

## CARR National Survey List

The following is a list of National Surveys and the principal investigators/key contacts who the ARCH Committee for Advancement of Respite Research (CARR) plans to contact with a request to schedule a meeting. While some national surveys conducted by federal government agencies may require an act of Congress to amend, the purpose of this meeting is to share information about the *Measuring the Value of Respite* and *Common Data Elements* White Papers and inquire about the process for recommending or providing information to support the addition/enhancement of respite-related survey questions.

<i>Survey Name</i>	<i>Brief Description and Link to More Information</i>	<i>Principal Investigator(s)/ Key Contact(s)</i>
Behavioral Risk Factor Surveillance System’s (BRFSS) optional Caregiver module	<p>The revised 9-item module allows states to understand multiple aspects of the caregiver-care recipient relationship, including:</p> <ul style="list-style-type: none"> <li>• Percentage of adults 18 years or older who self-report being a caregiver to a person with a health problem or disability.</li> <li>• Relationship between the caregiver and the care recipient.</li> <li>• Main health problem or disability of the care recipient.</li> <li>• Caregiver assistance with household tasks.</li> <li>• Caregiver assistance with personal care tasks.</li> <li>• Average hours of caregiving provided per week.</li> <li>• Length of time as a caregiver.</li> <li>• Type of assistance most needed by the caregiver that they do not receive (question included for years 2015–2018).</li> <li>• If the care recipient has Alzheimer’s disease or another dementia in addition to another health problem or disability (question added in 2019).</li> <li>• Percentage of adults aged 18 years or older who are not caregivers and expect to be caregivers in the next 2 years.</li> </ul> <p><a href="https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm">https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm</a></p>	BRFSS State Coordinators <a href="https://www.cdc.gov/brfss/state_info/coordinators.htm">https://www.cdc.gov/brfss/state_info/coordinators.htm</a>

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Caregiving in the US	<p>First conducted in 1997 by the National Alliance for Caregiving and <u>AARP</u>, the Caregiving in the US studies are widely regarded as one of the most authoritative resources available to describe the American caregiver. With previous studies conducted in 2004 and 2009, each edition provides new information on demographics and other factors affecting caregiving. The 2020 update, a renewed partnership between the Alliance and AARP, will be the most detailed examination of this critical area of American life to date. Special focus will be given to understanding the role of technology in caregiving and the relationships between friends and neighbors who provide unpaid care.</p> <p><a href="https://www.caregiving.org/research/caregiving-in-the-us/">https://www.caregiving.org/research/caregiving-in-the-us/</a></p>	<p>Dr. Fawn Cothran PhD, RN, GCNS-BC, FGSA, Hunt Research Director, National Alliance for Caregiving</p> <p><a href="mailto:fawn@caregiving.org">fawn@caregiving.org</a></p>
Health and Retirement Survey (HRS)	<p>The University of Michigan Health and Retirement Study (HRS) is a longitudinal panel study that surveys a representative sample of approximately 20,000 people in America, supported by the National Institute on Aging (NIA U01AG009740) and the Social Security Administration.</p> <p>Through its unique and in-depth interviews, the HRS provides an invaluable and growing body of multidisciplinary data that researchers can use to address important questions about the challenges and opportunities of aging.</p> <p><a href="https://hrs.isr.umich.edu/about">https://hrs.isr.umich.edu/about</a></p>	<p>HRS Coinvestigators and Committees</p> <p><a href="https://hrs.isr.umich.edu/about/co-investigators-committees">https://hrs.isr.umich.edu/about/co-investigators-committees</a></p> <p>Director, David Weir</p> <p><a href="mailto:dweir@umich.edu">dweir@umich.edu</a></p> <p><a href="mailto:hrsquestions@umich.edu">hrsquestions@umich.edu</a></p>

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National Core Indicators (NCI-IDD and NCI-AD)	<p>National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) is a national effort to measure and improve the performance of public developmental disabilities agencies. National Core Indicators – Aging and Disabilities (NCI-AD™) is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance.</p> <p>The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including service planning, rights, community inclusion, choice, health and care coordination, safety and relationships.</p> <p><a href="https://www.nationalcoreindicators.org/">https://www.nationalcoreindicators.org/</a></p>	<p><a href="mailto:nci@nationalcoreindicators.org">nci@nationalcoreindicators.org</a></p> <p>Lindsay DuBois and Dorothy Hiersteiner (Sarah Swanson can make a connection)</p>
National Health and Nutrition Examination Survey (NHANES)	<p>The National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations.</p> <p><a href="https://www.cdc.gov/nchs/nhanes/about_nhanes.htm">https://www.cdc.gov/nchs/nhanes/about_nhanes.htm</a></p>	<p>Director Alan Simon</p> <p><a href="https://wwwn.cdc.gov/DCS/ContactUs/Form">https://wwwn.cdc.gov/DCS/ContactUs/Form</a></p>
National Health Interview Survey (NHIS)	<p>The National Health Interview Survey (NHIS) has monitored the health of the nation since 1957. NHIS data on a broad range of health topics are collected through personal household interviews. Survey results have been instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.</p> <p><a href="https://www.cdc.gov/nchs/nhis/index.htm">https://www.cdc.gov/nchs/nhis/index.htm</a></p>	<p><a href="mailto:nhis@cdc.gov">nhis@cdc.gov</a></p>

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National Post-acute and Long-term Care Study (NPALS)	<p>The National Study of Long-Term Care Providers (NSLTCP) is now called the National Post-acute and Long-term Care Study (NPALS). This new name reflects the addition of more post-acute sectors (i.e., inpatient rehabilitation facilities and long-term care hospitals), while keeping the same sectors that have been in the study since it launched in 2012 (adult day services centers, assisted living and similar residential care communities, home health agencies, hospices, and nursing homes).</p> <p><a href="https://www.cdc.gov/nchs/npals/index.htm">https://www.cdc.gov/nchs/npals/index.htm</a></p>	<a href="mailto:ltcsbfeedback@cdc.gov">ltcsbfeedback@cdc.gov</a>
National Survey of Caregiving (NSOC)	<p>Periodically caregivers of NHATS participants are interviewed in the supplemental National Study of Caregiving (NSOC). Interviews are conducted with family and unpaid helpers to NHATS participants who report receiving assistance with self-care, mobility, medical or household activities. The interview includes questions on caregiving activities, duration and intensity of care, effects on caregivers' wellbeing and participation, along with demographic factors.</p> <p><a href="https://www.nhats.org/researcher/nsoc">https://www.nhats.org/researcher/nsoc</a></p>	<p>Co-PIs:</p> <ul style="list-style-type: none"> <li>• Vicki Freedman, University of Michigan</li> <li>• Jennifer Wolff, Johns Hopkins Bloomberg School of Public Health</li> </ul>
National Survey of Children's Health (NSCH)	<p>The National Survey of Children's Health (NSCH) provides rich data on multiple, intersecting aspects of children's lives—including physical and mental health, access to and quality of health care, and the child's family, neighborhood, school, and social context.</p> <p><a href="https://www.childhealthdata.org/learn-about-the-nsch/NSCH">https://www.childhealthdata.org/learn-about-the-nsch/NSCH</a></p>	<a href="mailto:info@cahmi.org">info@cahmi.org</a>

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The American Community Survey (ACS)	<p>The American Community Survey (ACS) helps local officials, community leaders, and businesses understand the changes taking place in their communities. It is the premier source for detailed population and housing information about our nation.</p> <p>In partnership with the U.S. Census Bureau, the Population Reference Bureau (PRB) maintains an American Community Survey (ACS) Data Users Group. The purpose of the ACS Data Users Group is to improve understanding of the value and utility of ACS data and to promote information sharing among data users about key ACS data issues and applications. Membership in the group is free and open to all interested ACS data users. The group is led by a Steering Committee representing a broad spectrum of ACS data users with different interests.</p> <p><a href="https://www.census.gov/programs-surveys/acs">https://www.census.gov/programs-surveys/acs</a></p>	<p>For more information about the ACS Data Users Group or Online Community, contact:</p> <p>Mark Mather, Associate Vice President of U.S. Programs, Population Reference Bureau, <a href="mailto:mmather@prb.org">mmather@prb.org</a> or 202-939-5433</p>
The National Health and Aging Trends Study (NHATS)	<p>The National Health and Aging Trends Study (NHATS) gathers information from a nationally representative sample of Medicare beneficiaries ages 65 and older. Annual, in-person interviews collect detailed information on the disablement process and its consequences.</p> <p><a href="https://www.nhats.org/researcher/nhats">https://www.nhats.org/researcher/nhats</a></p>	<p>Co-PIs:</p> <ul style="list-style-type: none"> <li>• Jennifer Schrack, Johns Hopkins Bloomberg School of Public Health</li> <li>• Vicki Freedman, University of Michigan</li> </ul>
Youth Risk Behavior Surveillance System (YRBSS)	<p>The Youth Risk Behavior Surveillance System (YRBSS) is a set of surveys that track behaviors that can lead to poor health in students grades 9 through 12.</p> <p><a href="https://www.cdc.gov/healthyyouth/data/yrbs/overview.htm">https://www.cdc.gov/healthyyouth/data/yrbs/overview.htm</a></p>	<p>Jonetta J. Mpofu (Most recent first author on report)</p> <p><a href="mailto:jmpofu@cdc.gov">jmpofu@cdc.gov</a></p>

*\*Prepared by Dr. Kim Whitmore for the ARCH Committee for the Advancement of Respite Research, October 2023*



This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.