CMS sharing Medicaid data with immigration authorities

What we know; National Bleeding Disorders Foundation (NBDF) and Hemophilia Federation of America (HFA) joint statement

Medicaid Data Shared with Immigration Authorities
Joint Statement from NBDF and HFA on Patient Privacy

<u>Background</u>. According to multiple news outlets, the U.S. Centers for Medicare & Medicaid Services (CMS) in mid-July provided the personal data of millions of Medicaid enrollees to the U.S. Department of Homeland Security (DHS), as part of the Administration's ongoing immigration enforcement efforts. This action marked a change from longstanding policy and previous practice barring such information sharing.

The data reportedly included names, addresses, social security numbers, and health claims data for Medicaid enrollees in states including California, Washington, Illinois, and the District of Columbia.

A coalition of 20 states has sued the Administration in federal district court, arguing that the data sharing violates federal health and privacy laws. And the National Health Law Program (a legal nonprofit dedicated to the defense of health and civil rights in the U.S.) has filed a Freedom of Information Act request with CMS's parent agency, the Department of Health and Human Services (HHS), to understand the scope of the CMS data request.

NBDF and HFA position. The privacy of personal health information is deeply important to all members of the bleeding disorders community and to NBDF and HFA as patient advocates. Both NBDF and HFA participated in the successful multi-year effort to pass the Genetic Information Nondiscrimination Act of 2008 – a law that bars the use of genetic information in health insurance and employment. Both organizations also joined forces in 2017 to file a formal complaint with the HHS Office for Civil Rights, when an lowa insurance executive disclosed personal health information of a community member, in violation of the Health Insurance Portability and Accountability Act (HIPAA) privacy rule.

NBDF and HFA believe it is critically important to protect patients' personal and health information against disclosure or misuse that could expose them to harm or discourage them from seeking medical care. We will closely monitor litigation over the new data

sharing policy and will look for opportunities to partner with groups defending medical privacy. We will continue to update the community as the situation evolves.

Resources:

Personal Medicaid data given to ICE for immigration enforcement (July 18, 2025)

<u>Trump administration hands over Medicaid recipients' personal data, including addresses, to ICE</u> (July 18, 2025)

<u>Trump administration gives data of immigrant Medicaid enrollees to deportation officials</u> (June 13, 2025)