

Tribal Technical Advisory Group

To the Centers for Medicare & Medicaid

National Indian Health Board | 910 Pennsylvania Avenue SE, Washington, DC 20003 | (203) 507-4070 | (203) 507-4071 (fax)

August 12, 2022

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Submitted via regulations.gov

Re: Medicare Program; Calendar Year (CY) 2023 Home Health Prospective Payment System Rate Update; Home Health Quality Reporting Program Requirements; Home Health Value-Based Purchasing Expanded Model Requirements; and Home Infusion Therapy Services Requirements

Dear Dr. Brooks-LaSure:

On behalf of the CMS Tribal Technical Advisory Group (TTAG), I write to provide a response to the Centers for Medicare and Medicaid Services (CMS) proposed rule, “Medicare Program; Calendar Year (CY) 2023 Home Health Prospective Payment System Rate Update; Home Health Quality Reporting Program Requirements; Home Health Value-Based Purchasing Expanded Model Requirements; and Home Infusion Therapy Services Requirements” (CMS-1766-P).

Preamble to Comments

It’s important to underscore the TTAG comments on this regulation in the context of the CMS Framework for Health Equity 2022-2032. Over the last year the entire federal government and CMS have been working to respond to the President’s Executive Order 13985 on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (EO 13985). For the first time, the federal government is taking a systematic approach to address equity issues. CMS has responded by first issuing its CMS Strategic Plan, “Pillar: Health Equity” that laid out CMS’ definition of health equity and a broad strategy to advance equity through its programs. More recently, CMS has published its Framework for Health Equity that is a more detailed ten-year plan intended to address equity and health disparity issues across Medicare, Medicaid, CHIP, and the Health Insurance Marketplaces.

Important to understand about health disparities is that American Indian and Alaska Native (AI/AN) people were once one of the healthiest people on this continent. However, it is a direct result of colonialism and the effects of the United States policies of termination, assimilation, and boarding schools that have led to an “intergenerational pattern of cultural and familial disruption”¹ that are the drivers of health disparities for many of our AI/AN people. These drivers have manifested in some of the worst health disparities for AI/AN people that include infant and maternal mortality, cancer, cardiovascular disease and depression and other behavioral

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health conditions. The recent Department of Interior Boarding School Report explains that “Native Americans continue to rank near the bottom of all Americans in terms of health, education, and employment. Many AI/ANs face unique challenges and harsh living conditions resulting from the United States having removed their tribes to locations without access to adequate resources and basic infrastructure upon which their tribal governments can foster thriving communities.”² It is important to acknowledge that efforts to address these disparities are often complicated by culturally inappropriate interventions and an inadequate understanding of the historical effects of United States policies and ongoing trauma of AI/AN people.³ It is this history that is the root cause of the significant health disparities that affect AI/AN populations.

The TTAG is pleased that the President’s EO 13985 and the CMS Framework for Health Equity provide an opportunity to address the issues we discussed above. We are pleased to see that the CMS Framework provides an opportunity to design, implement, and operationalize policies and programs to address health equity issues. The TTAG has always taken a position that CMS has ample legal authority to undertake distinct policy making when dealing with AI/AN beneficiaries, and the IHS programs that provide their care. This unique and special treatment of CMS administering the statutes under its jurisdiction is rationally related to the federal government’s unique trust responsibility to AI/ANs.⁴ Under familiar principles of Indian law, such actions are political in nature, and as a result do not constitute prohibited race-based classifications. This authority taken together with EO 13985 and CMS’ Framework for Health Equity provide a sound basis to adopt the TTAG recommendations on the Proposed Rule. We hope you will agree that the TTAG recommendations are directly related to CMS’ Framework discussed in “Priority 2: Assess Causes of Disparities Within CMS Programs, and Address Inequities in Policies and Operations to Close Gaps.” The TTAG’s recommendations fit clearly in the intended outcomes of this chapter of the Framework as well as other priority areas of the Framework.

Introduction

We appreciate the agency’s dedication to promoting interoperability and improving care coordination operations across the health and social care continuum by encouraging the use of health information exchange (HIE) networks, especially given the opportunity they bring to further integrate behavioral health and dental services into primary care settings. We have long advocated for the treatment of beneficiaries as a whole patient, which includes these important services.

However, we do have some recommendations for the agency to consider in developing these networks, and special considerations regarding the AI/AN communities that they may serve.

Recommendations:

I. CMS should engage with Tribes early in the HIE development process in order to start building relationships and trust in data sharing

In order to get buy in from Tribal organizations and citizens, CMS should engage early and often with Indian Country so that it can understand how best to navigate data sharing and the privacy

issues that come along with it. CMS should focus on building this trust by soliciting Tribal input in the decision-making stage on use of AI/AN data. We urge CMS to engage with Tribal liaisons and the equivalent wherever and whenever they are available. We also encourage CMS to recognize Tribal ownership of data from the beginning stages of this process. Lastly, CMS can build this trust by providing equitable access by Tribal nations to AI/AN data necessary to perform their governmental functions.

II. CMS should encourage HIE agreements to include language that recognizes data sovereignty for Tribal nations and clearly addresses ownership of data

We urge CMS to encourage agreements to include specific language that recognizes indigenous data sovereignty as the right of a nation to govern the collection, ownership, and application of its own data.¹ There are significant concerns in Indian Country around data ownership, as well as where the data goes and how it is used. In order to further gain trust and get Tribal organizations and citizens to buy into participating in HIEs, CMS should focus on ways it can build this trust, which should include making it clear to participants that safety measures are in place to protect data and ensure that data is only used for the purpose of advancing their health and health care experience.

In moving forward with these agreements, we have concerns around data ownership and where it goes. Data sovereignty recognition and other provisions are needed in these data sharing agreements. Any AI/AN data that is utilized in an HIE should be used solely for the improvement of the care by giving a healthcare provider a complete perspective of the patient's health conditions and prior issues. All use of this data should be appropriate, and not to be used for purposes outside of medical treatment. Further, participants (whether Tribal citizens, nations, or organizations) must be granted explicit ownership of the data.² Tribal governments are public health jurisdictions with the inherent right to control their data.³ Tribes retain an ownership interest in data, even when the Tribe's data are located in a state, federal, or other dataset. This interest remains when the Tribe's data are aggregated with other data.⁴

The Network for Public Health Law has stated that "Tribes, tribal organizations, and Tribal Epidemiology Centers (TECs) (tribal organizations) need continuous and routine access to comprehensive and specific public health data to drive public health decision making, particularly during the current pandemic. Nothing in HIPAA prevents public health departments from sharing public health data with tribal organizations just as they can share data with any other public health authority. Sharing these data with tribal public health authorities is essential

¹ U.S. Indigenous Sovereignty Network, <https://nni.arizona.edu/programs-projects/policy-analysis-research/indigenous-data-sovereignty-and-governance>.

² See NCAI Resolution #TUL-05-059 re: Tribal Ownership of Health-Related Data, [Microsoft Word - TUL-05-059.doc \(ncai.org\)](#).

³ See 45 CFR § 164.501; [Tribal Data Sovereignty and the Critical Role of Data in Public Health Governance \(ojp.gov\)](#).

⁴ Powering Health Equity Action with Online Data Tools: 10 Design Principles, [10-Design-Principles-For-Online-Data-Tools.pdf \(nationalequityatlas.org\)](#) (Sept. 2017).

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for addressing the health disparities American Indians and Alaska Natives experience.”⁵ The TTAG would welcome collaboration with the agency on developing standard language for these agreements.

Conclusion

We appreciate your consideration of the above comments and recommendations and look forward to engaging with the agency further.

Sincerely,

A handwritten signature in black ink that reads "W. Ron Allen". The signature is written in a cursive style with a long, sweeping underline.

W. Ron Allen, CMS/TTAG Chair
Jamestown S’Klallam Tribe, Chairman/CEO

⁵ The Public Health Network, [Improving Data Sharing for Tribal Health: What Public Health Departments Need to Understand About HIPAA Data Privacy Requirements - Network for Public Health Law \(networkforphl.org\)](https://networkforphl.org/).