

## Methodology

On behalf of the Partnership, Leavitt Partners sent a survey to current and former Medicaid directors. Survey participants were informed that their name and state would be kept confidential, and responses would be deidentified.

No survey respondent was compensated for their participation; survey participants were informed that for each completed survey response a donation would be made to a non-profit SCD community-based organization.

The survey received about a 20 percent response rate, including responses from both current and former state Medicaid directors. The survey responses present geographical diversity (e.g., the Partnership received responses from individuals representing small and large states, different regions of the United States, states with different political leadership, etc.). Additionally, the survey received responses from individuals with a wide range of familiarity regarding how Medicaid covers SCD-related services (ranging from “very familiar” to “unfamiliar”).

The survey was conducted over email and a web-based survey tool over a few week period. The survey was designed to provide timely, qualitative feedback on important federal and state policy issues related to SCD.

Survey limitations may include the length of the survey, the wording of specific questions, the duration of time in which the survey was open, etc. Additionally, in limited cases, updated contact information for Medicaid directors was not readily publicly available.

The timing of the survey presents potential limitations that should be acknowledged. For example, with regard to the CMS Innovation Center’s Cell and Gene Therapy Access Model, one survey limitation is that, at the time of the survey, relatively limited public information was available about the Model. Additionally, the survey was conducted on the heels of [FDA’s approval of two gene therapy treatments for SCD](#) - a time in which familiarity with these new treatments was likely much lower for respondents than it will be in coming months. The survey was distributed to current and former Medicaid directors. In the future, a more comprehensive view of the Medicaid program could potentially be gained by also surveying Medicaid program staff and/or members of a state Medicaid P&T committee.

