Needs Assessment Toolkit:
Summary of Potential Data Sources

Category	Description	Examples and Links
Prevalence and Disparities	Number of persons and percentage of population with Alzheimer's disease and/or other dementias, by key demographic indicators (as available), such as: age, gender, race, ethnicity, marital status, sexual orientation, income, educational attainment, home ownership, employment status, disability status	- State Alzheimer's disease registry data or data portals (e.g., Georgia Department of Public Health Alzheimer's Disease and Related Dementia State Registry) - BRFSS Cognitive Decline module[1] http://www.cdc.gov/aging/pdf/2015-brfss-cognitive-decline-module.pdf - CDC Healthy Aging Data Portal http://www.cdc.gov/aging/agingdata/index.html - Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures (http://alz.org/facts)
Mortality	Number of deaths due to Alzheimer's and other dementias, by key demographic indicators (as available)	- State registries or data portals, such as death certificate records - Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures (http://alz.org/facts)
Caregiving	- Number of family and other unpaid caregivers - Hours of care provided	- Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures (http://alz.org/facts) - BRFSS Caregiver Module

Category	Description	Examples and Links
	- Economic value of unpaid care - Impact of caregiving on caregivers - Unmet needs, such as for information, psychosocial support, respite	http://www.cdc.gov/aging/pdf/2015-caregiving-module.pdf - Service needs from state or regional information, referral/assistance networks, such as 2-1-1 call systems or aging and disability resource centers (ADRCs) [2] (National Information and Referral Support Center has background information: http://www.nasuad.org/initiatives/information-and-referralassistance/ir-news) - Local Alzheimer's Association chapters may have local data about requests for assistance, care consultations - Qualitative data from focus groups (Example from Arizona: www.AzHealthyAging.com)
Modifiable Risk Factors	- Number of persons and percentage of population who smoke, have diabetes, are obese, have hypertension, are physically inactive, or eat an unhealthy diet - Health status of caregivers	- CDC Healthy Aging Data Portal (http://www.cdc.gov/aging/agingdata/index.html) - BRFSS Caregiver Module data - Caregiver surveys - CDC's 500 Cities project provides city- and census tract-level estimates for chronic disease risk factors, health outcomes, and clinical preventive service use for the 500 largest cities in the U.S. (https://www.cdc.gov/500cities)

Category	Description	Examples and Links
Costs	▪ Use and costs of health care, long-term care, and hospice care for people with Alzheimer's and other dementias ▪ Use and costs of community services, such as transportation, meal delivery, home health care and case management ▪ Financial impact of Alzheimer's and other dementias on families, including annual costs and effect on family income	▪ Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures (http://alz.org/facts) ▪ State Emergency Department Databases (SEDD) ▪ Hospital, vital records, home and community-based services, nursing home, health plans, all-payers claims databases, Silver Alert and similar Medicare, and Medicaid data[3] ▪ Community service providers ▪ Information and referral/assistance network records
Assets and Resources	Assets and resources that can be mobilized and employed to address needs and issues related to Alzheimer's and other dementias (e.g., support groups, area agencies on aging, volunteer networks, clinical services, hospitals, adult day care services, home care services, community resources)	▪ Sample tools for identifying existing assets from Minnesota's ACT on Alzheimer's website http://www.actonalz.org/assess ▪ Network analyses or surveys of local Alzheimer's Association chapters and partners

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[1] The BRFSS Cognitive Decline module measures the prevalence of "subjective cognitive decline" (SCD)—a non-medical term that identifies the percentage of individuals who self-report they are having increasing memory problems. A growing number of studies

has shown that SCD is associated with an increased risk of future dementia. Thus, these data indicate the potential future problem and burden.

[2] Access to such data varies and may not be universally available, due to inconsistencies in data collection and management. Consider consulting the state aging department to learn more about state/regional data sets.

[3] Access to such data varies and may not be universally available, due to restrictions on database access and use. Consider consulting a health department or university-based epidemiologist for additional guidance on state/local data sets.