

# Found in Translation

## *Cultural and Ethical Considerations & Practical Strategies for Providing Palliative Care when Cultural Differences are Present*

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# Objectives

1. Recognize best practice standards for communicating with patients with Limited English Proficiency (LEP).
2. Identify two cultural considerations germane to goals of care conversations in the setting of LEP.
3. Name two ethical principles potentially involved in disclosing diagnosis and prognosis in the context of linguistic and cultural diversity.

# History

- Medical Decision Makers prior to era of contemporary Bioethics in mid 1970's were physicians
- Responsibilities included<sup>1</sup>:
  1. Visit patients
  2. Prescribe medications
  3. Save lives
  4. Avoid death

# Birth of Bioethics & Ethical Principles

- **Non-maleficence** – to do no harm. The more pertinent issue is whether the benefits outweigh the burdens.<sup>2</sup>
- **Respect for autonomy** – The principle of autonomy, or patient self-determination, recognizes the right of the patient with decision-making capacity to make decisions about treatments according to his or her beliefs, cultural and personal values, and life plan, even when these decisions are not in agreement with the physician's advice or recommendations.<sup>3</sup>

# Truth Telling – To tell or not to tell

- Western cultures – the ‘right to know’
- “In western countries, overall, approximately 80-90% of patients are given the truth about their diagnosis, whereas in other cultures, figures can range from 0 to 50%”<sup>4</sup>
- Beliefs and practices differ in populations originating from China, Japan, Nepal, the Middle East, and Eastern and Southern Europe as well as others<sup>5</sup>

# LEP – Limited English Proficiency<sup>6</sup>

- More than 60.6 million Americans (21%) over the age of five years speak a language other than English at home
- Of these individuals, approximately 25 million (41.8%) report speaking English less than “very well” or have limited English proficiency (LEP)

# Languages Spoken in Michigan<sup>7</sup>

Language	Population	Percent
Speak Only English at home	8,457,581	90.1%
<b>Speak a language other than English at home</b>	<b>843,256</b>	<b>9%</b>
Spanish or Spanish Creole	270,708	2.9%
Arabic	111,944	1.2%



# The Health Care Provider Culture<sup>8</sup>

<b>Beliefs</b>	<ul style="list-style-type: none"><li>• Standardize definitions of health and illness</li><li>• The omnipotence of technology</li></ul>
<b>Practices</b>	<ul style="list-style-type: none"><li>• Maintenance of health and prevention of disease via mechanisms such as the use of immunizations</li><li>• Annual physical examinations and diagnostic procedures</li></ul>
<b>Habits</b>	<ul style="list-style-type: none"><li>• Charting</li><li>• Constant use of specialized/technical vocabulary (jargon)</li><li>• Use of a systematic approach and problem solving methodology</li></ul>
<b>Preferences</b>	<ul style="list-style-type: none"><li>• Promptness</li><li>• Neatness and organization</li><li>• Compliance</li></ul>
<b>Rituals</b>	<ul style="list-style-type: none"><li>• Physical examination</li><li>• Surgical procedure</li><li>• Limiting visitors and visiting hours</li></ul>

# Defining Culture

*“Integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.”<sup>9</sup>*

(Joint Commission, 2007)

# Defining Cultural Competence

*“The ability of health care providers and organizations to understand and respond effectively to the cultural and language needs brought by the patient to the health care encounter.”<sup>10</sup>*

(Joint Commission, 2008)

# Cultural Factors to Consider<sup>11</sup>

- Death as a taboo subject
- Collective decision-making
- Historical & political context
- Dynamics of acculturation
- Perception of the physician's status
- Meaning & significance of pain
- Role of religion and faith (Traditional healing)
- Non-verbal communication & expression of emotion

# Hays' ADDRESING Model<sup>12</sup>

Cultural Influences	Dominant Group	Non-dominant/Minority Group
<b>A</b> ge & Generational influences	Young/middle aged adults	Children, older adults
<b>D</b> evelopmental disabilities & other <b>D</b> isabilities	Nondisabled people	People with cognitive, sensory, physical, and/or psychiatric disabilities
<b>R</b> eligion & Spirituality	Christian & secular	Muslims, Jews, Hindus, & others
<b>E</b> thnic & Racial Identity	European Americans	Asian, Latino, African American, Arab, Middle Eastern people
<b>S</b> ocioeconomic Status	Upper & middle class	People of lower status
<b>S</b> exual orientation	Heterosexual	LGBTQIA
<b>I</b> ndigenous heritage	European Americans	American Indians
<b>N</b> ational Origin	U.S.-born Americans	Immigrants, refugees
<b>G</b> ender	Men	Women & Transgender

Aspects of Culture	Mainstream American Culture	Other Cultures
Sense of self and space	Informal, handshake	Formal, bows, handshakes
Communication and Language	Explicit, direct. Emphasis on content – meaning found in words	Implicit, indirect. Emphasis on context – meaning found around words
Dress and Appearance	“Dress for success” ideal. Wide range in accepted dress	Dress seen as a sign of position, wealth, prestige, or religious rules
Food and Eating Habits	Eating as a necessity (fast food)	Dining as a social experience, religious rules
Time and Time Consciousness	Linear and exact time consciousness. Value on promptness. Time = money	Elastic and relative time consciousness. Time spent on enjoyment of relationships

Aspects of Culture	Mainstream American Culture	Other Cultures
Relationships, family, friends	Focus on nuclear family. Responsibility for self. Value on youth, age seen as handicap	Focus on extended family. Loyalty and responsibility to family. Age given status and respect
Values and Norms	Individual orientation. Independence preference for direct confrontation of conflict	Group orientation. Conformity. Preference for harmony
Beliefs and Attitudes	Egalitarian. Challenging of authority. Individuals control their destiny. Gender equality.	Hierarchical. Respect for authority and social order. Individuals accept destiny. Different roles for men and women
Mental Processes and Learning	Linear, logical, sequential, problem-solving focus	Lateral, holistic, simultaneous. Accepting of life's difficulties.
Work Habits and Practices	Emphasis on task. Reward based on individual achievement	Emphasis on relationships. Reward based on seniority

# Emotional Expression<sup>13</sup>

- Emotional antecedents & appraisal
- Cultural display rules
- Judging emotions in others
- Concept and Social Meaning

	Individualistic Culture	Collectivistic Culture
Self-Ingroup Relations	Okay to express negative feelings; less need to display positive feelings	Suppress expressions of negative feelings; more pressure to display positive feelings
Self-Outgroup Relations	Suppress negative feelings; okay to express positive feelings as would toward ingroups	Encouraged to express negative feelings; suppress display of positive feelings reserved for ingroups



# The Explanatory Model (FF #26)<sup>14</sup>

- **What** do you call the problem, **What** do you think the illness does, **What** do you think the natural course of the illness is, **What** do you fear?
- **Why** do you think this illness or problem has occurred?
- **How** do you think the sickness should be treated, **How** do you want us to help you?
- **Who** do you turn to for help, **Who** should be involved in decision making?

# Practicing Cultural Competence<sup>8</sup>

- Don't treat others as YOU would wanted to be treated
- Address all adult patients by their surnames unless invited to use a first name
- Be aware of your tone of voice
- Every person has their own comfort-zone for touching and distance
- Don't ask a Limited English-Speaking patient or family member "Do you understand?"
- Informed consent forms can be upsetting or frightening
- Making a telephone call is about the most difficult thing to do in a foreign language

# Never Assume

When negotiating truth telling and goals of care with patients of different cultural backgrounds...

- Inquire about current knowledge
- Inquire about desire to know medical details
- Inquire about preferred decision making strategy

# Working with LEP Patients & Families

- Communication skills are a core competency for palliative care physicians (and teams)<sup>15</sup>
- Best practice standards emphasize effective communication as essential to delivering high-quality palliative care<sup>16</sup>
- Use of professional interpreters encouraged<sup>17</sup>
  - Ad hoc interpreters should not be used<sup>18</sup>
    - Quality
    - Roles
    - Emotional strain
  - Use of professional interpreters...<sup>18</sup>
    - Mitigates errors in interpretation and healthcare disparities<sup>15,19</sup>
    - Improves patient satisfaction
    - Preferred by some patient groups<sup>20</sup>
    - Improved quality<sup>6</sup>

# Regulatory Requirements

Regulatory requirements require health care institutions receiving federal funds (Medicare) to provide language services to patients with LEP<sup>21,22</sup>

- Title VI of Civil Rights Act
- Section 504 of the Rehabilitation Act of 1973

# Working with Interpreters<sup>18,22</sup>

- **Before the encounter**
  - Disclose intent of discussion and preview of content
  - Set expectations with interpreter
  - Cultural consideration inquiry
- **At the beginning of the encounter**
  - Introduce interpreter
  - Explain interpreter's role
  - Lay ground rules
- **During the encounter**
  - Speak in the first person, directly to the patient/family
  - Pause frequently/confirm understanding
- **At conclusion of encounter**
  - Summarize discussion and next steps
  - Ask if patient or family have any additional comments or questions
- **After the encounter**
  - Debrief with interpreter and any other members of the healthcare team

# **The Law on Language Access: Section 1557 of the ACA and How It Will Impact Care**

- Review overall trends for the demand of interpreter services
- Affordable Care Act (section 1557)
- Beaumont Health Dearborn

# Overall Trends

The demand for interpreters continues to accelerate at a steady pace for the last few years, more recent spikes in demand are attributed to...

- Increase in minority populations health insurance coverage as a result of the Affordable Care Act (section 1557)
- Increased awareness of Joint Commission requirements for “Patient Centered Communication Standards”
- Growing area demographics and shifts
- Meaningful Use criteria for EHR applications.



# Communication

*“To communicate, we must realize that we are all different in the way we perceive the world and use this understanding as a guide to our communication with others”*

-- Tony Robbins



# What is Section 1557 and who does it apply to?

- Section 1557 is the nondiscrimination provision of the ACA
  - Went into effect 2010
  - Effective as July 18<sup>th</sup>, 2016
  - 90 day implementation (October 17<sup>th</sup>, 2016)
- The law prohibits the discrimination on the basis of race, color, national origin, sex, age or disability in certain health programs or activities.
- Enforcement through the HHS office of civil rights.

# Quick Facts on Section 1557

Mandates	Grants	Prohibits	Requires
<p>Posting Notices of Nondiscrimination (<i>in the state's top two non-English languages</i>) and signage explaining the availability of language services (<i>in the state's top 15 non-English languages</i>).</p> <p>Using “qualified interpreters” in healthcare scenarios.</p>	<p>Individuals a private cause of action to sue healthcare organizations that fail to provide language services, based on disparate impact.</p> <p>A patient’s family, spouse, or partner access to an interpreter even if the patient does not need one.</p>	<p>Minor children from interpreting except in short-term emergency scenarios.</p> <p>Adult family/friends from interpreting unless the patient specifically requests it.</p> <p>Healthcare staff from interpreting unless they are qualified and interpreting is an official job duty.</p>	<p>Provision of “meaningful access to each individual with limited English proficiency eligible to be served or likely to be encountered” from any organization receiving HHS funding, any HHS-administered health program, and any insurer on the Health Insurance Marketplace.</p> <p>Standards for all video remote interpretation to comply with those set for ASL VRI in the ADA.</p>

# What is Section 1557 and who does it apply to?

- Section 1557 applies to health programs and activities of which receives Federal financial assistance from any Federal agency including:
  - All health programs and activities, any part of which receives Federal financial assistance administered by HHS;
  - Health programs and activities administered by the Department, including the Federally-facilitated Marketplaces; and
  - Health programs and activities administered by entities established under Title I of the ACA, including State-based Marketplaces

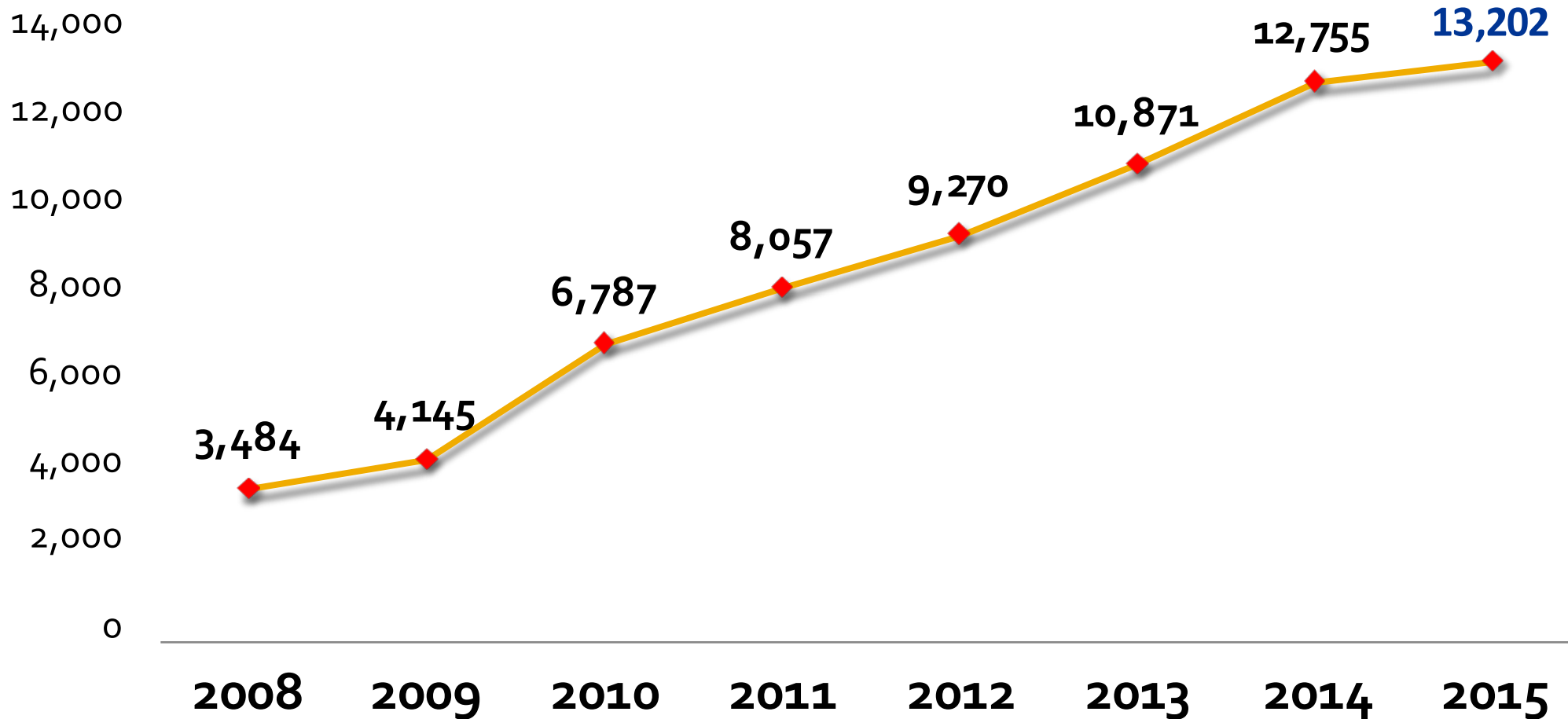
# Taglines of the top 15 Languages

- Covered entities are required to post tagline in the top 15 language spoken by individuals with LEP in the states in which the covered entity operates
- The taglines must advise consumers of the availability of free assistance services
- Not required to post sign language as a tagline

# Beaumont Health Dearborn

- A total of **60** departments were served
- Interpretation provided for a total of **57** languages
- Bilingual staff accounted to almost **7%** of entire workforce
- Patient Care Documents translated up to date: **596**
- Translations were completed for: **51** departments and sites
- Number of Deaf Patients seen at BH-D= 40
- Sign Language Hours provided=**922**
- Number of BH-D Departments requesting Deaf Interpreters= **26**

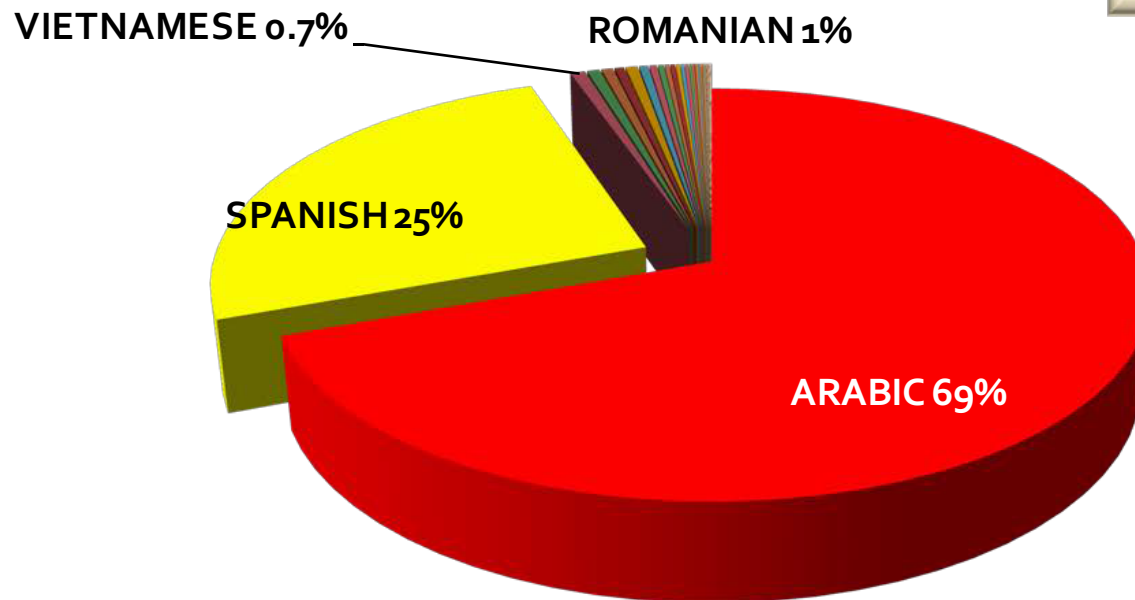
# Interpreter Requests



In 2015, there was a 3.5% increase in interpreter requests over 2014 and 278% since 2008  
An interpreter request is a single encounter with a patient for the purpose of medical interpreting

# 2015 Total Patients' Languages Interpreted (57)

Beaumont Hospital-Dearborn  
2015 Patient Languages (Total 57)



Arabic  
Mandarin  
American Sign Language  
Wolof  
Thai  
Pashto (Afghanistan)  
Croatian  
Luganda  
Amharic (Ethiopia)  
Ethiopian

Spanish  
Yemeni Arabic  
Hindi  
Bengali  
French  
Hungarian  
Tigrigna (Eritrea)  
Telugu  
Moroccan Arabic  
Karenni

Romanian  
Russian  
Gujarati  
Korean  
Tagalog  
Serbian  
Macedonian  
Uzbek  
Filipino  
Swahili

Vietnamese  
Punjabi  
Bosnian  
Greek  
Tamil  
Ukrainian  
Dari (Afghanistan)  
Brazil-Portuguese  
Dutch

Polish  
Urdu  
Levantine Arabic  
Italian  
German  
Chaldean  
Kunama  
Turkish  
Bulgarian

Albanian  
Haitian Creole  
Iraqi Arabic  
Farsi  
Cantonese  
Persian  
Karen  
Nepali  
Czech



The screenshot shows the HHS.gov Civil Rights page. The header includes the HHS.gov logo, the text "Civil Rights", and the U.S. Department of Health & Human Services. A navigation bar contains links for "Information for Individuals", "Filing a Complaint", "Information for Providers", and "Newsroom". The "Information for Individuals" section is active, displaying a list of topics: Advocates, Race, Color, National Origin, Disability, Age Discrimination, Sex Discrimination, Religion, Section 1557, Hill-Burton, Health Care Conscience Protection, Section 1553, Special Topics, Civil Rights FAQs, Fact Sheets, HHS Nondiscrimination Notice, and Language Assistance Services. The main content area is titled "Translated Resources for Covered Entities" and includes a paragraph explaining that covered entities must post notices of nondiscrimination and taglines for individuals with limited English proficiency (LEP). Below this, there is a section for "Sample Resources in English" with links for "Notice of Nondiscrimination", "Statement of Nondiscrimination", and "Tagline". A table provides links for these resources in various languages: Español (Spanish), 繁體中文 (Chinese), Tiếng Việt (Vietnamese), 한국어 (Korean), Tagalog (Tagalog – Filipino), and Русский (Russian). Each language entry includes links for the "Notice of Nondiscrimination", "Statement of Nondiscrimination", and "Tagline" in both PDF and .docx formats. A "top" button is located at the bottom right of the table.

## Translated Resources for Covered Entities

Translated Resources for Covered Entities

Under Section 1557 of the Affordable Care Act (ACA), covered entities are required to post notices of nondiscrimination and taglines that alert individuals with limited English proficiency (LEP) to the availability of language assistance services. The translated resources below are available for use by covered entities.

**Sample Resources in English**

[Notice of Nondiscrimination. - PDF | .docx](#)

[Statement of Nondiscrimination - PDF | .docx](#)

[Tagline. - PDF | .docx](#)

<b>Español (Spanish)</b> <a href="#">Notice of Nondiscrimination. - PDF   .docx</a> <a href="#">Statement of Nondiscrimination. - PDF   .docx</a> <a href="#">Tagline. - PDF   .docx</a>	<b>繁體中文 (Chinese)</b> <a href="#">Notice of Nondiscrimination. - PDF   .docx</a> <a href="#">Statement of Nondiscrimination. - PDF   .docx</a> <a href="#">Tagline. - PDF   .docx</a>
<b>Tiếng Việt (Vietnamese)</b> <a href="#">Notice of Nondiscrimination. - PDF   .docx</a> <a href="#">Statement of Nondiscrimination. - PDF   .docx</a> <a href="#">Tagline. - PDF   .docx</a>	<b>한국어 (Korean)</b> <a href="#">Notice of Nondiscrimination. - PDF   .docx</a> <a href="#">Statement of Nondiscrimination. - PDF   .docx</a> <a href="#">Tagline. - PDF   .docx</a>
<b>Tagalog (Tagalog – Filipino)</b>	<b>Русский (Russian)</b>

[top](#)

# 5 Immediate Steps to Ensure Compliance

1. Develop & post notice of non-discrimination that includes necessary language to comply with the final rule.
2. Include top 15 taglines.
3. Determine language assistance services available in your area, if requested by an individual. In other words know who to call if requested.
4. Covered entities with 15 or more employees must have a civil rights grievance procedure and compliance office.
5. Visit OCR attestation portal, complete and submit the Assurance of Compliance.

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