CASE STUDY DISCUSSION GUIDE
Jeannie Johnson

Creating Partnerships with Patients:
Integrating Religion and Spirituality and
Addressing Health Literacy in the Patient Encounter

PURPOSE

This guide is designed to accompany the Jeannie Johnson case study and to provide guidance to those responsible for leading discussion groups with residents. The guide includes conceptual frameworks and definitions for culture, cultural competence, and linguistic competence; key takeaways points; content to inform dialogue on the reflection questions; references; and suggested resources. While the guide provides an array of information, the references and resource list offer additional sources to enhance learning and professional development in providing culturally and linguistically competent care to patients who have lupus.

GETTING ON THE SAME PAGE

The following provide a list of key terms and their definitions. Engage the residents in discussion about these concepts and to make sure they are "on the same page" and using terms in the same way.

What do we mean by culture? Culture is perceived of and defined in many different ways. Have group members discuss their definitions and understanding of culture and how culture impacts both health and health care.

The following is a definition of culture used by the Georgetown University National Center for Cultural Competence:

> *Culture is the learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world.* It comprises beliefs about reality, how people should interact with each other, what they "know" about the world, and how they should respond to the social and material environments in which they find themselves. It is reflected in their religions, morals, customs, technologies, and survival strategies. It affects how they work, parent, love, marry, and understand health, mental health, wellness, illness, disability, and death.
>
> Culture includes but is not limited to—thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manners of interacting, roles, relationships, and expected behaviors of an ethnic group or social groups whose members are uniquely identifiable by that pattern of human behavior.[1]

While the aforementioned definition and conceptualization present culture in terms of the group and group behavior, it is essential to note however, that aspects of culture are manifested differently in each person. A member of a cultural group may neither exhibit nor embrace all of the beliefs, values, practices, modes of communication, or behaviors attributed to a given group. This understanding of culture recognizes the individuality of human beings and the unique diversity among group members. This may include but is not limited to race, ethnicity, age, gender, gender identity, socioeconomic status, education, profession, country of origin, languages spoken, and the lived experience of chronic illness, disability, or mental illness. Importantly, accepting this understanding of culture minimizes the tendency to stereotype and reminds us that one's cultural identity is influenced by a constellation of interrelated and distinct factors. This conceptualization of culture also acknowledges professional culture, specifically *the culture of medicine* and its impact on one's values, beliefs, and world view.

Lastly, it is important within the health care context to expand our conceptualization of culture beyond individual people and groups to organizations, systems, and the socio-cultural contexts of communities in which patients and their families live. Health care practices, organizations, and systems have their own cultures – norms, rules, language, decision-making processes, approaches to communication, defined roles and responsibilities, ways of interacting with those seeking and receiving care. Figure 1 illustrates this concept by depicting the multiple dimensions of culture that converge and how they are integrally linked in health and health care. Figure 1 asks you to consider the cultures of the patient, his/her family, the health care practitioner, the health care practice/organization, and cultural contexts of the communities that impact health and well-being of patients.

Figure 1.
CONVERGENCE OF CULTURAL CONTEXTS IN HEALTH AND HEALTH CARE

Community
Health Care Practice/Organization
Health Care Practitioner
Patient's Family
Patient
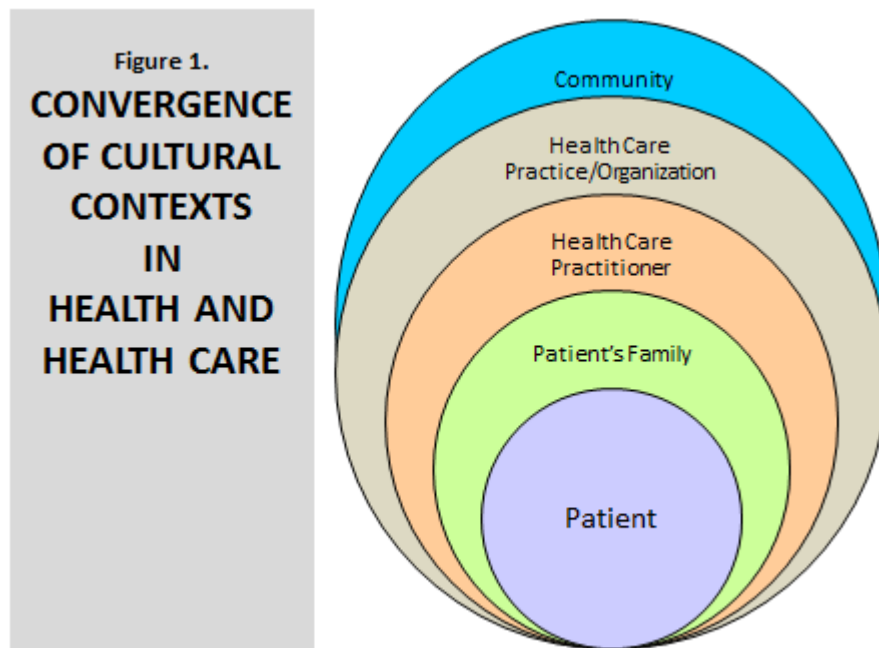
Take away points
The following take away point offer insight about culture within the context of health and health care.

- Understanding another culture is a continuous and not a discreet process.
- It takes experience as well as study to understand the many subtleties of a culture other than your own.
- Culture informs attitudes, beliefs, and practices of individual patients and their families who seek and use health care.
- You are a cultural being and have multiple cultural identities, one of which is your profession – a physician or health care practitioner.
- You view and interpret the world through your own cultural lens which is comprised of both individual and group experiences over time.
- Your world view influences how you deliver health care. This world view may or may not be shared by the patients and families to whom you provide health care.
- You are influenced by the culture of the practice or organizational setting in which you provide health care.

What do we mean by cultural competence?
Encourage the group to discuss their conceptualizations and definitions of cultural competence. This will allow group members to hear how the concept of cultural competence has been taught in medical education and is understood and practiced in residency. Acknowledge that there are many definitions of cultural competence. Some definitions focus on the health care practitioner and others at the system or organizational level. Have the group to discuss the following definition and how it consistent with or different from their understanding of the concept of cultural competence at both levels.

The Georgetown University National Center for Cultural Competence embraces a definition that of cultural competence that requires organizations:
- have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally.
- have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve.
- incorporate the above in all aspects of policy making, administration, practice, service delivery and involve systematically consumers, key stakeholders, and communities.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum. [2]

Cultural competence at the individual level requires
the capacity to:

1. *Acknowledge cultural differences* that exist between patients, their families, and health professionals and how such differences impact health care. Demonstrate valuing these differences, for example, in your manner of communication with patients and their families and partnering in medical decision-making.

2. *Understand your own culture* – willingness to reflect upon your own cultural belief systems, including the culture of medicine, and how they influence your interactions with patients and their families.

3. *Engage in self-assessment* – responding to assessment instruments/checklists and taking time for self-reflection to examine one's own attitudes, values, and biases that may contribute to or compromise positive patient-provider relationships and your approach to health care.

4. *Acquire cultural knowledge and skills* – pursuing formal and informal opportunities to learn about the cultures of your patients, the environments in which they live including the social determinants of health, culture-specific and evidence-based practices and interventions to improve health care outcomes.

5. *View behavior within a cultural context* – even if a behavior seems illogical, seek to understand the beliefs or practices of patients (without judgement) and partner with them to overcome problems that may compromise their health and well-being. This may involve spanning the boundaries or health care to engage with social services and others in the helping professions. [3-5]

Take away points
Cultural competence:
- is a developmental process and is enhanced over time, at both the individual and organizational levels.
- must be supported by organizational policy, procedures, practices, and resources.
- is an intentional, evidenced-based practice and involves gaining knowledge and skills in order to provide care that is effective and acceptable to diverse patient populations.
- involves examining one's own beliefs and attitudes about patient behaviors including one's biases and stereotypes about patients.

What is linguistic competence?

Linguistic competence is a relatively new term that has gained in credibility, usage, and evidence over the past 15 years. There are many definitions, most which until recently have focused on interpretation and translation services for individuals with limited English proficiency.[6-8] The *National Standards for Culturally and Linguistically Services in Health and Health Care*, (commonly referred to The National CLAS Standards), promulgated by the Office of Minority Health, U.S. Department of Health and Human Services, put forth a broader conceptualization of linguistic competence in its Blueprint which was released in 2013.[9] Linguistic competence as conceptualized by the Georgetown University National Center for Cultural Competence is consistent with this broader definition and is defined: as the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity.[10]

Linguistic competence may include but is not limited the use of the following:

- bilingual/bicultural or multilingual/multicultural staff;
- cross-cultural communication approaches;
- cultural brokers;
- foreign language interpretation services including distance technologies;
- sign language interpretation services;
- multilingual telecommunication systems;
- videoconferencing and telehealth technologies;
- assistive devices and technologies for individuals who are deaf or hard of hearing;
- print materials in easy to read, low literacy, picture and symbol formats;
- materials in alternative formats (e.g., audiotape, Braille, enlarged print);
- varied approaches to share information with individuals who experience cognitive disabilities;
- materials developed and tested for specific cultural, ethnic, and linguistic groups;
- translation services including those of:
  - legally binding documents (e.g., consent forms, confidentiality and patient rights statements, release of information, applications)
  - signage
  - health education materials
  - public awareness materials and campaigns; and
  - ethnic media in languages other than English (e.g., television, radio, Internet, newspapers,
  - periodicals, social media sites).[10]

Take away points

Linguistic competence is not only about providing interpretation and translation services to patients with limited English proficiency — it is about assuring effective communication with all patients, including those with limited health literacy, those with disabilities, and providing information in formats that patients prefer and need.

> "Healthcare professionals have their own culture and language. Many adopt the 'culture of medicine' and the language of their specialty as a result of their training and work environment. This can affect how health professionals communicate with the public."
> **U.S. Department of Health and Human**[11]

What is health literacy?

There are a number of definitions of health literacy that are prevalent in the literature. Most recently we have witnessed a shift from the oneness resting with the individual patient to the responsibility of health care practitioners and professionals. In 2004, the Institute of Medicine provided the following definition of health literacy. "Health literacy is a shared function of social and individual factors. Individuals' health literacy skills and capacities are mediated by their education, culture, and language. Equally important are the communication and assessment skills of the people with whom individuals interact regarding health, as well as the ability of the media, the marketplace, and government agencies to provide health information in a manner appropriate to the audience."[12] One of the foremost researchers, Rima Rudd, Ph.D., captures this evolution of the concept of health literacy in the following definitions.[13]

Evolving conceptualizations and definitions of health literacy.
Health literacy is:

the cognitive and social **skills** which determine the motivation ***and ability of individuals*** to gain access to, understand and use information in ways which promote and maintain good health.
Nutbeam, D., World Health Organization, 1998

the degree to which ***individuals have the capacity to obtain, process, and understand*** basic health information and services needed to make appropriate health decisions.
U.S. Department of Health and Human Services, 2010

engagement in a wide range of health actions that extend from personal behaviors to social action to address the determinants of health.
Nutbeam, D., 2008

Dr. Rudd pushes us to consider a definition of health literacy that sheds light on the knowledge and responsibility of health care practitioners and professionals and the organizations and settings in which they provide care, services, and supports – ***the capacity of professionals and health institutions*** to provide access to information and support the active engagement of people.[13]

Health Literacy in a Cultural Context

Researchers and practitioners are also placing increased emphasis on the role of culture and health literacy. Guidance to health care practitioners and other professionals focus on the integration of culture and cultural and linguistic competence so that these practices are seen as integral to rather than separate aspects of care. The National Libraries of Medicine states:

> "Recognizing that culture plays an important role in communication helps us better understand health literacy. For people from different cultural backgrounds,
> health literacy is affected by belief systems, communication
> styles, and understanding and response to health information. Even though culture is only one part of health literacy, it is a very important piece of the complicated topic of health literacy. The United States Department of Health and Human Services (HHS) recognizes that 'culture affects how people communicate, understand and respond to health information.' According to the American Medical Association report,
> Health Literacy and Patient Safety: Help Patients Understand, 'poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race'.
> http://nnlm.gov/outreach/consumer/hlthlit.html "[14]

A word about mental health literacy

While there is a movement for integrative care, coordinating and providing behavioral health care in primary care settings, there is still a lack of recognition of the need for such integration in many health care systems and practices. Substantial number of individuals with chronic illness, such as lupus, may also comorbidity of depression or other mental health disorder. The following definition of mental health literacy is offered to raise awareness of the need to address this among the diverse patient populations. Mental health literacy is defined by the Canadian Mental as the knowledge, beliefs, and abilities that enable the recognition, management or prevention of mental health problems. Enhanced mental health literacy is thought to confer a range of benefits -prevention, early recognition and intervention, and reduction of stigma associated with mental illness.[13]

Take away points

- Health literacy is an essential component of health care and positively affects patient-provider communication and health outcomes for diverse patient populations.
- There is an abundance of evidence which indicates that when practitioners fail to attend to and address the health literacy needs of their patients, the outcomes can have adverse outcomes on the patient's health and well-being.
- "Health information can overwhelm even persons with advanced literacy skills. Medical science progresses rapidly. What people may have learned about health or biology during their school years often becomes outdated or forgotten, or it is incomplete. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained."[11]

JEANNIE JOHNSON DISCUSSION GUIDE ▪ THE LUPUS INITIATIVE
Developed by the Georgetown University National Center for Cultural Competence - August 2015

What do we mean by spirituality and religion?
The beliefs and practices related to spirituality and religion are numerous. The following definitions are offered to fuel your discussion.

As Anandarajah and Hight[16] note that spirituality encompasses such realms as the cognitive or philosophic, the experiential and emotional, and the behavioral. Some see religion as the manifestation of one's spirituality, yet a person can be spiritual without being religious. A person can also be observant of a particular set of religious tenets, yet not experience or value the underlying principles of spirituality.

Spirituality
1. "the experience or expression of the sacred" (Adapted from Random House Dictionary of the English Language, 1967).
2. "a quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite, and comes essentially into focus in times of emotional stress, physical (and mental) illness, loss, bereavement and death."[17]

Religion
1. "set of beliefs, practices, and language that characterizes a community that is searching for transcendent meaning in a particular way, generally based upon belief in a deity"[18]
2. "outward practice of a spiritual system of beliefs, values, codes of conduct, and rituals"[19]

Take away points
- A guiding principle of cultural competence involves working in conjunction with natural, informal support and helping networks. For many patients their faith and spiritual connections are a key component to supporting them in the healing process.

- Although the "culture of medicine" often makes a distinction between the roles of science and spiritual and religious belief in the healing process, for patients the two are often intertwined. Creating effective partnerships with patients to manage chronic disease includes understanding the role of religion and spirituality in their lives.

Discussion of Reflection Questions

What role does religion and spirituality have in healthcare—for the healthcare provider? for the patients and their families?

How do you feel when patients bring their religious or spiritual views to the clinical encounter?

Engage participants in a discussion of their responses to the questions above. Below is information that can be used to inform the discussion.

1. What the research is telling us about spirituality, religion and health
The support gained from being a part of a religious or spiritual community can be important to health outcomes for patients with SLE. A number of research studies have reported the following:

- social support (having people in one's life that can provide tangible and emotional help) plays a critical role in the health and well-being of individuals with SLE.[20-21]

- poor social support has been found to be associated with higher levels of disease activity, as well as subjective health related quality of life for SLE patients; and

- over the course of the disease, demographic, behavioral and psychological variables, including Hispanic ethnicity (sample population from Texas) and social support are important mediators of disease, while genetic factors do not influence disease activity over time.[22]

The Association of American Medical Colleges noted: "Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts. All of these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another." [23]

Research conducted by Hart et. al.,[24] demonstrates that while patients do not expect their physicians to be their primary spiritual advisors, physicians still need to be aware of and comfortable in addressing spiritual and religious matters. If the provider is clear on his/her perspective, then being able to address the area of spirituality and religion and health and mental health is more comfortable and manageable.

Anandarajah & Hight[16] present an overview of the literature related to this issue. They report the following:

- 91% of patients report believing in God and 74% say they feel close to God;
- 77% believe their physicians should consider their spiritual needs
- 66% want physicians to inquire about religious or spiritual beliefs if they are gravely ill
- 37 to 40 percent believe that physicians should inquire about religious beliefs more

- 10-20 percent report that their physician discuses religion or spirituality with them
- 11 % of physicians report inquiring at least frequently about spiritual issues

Anandarajah & Hight[16] also report from the literature that the greatest barriers to discussion of spiritual issues are lack of time (71%), lack of training (59%), and difficulty in identifying patients who want such a discussion(56%).

2. <u>No need to share religious or spiritual beliefs ... just be comfortable and prepared to address them</u>
Dr. Green does not need to share Jeannie's religious beliefs in order to support hers. Culturally competent physicians engage in cultural self-assessment. A part of that is taking time to reflect on their own religious and spiritual beliefs in relation to their practice. Part of that self-assessment can include how to respond to patient requests such as praying with them at critical moments. Of course physicians should not impose their own beliefs on patients. However, they do need to consider how they can elicit and support their patients' beliefs and needs. Just asking and listening is a powerful approach that patients appreciate. Including a structured assessment of spirituality and religion using a model such as the HOPE model (referenced in this module) supports culturally competent practice. The group can consider what they have learned from their training and experiences. Use probe such as:
- ☑ How have they handled patient spirituality and religion?
- ☑ Have they seen and effective approaches modeled by others?

How does the concept of linguistic competence relate to Jeannie's care—after all she and her family speak English?

Why does Jeannie's family think of her as too sick to go out with her friends?

What factors contribute to Jeannie having such a hard time understanding her health, the meaning of her diagnosis, and how the healthcare system works?

Engage participants in their responses to the questions above. The following information is designed to inform the discussion.

1. <u>Health literacy is not just the ability to read</u>
Reference the definition of linguistic competence above (it is also provided in the module). Jeannie and her family have had limited contact with the health care system and may not understand how it is organized. This understanding is part of health literacy. The idea of primary and specialty care is not always understood by patients. In addition, even people with good general literacy skills and education may not be familiar with terminology from the medical world and may not have a good understanding of anatomy, physiology, and disease processes. So distinctions between acute and chronic disease may need to be explained.

2. <u>Recognizing and responding to different way patients need to receive information</u>
Patients may prefer to get health information in different formats. As noted in the definition of linguistic competence, the goal is effective communication of important information that patients need to address their health. Thus health information should be provided not only in the language patients prefer, but also at literacy and health literacy levels they can understand, using plain language

http://www.nih.gov/clearcommunication/plainlanguage.htm[25] and in a format that maximizes their learning. Jeannie did not find written materials useful and this preference may or may not relate to her literacy level. She sought out her pharmacist for a verbal explanation. Some patients prefer visual input with diagrams, pictures, and symbols. Culturally and linguistically competence healthcare settings and clinicians ask patients about their preferences for receiving important information. Of course, explanations directly from the physician are essential, however reinforcement of information can come from many sources. Thus Jeannie's problems with health literacy and the lack of personalization of how she has been provided important information – both reflect issues with linguistic competence in her care.

What could Dr. Green do to make sure Jeannie understands the complexity of her disease and its treatment?

Engage participants in a discussion about the above posed question. Information is provided to help guide the discussion.

1.   Stepping Up! Yes the responsibility for health literacy starts with you.
"The primary responsibility for improving health literacy lies with public health professionals and the healthcare and public health systems. We must work together to ensure that health information and services can be understood and used by all people who reside in the United States, its territories, and in tribal communities. We must engage in skill building with healthcare consumers and health professionals. Adult educators can be productive partners in reaching adults with limited literacy skills."[11] http://health.gov/communication/literacy/quickguide/factsbasic.htm

Linguistically competent physicians ensure that they effectively communicate with all patients, not just those who have limited English proficiency. The language of medicine is something that physicians learn in their training. Most people are not fluent in this jargon, yet physicians become so comfortable with it that they may not realize that they are speaking and providing written information in jargon that patient's struggle to understand. There are several approaches that can improve communication.

Plain language works!
Dr. Green should use what is termed "plain language." Key elements of plain language are to:

- Organize information so the most important behavioral or action points come first;
- Break complex information into understandable chunks;
- Use simple language or define technical terms; and
- For all written materials, provide ample white space so pages look easy to read.

Because some people learn better by listening than by reading and because the healthcare encounter is verbal, speaking plainly is just as important as writing plainly. Many of the same plain-language techniques that make the written word understandable also work with verbal messages. These include avoiding jargon and using everyday examples to explain technical or medical terms the first time they are used. Plain language is not just about vocabulary or grade level. Writing to a certain grade level does not necessarily ensure that the message is in plain language or understood by the intended audience, so

all materials should be evaluated for understanding with the intended users, regardless of grade-level score. http://www.health.gov/communication/literacy/plainlanguage/PlainLanguage.htm[26]

Here are some examples of how to translate terms from "medicalese" to plain English from the Plain Language Thesaurus for Health Communications.[27]

☑ Allergen   something like pollen that causes the body to react by sneezing or forming a rash
☑ Abdomen   stomach, stomach area, belly, tummy
☑ ability   skill
☑ abrasion   cut, scratch, scrape

Suggested Activity
Consider asking the group to give examples of common terms they use and how those could be changed into plain English when talking with patients or creating written materials for patient education.

The Teach Back Method Works!
Dr. Green can employ teach back approaches during healthcare encounters. One simple way to be sure that a patient understands and can act on information is to use the Teach Back method http://www.teachbacktraining.org/.[28]This approach is basically asking a patient to tell you what you have just told them. It is a good check on how effectively you have communicated important information. Effective communication is key to building a relationship and trust with patients.

Suggested Activity
Consider the following reference from the Teach Back Training website to share with the group and guide discussions. Follow-up with group participants to inquire the extent to which they are using the Teach Back method and how is impacting communication with patients.

10 Elements of Competence for Using Teach-back Effectively (PDF)[29]

1. Use a caring tone of voice and attitude.
2. Display comfortable body language and make eye contact.
3. Use plain language.
4. Ask the patient to explain back, using their own words.
5. Use non-shaming, open-ended questions.
6. Avoid asking questions that can be answered with a simple yes or no.
7. Emphasize that the responsibility to explain clearly is on you, the provider.
8. If the patient is not able to teach back correctly, explain again and re-check.
9. Use reader-friendly print materials to support learning.
10. Document use of and patient response to teach-back.

What approaches could Jeannie learn to help her understand her care?

An important approach to assuring that patients understand their health and healthcare is encouraging the use of the **Ask Me Three** [30] approach promoted by the National Patient Safety Foundation. Hospitals, clinics, and individual clinicians promote this approach with patients. It involves supporting patients to always ask the following three questions in healthcare encounters:

1. **What is my main problem?**
2. **What do I need to do?**
3. **Why is it important for me to do this?**

Like Jeannie, patients are often reluctant to appear to be asking stupid questions. Linguistically competent healthcare providers normalize asking questions and promote active involvement of patients in the discussion. Time constraints during appointments may be perceived as creating a challenge to using Teach Back and Ask Me Three approaches. However, practitioners and clinicians are successfully integrating these approaches in their communication with patients – it's not always how much time but how you use the time you have. Patients' understanding and involvement in their care is essential to outcomes in health and is consistent with principles and practices of patient-centered care. This is particularly true for a disease like lupus.

Suggested Activity
Pair members of the groups in dyads. Have them share with each other ways that they have encouraged patients to actively participate in decision-making and instances where they have not. Bring the group together to discuss their insights. Probe what is perceived as challenges and ask them to offer practical solutions.

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The Georgetown University National Center for Cultural Competence (NCCC) provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education and advocacy. The NCCC is a component of the Center for Child and Human Development and is housed within the Department of Pediatrics of the Georgetown University Medical Center. The NCCC provides training, technical assistance, and consultation, contributes to knowledge through publications and research, creates tools and resources to support health and mental health care providers and systems, supports leaders to promote and sustain cultural and linguistic competency, and collaborates with an extensive network of private and public entities to advance the implementation of these concepts. The NCCC provides services to local, state, federal and international governmental agencies, family and advocacy support organizations, local hospitals and health centers, healthcare systems, health plans, mental health systems, universities, quality improvement organizations, national professional associations, and foundations.

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