Health Leaders Advocate for Patient’s Full Health Record as Standard for Data Interoperability

Washington, DC -- In a commentary published today by StatNews [Link], Dr. John C. (Jack) Lewin, Administrator of the Hawai‘i State Health Planning and Development Agency in Honolulu, and Dr. Jane L. Delgado, President and CEO of the National Alliance for Hispanic Health, called for health data interoperability to move from selected elements to the patient’s full health record in order to advance patient safety and ensure providers have the full set of information they need to provide the best services possible.

Dr. Lewin emphasized the necessity of a broader definition: "Interoperability must be redefined to include the entire health record to truly benefit patient care." Dr. Delgado, reinforcing the need for comprehensive access, states, "Every piece of health information is a vital part of someone’s life story. We must ensure that story is complete and not just a summary. Full access to health records is not only fundamental for continuity of care but also a matter of respect for patient autonomy."

Dr. Delgado adds, "When we limit the data, we limit the potential for health innovations and equitable care. It's imperative that we break down these barriers for the benefit of all communities." The authors urge a revision of the HHS rule to reflect the full data sharing envisioned by the 21st Century Cures Act.

The newly established rule defines interoperability narrowly, limiting it to the U.S. Core Data for Interoperability (USCDI v3), and by doing so, it excludes critical parts of the full patient record. This myopic approach to health data sharing fails to leverage the wealth of available information that could revolutionize health and health outcomes while safeguarding privacy and reducing unnecessary health care costs. Patients rightfully expect that any provider to whom they grant access will see their entire health record. The limited scope of data sharing enforced by the current rule undermines patient autonomy and care continuity.

As business models of health systems increasingly prioritize their own interests over patient well-being, the need for Congress and HHS to act has never been more pressing. Lewin and Delgado call for urgent revisions to HHS’s rule to ensure it aligns with the original intent of the 21st Century Cures Act and enables a more effective use of AI and other new technology in healthcare to support better health outcomes by ensuring a full health record follows the patient.

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About the National Alliance for Hispanic Health (The Alliance)
The Alliance is the nation’s foremost science-based source of information and trusted advocate for the health of Hispanics in the United States with a mission to achieve the best health for all.

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