



NHC Response to the 2022 National Strategy to Support Family Caregivers

Question 1: Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 characters)

Transparency and Caregiver/Patient Engagement

It is crucial to have accountability and transparency as the National Strategy is being updated. If feasible, please ensure that agencies working to implement federal actions provide updates to the public prior to the release of the updated strategy.

The National Health Council recommends that ACL develop an implementation dashboard that can be used to educate agencies, policymakers, public policy stakeholders, and family caregivers about the status of actions across agencies.

We also request that a process is developed and put in place that allows agency leadership to identify and report on the outcomes of those actions.

Finally, it is essential to establish a process to communicate the meaningful impact on caregivers. To further advance policy and programmatic priorities, we request that a process is developed to allow agencies to identify and report on the impact of their efforts.

Equity

We applaud the critical focus in the National Strategy on efforts to build equity for family caregivers. However, the National Health Council strongly recommend the National Strategy be updated to identify the specific actions federal agencies will take to promote equity for marginalized populations of family caregivers. These actions should be explicitly organized as an equity agenda within the National Strategy.

Question 2: Are there issues that are not covered in this component that should be addressed in future updates? (1,500 characters)

One issue of importance identified by the National Health Council is the role of caregivers in reporting outcomes and impacts of chronic disease on them and their family members. It is critical that caregivers are engaged as an important part of the health care reporting system. This can include being a proxy reporter of outcomes, providing additive information to help providers understand the experience of the patient, and as a reporter of impacts on themselves as caregivers of health decisions. These measures can be instituted across the health care system, including in clinical development, coverage, reimbursement, and quality measurement.

Question 3: If you have additional comments on any aspect of the Strategy, please provide them below. (500 characters)

As the RAISE Advisory Council further addresses the issues faced by families by updating the National Family Caregiving Strategy, continued and increased appropriations are needed. Therefore, the National Health Council requests that HHS continues to prioritize the budget requests that will be needed to sustain the efforts of the RAISE Family Caregiving Advisory Council.