Data Abstraction</b> | <b>Comprehensive Literature Search</b> | <b>Publication Status</b> | <b>Lists of Included and Excluded Studies Provided?</b> | <b>Scientific Quality of Included Studies Assessed and Documented?</b> | <b>Scientific Quality of Included Studies Used Appropriately in Formulating Conclusions?</b> | <b>Methods of Combining Studies Appropriate?</b> | <b>Likelihood of Publication Bias Assessed?</b> | <b>Conflict of Interest Stated?</b> | <b>Overall Quality</b> |
|----------------------------|------------------------------|--|--|---------------------------|---|--|--|--|---|-------------------------------------|------------------------|
| Horvat, 2014 <sup>74</sup> | Yes                          | Yes  | Yes                                    | Yes                       | Yes   | Yes  | Yes  | Yes  | Unclear   | Yes                                 | Good                   |
| Truong, 2014 <sup>75</sup> | Yes                          | Yes  | Yes                                    | Yes                       | Yes   | Yes  | Unclear  | Unclear  | Unclear   | Yes                                 | Fair                   |

**Appendix Table D8. Outcomes reported by studies of cultural competence interventions for racial/ethnic minority populations**

| Study                                    | Clinical Outcomes                 | Patient Perceptions  | Patient Satisfaction  | Utilization/Adherence  | Provider Attitudes or Perceptions    | Adverse Events |
|--|-----------------------------------|--|---|--|--------------------------------------|----------------|
| <b>Patient/provider interaction</b>      |                                   |  |   |  |                                      |                |
| Alegria, 2014 <sup>38</sup>              | NR                                | Yes, patient assessment of patient activation and self-management  | NR  | Yes, engagement, retention   | NR                                   | NR             |
| Cooper, 2013 <sup>39</sup>               | Yes, depression symptom reduction | Yes, rating of clinicians' participatory decisionmaking  | Yes, rating care manager as helpful in identifying concerns, identifying barriers, providing support, and improving treatment adherence | Yes, treatment rates   | NR                                   | NR             |
| Penner, 2013 <sup>40</sup>               | NR                                | Yes, sense of being on the same team, perception of patient-centeredness, trust of physician and trust of physicians in general. | NR  | Yes, adherence to physicians' recommendations  | Yes, sense of being on the same team | NR             |
| Aragones, 2010 <sup>41</sup>             | NR                                | NR   | NR  | Yes, completed CRC screening, physician recommendation for CRC screening, and patient adherence to physician recommended CRC screening | NR                                   | NR             |
| Michalopoulou, 201 <sup>42</sup>         | NR                                | Yes, perceived Cultural Competency Measure, fair procedures, participation   | Yes   | NR   | NR                                   | NR             |
| Alegria, 2008 <sup>43</sup>              | NR                                | Yes, self-reported patient activation and empowerment  | NR  | Yes  | NR                                   | NR             |
| <b>Culturally tailored interventions</b> |                                   |  |   |  |                                      |                |
| Breitkopf, 2014 <sup>32</sup>            | NR                                | NR   | NR  | Yes, adherence, delay in care, completeness of care  | NR                                   | NR             |
| Kim, 2014 <sup>44</sup>                  | Yes                               | NR   | NR  | Yes, number of sessions completed  | NR                                   | NR             |
| Smith, 2014 <sup>45</sup>                | Yes                               | NR   | NR  | Yes  | NR                                   | Yes*           |
| Calsyn, 2013 <sup>46</sup>               | Yes                               | NR   | NR  | Yes  | NR                                   | NR             |
| Le, 2013 <sup>47</sup>                   | Yes                               | NR   | NR  | Yes  | NR                                   | NR             |
| Lee, 2013 <sup>48</sup>                  | Yes                               | NR   | NR  | NR   | NR                                   | NR             |
| Burrow-Sanchez, 2012 <sup>49</sup>       | Yes                               | NR   | Yes   | Yes  | NR                                   | NR             |
| Ell, 2011 <sup>50</sup>                  | Yes                               | NR   | NR  | Yes  | NR                                   | NR             |

| <b>Study</b>                       | <b>Clinical Outcomes</b> | <b>Patient Perceptions</b>                            | <b>Patient Satisfaction</b> | <b>Utilization/Adherence</b> | <b>Provider Attitudes or Perceptions</b>      | <b>Adverse Events</b> |
|------------------------------------|--------------------------|---|-----------------------------|------------------------------|---|-----------------------|
| Pan, 2011 <sup>51</sup>            | Yes                      | Yes, participant – therapeutic working alliance       | NR                          | NR                           | Yes, therapist – therapeutic working alliance | NR                    |
| D'Eramo Melkus, 2010 <sup>52</sup> | Yes                      | Yes, perceived provider support for diet and exercise | NR                          | NR                           | NR  | NR                    |
| Marsiglia, 2010 <sup>53</sup>      | NR                       | NR  | NR                          | Yes                          | NR  | NR                    |
| Kohn, 2002 <sup>54</sup>           | Yes                      | NR  | NR                          | NR                           | NR  | NR                    |

NR=not reported

\* Of the six participants who discontinued varenicline early, all six continued in the study; three discontinued varenicline because they returned to smoking; among the three other participants who stopped taking varenicline, one cited stomach pain, one reported changes in moods, and one reported nausea.

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## Appendix E. LGBT—Summary of Published Recommendations

**Table E1. LGBT—summary of published recommendations**

|                            | <b>General Recommendations</b>   | <b>Specific Recommendations</b>   |
|----------------------------|--|---|
| The Joint Commission, 2014 | <ul style="list-style-type: none"> <li>• Integrate unique LGBT patient needs into new policies or modify existing policies.</li> <li>• Creating a welcoming environment that is inclusive of LGBT patients.</li> <li>• Avoid assumptions about sexual orientation and gender identity.</li> <li>• Facilitate disclosure of sexual orientation and gender identity but be aware that this disclosure or “coming out” is an individual process.</li> <li>• Provide information and guidance for the specific health concerns facing lesbian and bisexual women, gay and bisexual men, and transgender people.</li> <li>• Ensure equitable treatment and inclusion for LGBT employees.</li> <li>• Demonstrate commitment to LGBT equity and inclusion in recruitment and hiring.</li> <li>• Educate staff on LGBT employee concerns.</li> <li>• Identify opportunities to collect LGBT-relevant data and information during the health care encounter.</li> <li>• Collect feedback from LGBT patients and families and the surrounding LGBT communities.</li> <li>• Ensure that communications and community outreach activities reflect a commitment to the LGBT community.</li> </ul> | <ul style="list-style-type: none"> <li>• Develop or adopt a nondiscrimination policy.</li> <li>• Develop or adopt a policy ensuring equal visitation.</li> <li>• Develop or adopt a policy identifying the patients’ right to identify a support person of their choice.</li> <li>• Integrate and incorporate a broad definition of family into new and existing policies.</li> <li>• Demonstrate ongoing leadership commitment to inclusivity for LGBT patients.</li> <li>• Develop clear mechanisms for reporting discrimination or disrespectful treatment.</li> <li>• Develop disciplinary processes.</li> <li>• Identify an individual directly accountable to leadership for overseeing organizational efforts.</li> <li>• Appoint high level advisory group to assess climate for LGBT patients.</li> <li>• Identify and support staff or physician champions who have special experience with LGBT issues.</li> <li>• Prominently post the hospitals’ nondiscrimination policy.</li> <li>• Waiting rooms and other common areas should reflect and be inclusive of LGBT patients and families.</li> <li>• Create or designate unisex or single stall restrooms.</li> <li>• Ensure visitation policies are implemented in a fair and nondiscriminatory manner.</li> <li>• Foster an environment that supports and nurtures all patients and families.</li> <li>• Be aware of misconceptions, bias stereotypes, and other communications barriers.</li> <li>• Recognize self-identification and behaviors that do not always align.</li> <li>• Honor and respect the individual’s decision and pacing in providing information.</li> <li>• All forms should contain gender-neutral language.</li> <li>• Become familiar with online and local resources for LGBT.</li> <li>• Add LGBT inclusive language to job notices.</li> <li>• Develop a plan to address the unique needs of transgender employees.</li> <li>• Add information about sexual orientation and gender identity to patient surveys.</li> </ul> |

|                      | <b>General Recommendations</b>   | <b>Specific Recommendations</b>   |
|----------------------|--|---|
| Hanssmann, 2008      | <ul style="list-style-type: none"> <li>• General need for more training.</li> <li>• Organizational or agency-wide change and support.</li> <li>• Integrate patient satisfaction measures into practice.</li> </ul>   |   |
| Heck, 2006           | <ul style="list-style-type: none"> <li>• More information in residency programs and CME for PCPs.</li> <li>• Encourage government and industry to offer health coverage for individuals involved in domestic partnerships.</li> </ul>  |   |
| Tillery, 2010        | <ul style="list-style-type: none"> <li>• Health professional students and health professionals to need training about sexual orientation, gender identity and expression, and HIV status.</li> <li>• Require all health care facilities and education programs that receive government funding to develop and implement goals, policies, and plans to ensure that LGBT people and people living with HIV are treated fairly and provide ongoing cultural competency training.</li> <li>• Prohibit discriminatory practices by insurance providers that deny or limit coverage for needed care by LGBT people.</li> </ul> | <ul style="list-style-type: none"> <li>• Develop and implement goals and plans to ensure that LGBT people and people living with HIV are treated fairly.</li> <li>• Establish nondiscrimination, fair visitation and other policies that prohibit bias and discrimination based on sexual orientation, gender identity and expression, and HIV status.</li> <li>• Report discriminatory practices, sharing stories, and contacting Lambda Legal and other advocacy organizations and/or attorneys.</li> </ul>                                     |
| Reed 2010            | Clinicians knowledgeable and skilled in the followup of abnormal anal cytology results, including high resolution anoscopy and biopsy.   | <ul style="list-style-type: none"> <li>• More than 25% of our respondents indicated that they had not disclosed that they have sex with men to their health care providers. This finding indicates a greater need for health care providers to create environments that facilitate disclosure of their sexual behaviors to allow providers to identify men most likely to benefit from anal cancer prevention services.</li> </ul>  |
| Mimiaga et al., 2007 | <ul style="list-style-type: none"> <li>• Training around the special needs and vulnerabilities of MSM.</li> <li>• Clinical presentation of STDs among MSM, and to project a nonjudgmental manner when performing STD screening, providers also need to be trained to understand that STD and HIV risk-taking behavior among MSM is often occurring in the context of intertwined syndemics.</li> </ul>   | <ul style="list-style-type: none"> <li>• Clinicians must demonstrate their comfort in addressing health issues tied to sexuality to draw people into testing and treatment.</li> <li>• Medical histories and examinations can be conducted in ways that do not presume heterosexuality but are inclusive of various sexual identities, family/relationship arrangements, and sexual behaviors.</li> <li>• Be especially attuned to patients who may be reticent to fully disclose issues around sexuality, health risks, and exposures</li> </ul> |
| Grant et al., 2010   | <ul style="list-style-type: none"> <li>• Medical establishment must fully integrate transgender-sensitive care into its professional standards, and this must be part of a broader commitment to cultural competency around race, class, and age.</li> <li>• Anti-transgender bias in the medical profession and U.S. health care system has catastrophic consequences for transgender and gender nonconforming people.</li> <li>• Public and private insurance systems must cover transgender-related care; it is urgently needed and is essential to basic health care for transgender people.</li> </ul>              | <ul style="list-style-type: none"> <li>• Doctors and other health care providers who harass, assault, or discriminate against transgender and gender nonconforming patients should be disciplined and held accountable according to the standards of their professions.</li> </ul>  |

|   | <b>General Recommendations</b>   | <b>Specific Recommendations</b>   |
|---|--|---|
| Gay & Lesbian Medical Association, 2006 | <ul style="list-style-type: none"> <li>• Training for all staff is critical to creating and maintaining practice environments deemed safe for LGBT patients. Training should be periodic to address staff changes and keep all staff up-to-date.</li> </ul>  | <ul style="list-style-type: none"> <li>• Filling out the intake form gives patients one of their first and most important impressions of your office. The experience sets the tone for how comfortable a patient feels being open about their sexual orientation or gender identity/expression.</li> <li>• LGBT patients often ‘scan’ an office for clues to help them determine what information they feel comfortable sharing with their health care provider.</li> <li>• When talking with transgender people, ask questions necessary to assess the issue, but avoid unrelated probing. Explaining why you need information can help avoid the perception of intrusion.</li> <li>• Discuss safer sex techniques and be prepared to answer questions about STDs and HIV transmission risk for various sexualities relevant to LGBT people.</li> <li>• When talking about sexual or relationship partners, use gender-neutral language such as ‘partner(s)’ or ‘significant other(s).’ Ask open-ended questions, and avoid making assumptions about the gender of a patient’s partner(s) or about sexual behavior(s).</li> <li>• Listen to your patients and how they describe their own sexual orientation, partner(s) and relationship(s), and reflect their choice of language.</li> <li>• Universal gender-inclusive ‘Restroom’.</li> </ul> |
| Dodge et al., 2012                      | <ul style="list-style-type: none"> <li>• Maintain privacy.</li> <li>• Normalize bisexuality on a structural level, so that other individuals’ potentially negative feelings about bisexual men do not interfere with decisions about health services.</li> <li>• Improved education and access for bisexual men are a critical for increasing knowledge and improving uptake of services for rectal STI.</li> </ul>  | <ul style="list-style-type: none"> <li>• The fear of inadvertent disclosure appeared throughout the narratives and across participants. Our data establish that the influence of others’ perceptions of their sexuality have an impact on their likelihood of engaging in health services.</li> <li>• Use broad terms like men’s health, or list all three sexual orientation categories (bisexual, heterosexual, and homosexual) on health service materials, since this diminishes concerns related to other’s perceptions of their sexuality.</li> <li>• Providing information that is pertinent to men of all behavioral repertoires would allow men the option to read about issues facing men of all sexual orientations without fear of inadvertent disclosure.</li> <li>• Set up systems that facilitate an individual being seen by the same provider over time, versus one of many providers at a clinic.</li> </ul>  |
| Kaestle et al., 2011                    | <ul style="list-style-type: none"> <li>• Sexual minorities may have particular difficulty communicating with their physicians, and physicians may be uncomfortable interacting with sexual minority patients.</li> <li>• To facilitate a more accurate perception of risk among sexual minorities, health practitioners can work to promote the development and implementation of more effective curricula and to break down some of the stigma. and barriers in communication about sensitive sexual behaviors in public health services and physician offices</li> </ul> | <ul style="list-style-type: none"> <li>• Health care providers should not make assumptions about sexual risk behaviors on the basis of a patient’s self-reported sexual identity; rather, they should take a careful sexual history of sexual minority patients and provide safer-sex information to all patients.</li> </ul>   |

|                       | <b>General Recommendations</b> | <b>Specific Recommendations</b>  |
|-----------------------|--------------------------------|--|
| Politi et al., 2009   |                                | <ul style="list-style-type: none"> <li>• Women who partner with women reported a strong preference for female providers because of perceived difficulties communicating about sexuality with male physicians. Male providers should be aware of both patients' and their own potential discomfort and should remain sensitive to discussions about sexual health.</li> <li>• [Prior] to obtaining a sexual history, primary care providers should explain the reason for asking questions about sexual health.</li> <li>• If written information is deemed necessary prior to a verbal history, questions should be phrased in ways that allow inclusion of all women regardless of partner gender or partner status.</li> </ul>   |
| Bradford et al., 2012 |                                | <ul style="list-style-type: none"> <li>• Providers may not be comfortable asking these questions, or lack knowledge on how to elicit information.... this should not prevent providers from asking such questions and trying to gather such data.</li> <li>• Providers should ask permission to include information about a patient's sexual orientation and gender identity in the medical record, remind the patient of its importance to quality health care, and assure him or her that the information will be kept confidential.</li> <li>• When seeing a patient for the first time, providers should also ask questions about sexual orientation, behavior, and gender identity during the patient's visit.</li> <li>• Questions both on registration forms and during patient exams will alert providers to screen patients for conditions disproportionately affecting LGBT people, and to provide preventative health education appropriate to LGBT people.</li> <li>• Respondents are 1.5 to 1.6 times more likely to report same-sex behavior and attraction on an audio computer assisted self-interviewing survey than in response to questions asked by an interviewer.</li> </ul> |
| Reisner et al., 2010  |                                | <ul style="list-style-type: none"> <li>• Safer sex education materials are needed that are tailored to meet the needs of TMSM, including differentiating by partner genders (i.e., male, female, transmen, transwomen), type (i.e., casual, anonymous, monogamous, etc.), and sexual behaviors (i.e., frontal/vaginal or anal sex; oral sex; body contact with the exchange of body fluids; sex toys, etc.). Also needed is information about sexual health more broadly, including information about pregnancy and how to navigate pregnancy-related health care services as a transman.</li> <li>• Integrating sexual health information 'by and for' transmen into other healthcare services, involving peer support, addressing mood triggers such as depression and anxiety, Internet-delivered information and services for transmen and their sexual partners, making safer sex materials 'hot' (i.e., erotic) and pleasure-focused.</li> </ul>   |
| Polek, et al., 2010   |                                | <ul style="list-style-type: none"> <li>• Healthcare providers can help reduce barriers that women may encounter by assessing their offices for approachability, attitudes, accountability, and awareness.</li> </ul>   |

|   | <b>General Recommendations</b> | <b>Specific Recommendations</b>  |
|---|--------------------------------|--|
| Heck, et al., 2006                          |                                | <ul style="list-style-type: none"> <li>• Outreach programs aimed toward the lesbian community to improve this population's regular use of health services.</li> </ul>  |
| National LGBT Health Education Center, 2013 |                                | <ul style="list-style-type: none"> <li>• Health care organizations should have a system that allows patients to input their preferred name, gender, and pronouns into registration forms and other relevant documents.</li> <li>• Avoid asking unnecessary questions: People are naturally curious about transgender people, which sometimes leads them to want to ask questions. However, like everyone else, transgender people want to keep their medical and personal lives private.</li> <li>• Have procedures in place that hold staff accountable for making negative or discriminatory comments or actions against transgender people.</li> <li>• Have single-occupancy bathrooms that are not designated as male or female.</li> <li>• Avoid gender terms.</li> </ul>                                   |
| Martinez et al., 2005                       |                                | <ul style="list-style-type: none"> <li>• Extend the health guidance (or anticipatory guidance) time that clinicians spend with young women engaging in sexual activity.</li> <li>• Have providers who can develop trusting relationships with them to have them openly disclose their sexual activities.</li> </ul>  |
| Marrazzo et al., 2005                       |                                | <ul style="list-style-type: none"> <li>• Because participants generally believed the risk of STD transmission between women to be low, interventions need to include an educational component explaining the evidence that exists to support such a possibility. If this is not adequately conveyed, women may have little motivation to practice protective behaviors.... interventions need to target a range of common sexual practices, including digital-vaginal penetration and use of vaginally insertive sex toys.</li> <li>• Emphasize cleanliness, particularly as part of 'natural health,' and if they frame the preventative practice in terms of sexual enjoyment and healthy sexuality, rather than in terms of disease and emphasize respect for one's body and one's sexual choices.</li> </ul> |



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