Act on Alzheimer’s®
Evaluation Appendix & Instruments Repository
Companion to Evaluation Report

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About this Document

This is a companion document to the Evaluation Report prepared by Deborah Paone, of Paone & Associates, describing a formative evaluation of the ACT on Alzheimer’s initiative (October 2013-October 2015).

This document contains the Executive Summary from that report and the related appendices and survey instruments used in the evaluation.

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Executive Summary

ACT on Alzheimer’s® is a voluntary, state-wide collaboration in Minnesota. It was launched in June 2011, building off of the work of the Alzheimer’s Disease Working Group (ADWG) and their recommendations to the Minnesota State Legislature.

Five goals were set forth in 2011 for the ACT on Alzheimer’s® initiative (formerly Prepare Minnesota for Alzheimer’s 2020) to advance the dementia capability of the state. A Leadership Council and five Leadership Groups of voluntary members were organized to perform the work:

1. Increase detection of Alzheimer’s disease and improve ongoing care and support.
2. Equip communities to be “dementia capable” to support residents who are touched by Alzheimer’s disease.
3. Sustain caregivers by offering them information, resources and in-person support.
4. Raise awareness and reduce stigma by engaging communities.
5. Identify and invest in promising approaches that reduce costs and improve care.

The five Leadership Groups were: (1) Detection and Quality Health Care, (2) Preparing Communities, (3) Caregivers, (4) Awareness, and (5) Investing in Promising Approaches. Each Leadership Group had a defined purpose and focus, corresponding to the five stated goals. Implementation plans for the first 18 months of work (mid 2011-2013) set targets and activities. Thereafter, each group set additional plans based on progress they had made and the evolving interests of group members. A sixth group was added in 2014 (Health Equity).

Most of the groups worked through 2014. The group that is still active is the Detection and Quality Health Care Leadership Group (as of October, 2015). The Leadership Council will hold its’ final meeting November, 2015. Plans for sustaining or transforming the initiative to its next stage are underway.

A modest formative evaluation provided opportunity to document progress and fold key learning back into the work. Four focus areas were chosen: (1) development and use of health care practice tools, (2) community engagement, (3) impact on caregivers, and (4) influence on policy.

By fall of 2015, progress had been made on the five stated goals. Given the organic and evolving nature of the initiative, working group activities responded to opportunities based on member interests and available funding throughout the 3+ years reviewed.

- Detection & Quality Health Care – Through the work of many experts and organizations, this working group created many tools and resources for use in the field (Minnesota and beyond) such as health care provider practice and decision-support tools, and educational curricula. Implementation of the health care tools and dementia curricula is growing in Minnesota and is a current area of focus for members who are interested in sustaining the effort around dissemination and implementation. Information from the early adopters of these practice tools offer insight into key factors that enable use in health care settings.
Communities – These working group members fostered community engagement by organizations and individuals in more than 30 communities throughout Minnesota—far exceeding expectations. Through the work of individuals and organizations and with the assistance of a technical consultant, a Dementia-Capable Community Toolkit was created and piloted. Four steps for community engagement guide communities using this Toolkit: (1) Convene, (2) Assess, (3) Analyze, and (4) Act. From the four pilot communities who first tested the Toolkit, lessons and modifications were wrapped into the next stage effort. Grant funding and structured technical assistance allowed an additional 30 communities from areas throughout Minnesota to be supported.

All “ACTion” communities have been utilizing the Dementia Capability Toolkit and community engagement process. Hundreds of people and organizations working together across sectors (e.g., social service agencies, government, health care, housing, education, faith communities, employers/businesses) have been involved. Key catalysts have included: grant funding, one-on-one and group technical assistance and education, access to additional resources through the ACT website (e.g., videos, templates), and peer-to-peer learning. These key supports facilitated the work of the ACTion community coordinator and team members (largely volunteers) and guided each community to work through the required steps and make progress.

Some changes to the Toolkit are needed, based on consistent input from coordinators and others in the field. Recommendations about refinements to the Toolkit, particularly changes to the surveys, have been synthesized and are offered in this report. Further work is needed on how to maintain community engagement and evaluate/measure impact. Communities are looking for technical assistance, funding support, and guidance in these areas. Communities also want to make best use of their collective experience and are looking for ways to maintain or increase shared learning.

Caregivers – Progress by this working group focused on assisting the State of Minnesota in its development of training and state data resources, as well as providing input into the other working groups. Progress toward ACT goals was made at the state level, including enhancements to the state web-based resources & information database (www.minnesotahelp.info) and caregiver consultant dementia training through the Minnesota Board on Aging and Area Agencies on Aging. The Caregiver Leadership Group provided extensive time, expertise, focused input, and information to support these state-led efforts. There is still work to be done to reach the capacity/access goals for all caregivers statewide to have access to care navigators, trained caregiver consultants, and dementia-specific resources. Caregivers who have been deeply involved in the ACT on Alzheimer’s efforts within their respective communities have offered measures for evaluating impact that would be meaningful from their unique perspectives.

Awareness – Working group members created a professional website (www.actonalz.org) that now has hundreds of resources and tools to support work within Minnesota and across the nation. The website has been funded through philanthropic contributions and is a comprehensive repository capturing and presenting the work of the initiative as well as...
organizing resources from other national and international sources—all in the framework of the five stated goals. The website is robust. It will need ongoing financial support to be maintained and updated. Suggestions for refinement with search functions and formatting to help with locating information have been recommended to the ACT staff.

- **State Policy Influence (Toward Goal of Investment in Promising Practices)** – Working group members created an economic model and utilized the model to conduct an analysis of one intervention showing potential cost savings to Minnesota to be achieved within 15 years. Authors published the findings in a credible industry journal (*Health Affairs*). The State has included this intervention as a covered service under the Title III-E Caregiver Services definitions. The State continues to sponsor training sessions for caregiver consultants to be certified to provide this evidence-based intervention. However, none of the Minnesota health plans have chosen to cover this intervention within their product lines of businesses. The State’s own forecast determined that cost savings did not accrue in the timeframe necessary for being included in defined services covered under Medicaid.

In addition to this economic modeling, individuals from two state departments—the Minnesota Department of Health and the Minnesota Department of Human Services—participated in the work of ACT on Alzheimer’s, offering expert advice and input in all of the ACT Leadership Groups. In addition, several MBA/DHS grants required use of the ACT on Alzheimer’s tools, such as the CSSD/LiveWell at Home grant for Alzheimer’s disease health care home demonstrations. Another noteworthy outcome is the 2015 legislative action by the Minnesota State Legislature authorizing $750,000 in grant funding to select/fund Minnesota community collaborative proposals in order to support next-stage efforts. This builds off of the work of the ACT on Alzheimer’s communities throughout the state. The focus is on health care detection, dementia care follow-up, linking caregivers to community support, increasing caregiver supports, and building awareness through educational and community engagement efforts.

Additional noteworthy activities and results, which *ACT of Alzheimer’s* fostered and which furthered and extended progress toward ACT’s stated goals, included:

- **Collective Action** - Extensive engagement of industry leaders and advocates throughout Minnesota far exceeded expectations. Engagement in all facets of the work included more than 600 individuals and 50 organizations—many devoting significant volunteer time and personal or organizational resources to working within this collective action structure where no one organization “owned the work.” The main involvement of these individuals through working groups has now been completed. The groups completed their product/tools development and disseminated these through the website, trainings, presentations, and the ACTion communities. There are plans to move this work from the original collaborative infrastructure to existing organizations, such as the AAAs and the Alzheimer’s Association, as well as the state government agencies and provider-associated organizations.

At the writing of this report, the *ACT on Alzheimer’s* initiative is evolving. Many individuals, including Leadership Group Chairs, have expressed interest in continuing this collective...
action effort—to absorb what has been learned, launch structured efforts around implementation of tools statewide, and set up an implementation evaluation approach that moves toward measuring outcomes and impact.

- **Funding Infrastructure, Tool Development & Communities’ Support** – One very important element, in addition to the volunteer human resources, was the financial support that was received from philanthropic organizations, advocacy organizations, federal grants, academic institutions, and health care systems/health plans. Over $2 million was secured in 3 years. These dollars covered the costs of the ACT management team as well as specific activities that received targeted funding—usually to pay for expert consultant time (e.g., economist, clinical consultants, marketing/communications consultant, evaluation consultant, etc.) as well as cover printing and meeting costs, website development, video training production, and other marketing and dissemination efforts. A significant portion of this outside funding provided seed money via small grants to the 30+ ACT on Alzheimer’s communities. Dollars were awarded based on a competitive review granting process that was managed by the ACT project director. Receipt of this level of outside funding was beyond expectations and allowed ACT participant members to develop professional-looking tools with sound content, utilizing industry and subject experts.

- **Health Equity** – In the course of the work, particularly around engaging communities, several ACT participant members identified a gap in the representation of diverse communities and individuals from various affinity groups (e.g., ethnic, language, religious, cultural, etc.). As a result, these members created an additional working group to develop the principles and framework for incorporating these perspectives. This was named the Health Equity Leadership Group. The group developed a “Call to Action” and agreed to work with the other leadership groups to incorporate the “health equity lens” into the tools and products of ACT. This has led to enhanced resources such as culturally-responsive screening tools for health care providers.

- **National Visibility & Influence** – The ACT initiative worked extensively to push content out beyond the state boarders—helping to gain visibility. These efforts worked very well, as ACT achieved unanticipated national and international attention around the products developed through the working groups. As of October, 2015, attention from Health Resources Services Administration, Administration for Community Living, National Institute on Aging, National Quality Forum, and other federal agencies and national working groups or committees, has provided the opportunity for ACT on Alzheimer’s to influence national efforts around health professions training, community engagement in addressing Alzheimer’s disease, and measuring dementia capability. This includes national curriculum scheduled for release in 2016 by HRSA, and the NAPA Advisory Council plan to foster up to 15 dementia friendly communities. Using ACT on Alzheimer’s as a model, a national replication called Dementia Friendly America Initiative (DFAi) has recently been launched. This went beyond the initial goal of influencing State of Minnesota practice and policy, but has provided additional support for the work done through the hundreds of individuals in Minnesota acting collectively around a common goal.
Evidence supports the conclusion that this has been a very successful statewide community engagement effort which exceeded expectations in terms of volunteer participation, creation of tools/resources, and dissemination of information and tools throughout the state, nationally and even internationally. The examination across nearly four years of effort suggests that important factors in this success included:

- The collective action approach and structure with an effective core management team of staff members (shared ownership; sufficient infrastructure; strategy for engagement)

- Clear purpose & defined goals for the initiative that were tied to foundational work conducted by experts and industry leaders (ADWG) two years prior to ACT. ACT’s goals derived directly from recommendations of this group (buy-in; credibility)

- Strategically invited individual experts, opinion leaders, and organizational representatives across sectors (credibility; buy-in; peer influence; systems thinking, leveraging for change)

- Significant additional funding for specific work efforts (sufficient resources; technical expertise; visibility)

- A professional and robust communication approach for raising visibility, disseminating products, and keeping individuals informed. This included effective use of the media (radio, television, print, electronic forums), professional website development as the primary vehicle for dissemination and diffusion of the tools, and purposeful outreach to local, state, and national media as well as presentations at national conferences (strategy; visibility; shared learning)

The initiative is moving into a new phase within Minnesota. Individuals and organizations are determining next steps toward the goal of “making Minnesota the first state in the nation prepared for Alzheimer’s” as set forth in the Alzheimer’s Disease Working Group Report to the Minnesota Legislature in 2011. Some funding has been allocated to the AAAs and the Alzheimer’s Association to assist communities and keep the website. State agencies and provider organizations will also continue to promote the goals in their respective settings.

Suggested next steps based on the evaluation findings are to:

- Absorb what has been learned in the field to make any necessary refinements to the tools and products and community engagement approach.
- Set forth a structured plan for assisting communities in their next phase efforts, with technical assistance and peer-to-peer learning.
- Moving from development to implementation, create a targeted implementation evaluation plan that identifies and defines consensus measures, methods, and concrete data sources to provide information that the volunteer members of this initiative, funders, policy makers and others can use to assess results.
- Keep the best of collective action so that individuals can work outside of their silos.
Appendix A: Charter – (2011)

PREPARING MINNESOTA FOR ALZHEIMER’S 2020 - PMA 2020 CHARTER

PMA 2020 PURPOSE AND VISION
Prepare Minnesota for Alzheimer’s 2020 (PMA 2020) is a state-wide, collaborative initiative seeking transformative change in the State’s medical and long term care systems and communities to better support individuals with Alzheimer’s disease and their families.

As Minnesota experiences a historic increase in its older population over the next 40 years, the number of people with Alzheimer’s disease and other dementias is expected to double for people ages 75-84 and triple for those over age 85. Younger onset Alzheimer’s, occurring in people under age 65, is also on the rise. The rapidly increasing prevalence of Alzheimer’s disease in Minnesota is an urgent call for us to prepare our systems and communities for the spiraling needs related to the disease. In the absence of system change, there will be significant cost and burden to individuals with the disease, their families and caregivers, employers, payors, communities and the state.

To more fully understand and address the mounting Alzheimer’s crisis in Minnesota, the 2009 Minnesota Legislature called on the Minnesota Board on Aging to establish the Alzheimer’s Disease Working Group (ADWG) to study the status of Alzheimer’s disease in Minnesota and make recommendations to the Legislature for needed policy and program changes that will prepare the state for the future. In response to its legislative mandate the ADWG developed a set of priority recommendations, which it delivered to the Minnesota Legislature in January 2011. The recommendations included needed policies and responses to the budgetary, social and personal issues related to Alzheimer’s disease and other dementias.

PMA 2020 is a voluntary, state-wide, collaborative effort of medical, academic, community, government, business and nonprofit stakeholders across Minnesota to implement needed system change, using the ADWG recommendations as a springboard for action.

PMA 2020 SCOPE, PRIORITIES AND INTENDED OUTCOMES
PMA 2020 seeks to implement system change relating to Alzheimer’s disease in five priority areas:

- Awareness, Stigma Reduction and Communication
- Early Identification and Quality Health Care
- Preparing Communities
- Sustaining Caregivers
- Economics of Alzheimer’s Disease

Specific outcomes for each priority area are included in Attachment A.

PMA 2020 GOVERNANCE AND ROLES
Chair. PMA 2020 will be led by a Chair, whose responsibilities include:

- Convening and presiding over all PMA 2020 Executive Committee Meetings;
- Convening and presiding over meetings of the Steering Team;
- Sending out communications to membership to apprise them of meetings, updates, needed actions and resources and other communications; and
- Other duties as needed.
Executive Committee. The Executive Committee directs and expressly shares overall responsibility for PMA 2020, which includes:

- Providing direction to the overall initiative;
- Identifying and determining means to address issues that overlap or cut across all priority areas;
- Identifying and helping to secure human and financial resources needed to further implementation of the intended outcomes;
- Providing guidance to the Leadership Groups to foster successful implementation of priority outcomes;
- Responding to issues raised by Leadership Groups or the Steering Team;
- Serving as an advocacy liaison in the broader community relating to Alzheimer’s disease issues;
- Communicating progress on PMA 2020, both internally and externally; and
- Serving as ambassadors for PMA 2020.

Leadership Groups. Leadership Groups will be formed to support the priority areas of PMA 2020. Membership will be comprised of individuals with expertise in or who have a passion for a Leadership Group topic area. Each Group has a Chair and Vice Chair, who may or may not be members of the Executive Committee. The roles and responsibilities of Leadership Groups includes:

- Sequencing and proposing prioritization of intended outcomes in their respective priority area;
- Developing an implementation plan for achieving the priority intended outcomes in their priority area;
- Developing success measures for the implementation plan;
- Identifying needed human resources needed to carry out the implementation plan;
- Executing on the implementation plans; and
- Reporting progress and barriers to the Executive Committee.

Steering Team. The Chair will be supported in leadership by a Steering Team, which will be comprised of the PMA 2020 initiators, the Executive Committee Chair, Leadership Group Chairs, Project Manager, Facilitator and Communications Support. The role of the Steering Team includes:

- Monitoring and coordinating overall work process;
- Preparing agendas for Executive Committee meetings;
- Carrying out interim work as directed by Executive Committee; and
- Identifying issues for the Executive Committee.

Organizational Support. Supportive resources are critical to successful collaborative action and must foster results without shifting responsibility for achieving results. To this end, PMA 2020 will be supported by The Collective Action Lab, which will provide process design and consultation, facilitation and project management support. Additionally, The Lab will provide a website for project communications and updates. (Link to The Lab website)

PARTICIPATING MEMBER EXPECTATIONS
PMA 2020 is comprised of members drawn from various perspectives, disciplines, and societal sectors who agree to serve in one or more roles within the Executive Committee, Leadership Groups, or the Steering Team. PMA 2020 member expectations include the following:

Term of Service. PMA 2020 members commit to a two year term of participation in one or more of the PMA 2020 groups, beginning in June, 2011.
Meeting Attendance (including attendance via electronic means). To the best of their ability, PMA 2020 Executive Committee members attend each Executive Committee meeting (approximately quarterly), either in person or via electronic means. If an Executive Committee member cannot attend a meeting by either means, s/he may send a representative to observe the meeting, but not vote on issues.

Resource Finding. Executive Committee members will help identify resources (their organization’s or potential resources available within their networks) that might foster successful implementation of the PMA 2020 outcomes.

Addition of New Membership. New membership to the Executive Committee or Steering Team may be recommended and approved by the Executive Committee at any time (voting may be in person or via electronic means). New members to the Leadership Groups may be added at any time based upon the approval of the Leadership Group Chair and Vice Chair.

PMA 2020 GUIDING VALUES AND NORMS: PMA 2020 operates under the following guiding values and norms:

Joint Ownership and Shared Responsibility. PMA 2020 is not convened, owned or controlled by one organization, but instead, is a collective banner under which multiple stakeholders can convene, direct and implement the initiative. This approach is grounded in a value that those seeking change must collectively own and invest in their desired future to achieve meaningful, lasting results. To this end, if something is needed in PMA 2020, members share a responsibility in collectively securing needed resources and addressing barriers to change.

Dialogue and Inquiry. PMA 2020 will conduct meetings, communications and other interactions using principles of dialogue and inquiry, including:

- Exhibiting a sense of mutual respect, trust, and inclusiveness.
- Exploring divergent views in a respectful rather than adversarial manner.
- Continually identifying what is working and opportunities for improvement.
- Gathering relevant information to inform decisions.
- Assuring transparency of and equal access to information.
- Committing to consensus based decisions, plans of action and being accountable for following through on agreements.

Decision Making. All PMA 2020 business shall be conducted based on the philosophy of consensus based decision making (defined as being able to support a decision, even if not one’s first choice). If, after due discussion consensus cannot be reached, a vote will be taken. Simple majority rules will apply. PMA 2020 members are entitled to one vote per organization.

Voting. Voting may be conducted in person or via electronic means during or in advance of a meeting, but not by proxy.

Conflicts. No one may profit financially from membership in PMA 2020 sales or solicitation at meetings or workshops, without prior approval of PMA 2020.

PMA 2020 Communications
- All PMA 2020 members are ambassadors to the initiative and may speak regarding its vision and goals to external audiences; however, any communications to governmental bodies or the media should be directed to the PMA 2020 Chair or a representative authorized by the Executive Committee.
Documents bearing the PMA 2020 identifier or other communications representing PMA 2020 to external audiences shall be forwarded to the Steering Team for approval before being disseminated outside of the PMA 2020 membership.

AMENDING THE CHARTER
Members may propose an amendment to this Charter at any regular meeting. Proposed changes shall be circulated to all the Members before the vote is taken. Regular decision making processes will govern adoption of Charter Amendments.
Appendix B: First Generation Goals

**ACT on ALZHEIMER’S: First Generation Goals (January 2012-June 2013)**

- **January 2012**
  - State of MN Health Care Home incorporates dementia standards into the health care home certification process and develops Alzheimer’s health care home.

- **June 2012-December 2012**
  - A Provider Practice Tool is developed outlining evidence-based and evidence-informed step by step, dementia care guidance from cognitive assessment through quality care interventions and care management.
  - A Community Preparation Tool Kit is developed and piloted in communities with availability for broader dissemination in 2013.

- **January-June 2013**
  - An Economic Model and White paper identifies the costs of Alzheimer’s disease and related dementias for MN with and without investment in two promising interventions.
  - An online interdisciplinary educational curriculum is available for use and customization by universities and continuing education for health and community based providers throughout the state.
  - A Provider Practice Tool is disseminated and implemented to HCHs throughout Minnesota.
  - A community engagement plan and community preparation tool is implemented in communities statewide in integrating Alzheimer’s resources that assure early detection, quality dementia care and community readiness for the disease.

- **2013**
  - A statewide, user-friendly organization of resources (including a care navigator and care consultants) is available to caregivers as well as providers www.minnesotahelp.info.
Appendix C: Anticipated Long-Range Outcomes

**ACT on Alzheimer’s Long-Range Outcomes**

**2025**
- An effective treatment for Alzheimer’s is available at early stages of the disease (aligns with President Obama’s national agenda)
- Increased quality of life for those with the disease and their caregivers
- Reduced health care costs
- Interventions replicated for and benefit other chronic care disease processes
- Community health goals are set and implemented at the local level on multiple community health issues using the PMA model

**2020**
- Screening, diagnosis and quality care early in the disease process is common in medical practices
- Research begins to identify effective treatments (drug-based and non-drug-based)
- Patients and their caregivers are supported through a variety of interventions that are covered by insurance
- Health care costs are reduced in connection with dementia care as a result of better care management and transitions and caregivers and community supports that allow individuals to live in community longer
- Most communities are prepared to and are supporting individuals with dementia and their caregivers

**2018**
- Due to shifting practices in screening and diagnosis, increase in individuals diagnosed earlier in the disease process
- Increase in research of early stage dementia providing greater opportunities to discover effective treatments
- Early interventions and ongoing quality care for individuals and their caregivers delay symptoms and higher costs including reducing hospital admissions and re-admissions
- Communities act on more wide-scale basis
- Third party payers cover promising interventions on demonstration basis (drug and non-drug based)
- Dramatically increased awareness of disease and demand for early intervention and support

**2013**
- Recommended dementia practices implemented in MN Health Care Homes
- Recommended practices for early detection and intervention disseminated
- Action plans established by targeted communities
- Increased capacity of community based service supports
- Increase in caregiver identification and enhanced in-person caregiver consultation, information and service navigation
- Identification of promising interventions with potential to stabilize spiraling costs
Appendix D: Anticipated Budget

As of 2015, funders included:

- Alzheimer’s Association
- Aging Services of Minnesota Foundation
- Bigelow Foundation
- Blue Cross Blue Shield of Minnesota
- Care Provider of Minnesota Foundation
- GHR Foundation
- Greater Twin Cities United Way
- Medica Foundation
- Pohlad Foundation
- St. Paul Foundation
- UCare
- University of Minnesota Geriatric Education Center (HRSA Funding)

*INFRASSTRUCTURE*: To continue the work identified above and assure achievement of goals, Act on Alzheimer’s will need approximately $500,000 over the next three years ($170,000 per year for 2013-2015). A breakdown of the infrastructure budget and annual goals is provided on the next page. After 2015, further infrastructure funding will not be needed because Prepare MN’s efforts will be absorbed by and embedded in existing partner organizations, systems, communities and state government.
Appendix E: 2013 Governance and Management Structure

**2013 PROPOSED INITIATIVE GOVERNANCE STRUCTURE**

**LEADERSHIP COUNCIL (previously Executive Committee)**

Roles and Responsibilities:
- Provide direction, strategy and oversight for overall initiative;
- Identify and help to secure human and financial resources needed to further implementation of the intended outcomes;
- Provide guidance to the Leadership Groups to foster successful implementation of priority outcomes;
- Respond to issues raised by Leadership Groups or Operations Team as needed;
- Serve as an advocacy liaison in the broader community relating to Alzheimer’s disease issues;
- Communicate progress on initiative, both internally and externally;
- Serve as ambassadors for Initiative;
- When requested by the Steering Team make initiative-wide decisions using consensus process.

**MANAGEMENT STEERING COMMITTEE**

(Comprised of those organizations/individuals involved in day-to-day execution of goals e.g., Alzheimer’s Association, Metro Area Agency on Aging, Care Providers, Aging Services of MN, LG Group Chairs not from any of the above organizations, Mayo Clinic-providing link to National NAPA initiative, ACT on Alzheimer’s Chair And volunteer Treasurer, Executive Coordinator, Project Manager)

Roles and Responsibilities:
- Identify and determine means to address issues that overlap or cut across all priority areas;
- Make decisions on cross-cutting initiative issues;
- Make decisions that require quick responses to further work;
- Provide financial and in-kind resources to maintain basic infrastructure;
- Governance organizations do not co-brand with Initiative unless provided for under Initiative Style Guide, which is applicable to any Initiative Partner
- Metro Area Agency on Aging serves as fiscal sponsor, which includes accounting, contracting, and ownership of intellectual property
- Aging Services of MN Foundation provides day-to-day “host” services such as administrative and some communications support

**DAY-TO-DAY INITIATIVE OPERATIONS**

- Executive leadership and corresponding budget
- Project management and corresponding budget
- Grant development to seek funds for specific initiatives
- Leadership Group Initiatives
- Network of LG volunteers and in-kind support
- Contracted consultants in LG initiatives (e.g., economic model, community tool kit, provider guidelines), and corresponding budgets
- Fiscal Sponsorship
- Hosting services
- Financial Support/grants
Appendix F: Minnesota Organizations’ Collaborative Involvement

(Source: ACT Progress Report, 2012)
## Appendix G: ACT Leadership Council Members (2015)

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<th>Name</th>
<th>Organization</th>
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<tbody>
<tr>
<td>Michelle Barclay</td>
<td>Vice President, HealthCare Interactive</td>
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<tr>
<td>Terry Barclay, PhD</td>
<td>Clinical Director, HealthPartners Neuropsychology</td>
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<td>Seth Boffeli</td>
<td>Communications Director, AARP MN</td>
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<td>Bobbi Cordano</td>
<td>Vice President of Programs, Amherst H. Wilder Foundation</td>
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<td>Patti Cullen</td>
<td>President and CEO, Care Providers Minnesota</td>
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<td>Chuck Denny</td>
<td>Community Volunteer</td>
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<tr>
<td>Frank Fernandez</td>
<td>Board of Directors, CLUES; VP, Government Programs/Blue Cross CEO of Blue Plus</td>
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<tr>
<td>Alice Hill</td>
<td>Senior Philanthropic Advisor, Steven’s Square Foundation</td>
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<tr>
<td>Nancy Lee</td>
<td>Sr. Project Consultant, DHS, Aging and Adult Services Division/MN Board on Aging</td>
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<td>Kennard &amp; Mary Margaret Lehmann</td>
<td>Community Members</td>
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<td>Ross Levin</td>
<td>Founding Principal and President, Accredited Investors Inc.</td>
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<tr>
<td>Jennifer Lundblad, PhD</td>
<td>President and CEO, Stratis Health</td>
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<tr>
<td>Tom Mahowald</td>
<td>Senior Vice President, Strategy and Product Management, UCare</td>
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<tr>
<td>Lorry Massa</td>
<td>President and CEO, Minnesota Hospital Association</td>
</tr>
<tr>
<td>Riley McCarten, MD</td>
<td>Neurologist, VA Medical Center</td>
</tr>
<tr>
<td>Kathy Messerli</td>
<td>Executive Director, Minnesota Home Care Association</td>
</tr>
<tr>
<td>Vanne Owens Hayes</td>
<td>African American Leadership Forum Health and Wellness Committee</td>
</tr>
<tr>
<td>Deborah Paone, DrPH</td>
<td>President, Paone &amp; Associates, LLC and Executive Director, Normandale Center for Healing and Wholeness</td>
</tr>
<tr>
<td>Patricia Riley</td>
<td>Senior Vice President of Government Programs, Blue Cross Blue Shield</td>
</tr>
<tr>
<td>Michael Rosenbloom, MD</td>
<td>Neurologist, Health Partners Director, Center for Memory and Aging</td>
</tr>
<tr>
<td>George Schoephoerster, MD</td>
<td>Geriatric Services of Minnesota</td>
</tr>
<tr>
<td>John Selstad</td>
<td>Community Volunteer</td>
</tr>
<tr>
<td>Mark Schulz</td>
<td>Aging and Adult Services Division, MN Department of Human Services-MN Board on Aging</td>
</tr>
<tr>
<td>Carol Shapiro</td>
<td>Spousal Caregiver &amp; ADWG member</td>
</tr>
<tr>
<td>Dawn Simonson</td>
<td>Executive Director, Metropolitan Area Agency on Aging</td>
</tr>
<tr>
<td>Susan Spalding</td>
<td>Executive Director, Alzheimer’s Association MN</td>
</tr>
<tr>
<td>Cally Vinz (phone)</td>
<td>VP of Clinical Projects and Strategic Initiatives, Institute for Clinical Systems Improvement</td>
</tr>
<tr>
<td>Donna Walberg</td>
<td>Alzheimer’s Disease Support Services, MN Board on Aging</td>
</tr>
<tr>
<td>Steve Waring, PhD (phone)</td>
<td>Senior Research Scientist, Essentia Institute of Rural Health</td>
</tr>
</tbody>
</table>
Appendix H: Evaluation Presentation Materials to ACT Leadership Council, October 2013

ACT Evaluation

4 Areas:
- Enhancing capacity of providers, service organizations, and educational institutions
- Influencing State guidelines and policies
- Enhancing support to care partners through state-sponsored training for providers of information & referral and consultation
- Building community capacity

Indicators
- Awareness of tools & resources
- Use – for strategy, planning, capacity building
- Adoption – for practice/service
- Influence – embed in policies, standards, payment, training
- Impact – increase in AD identification and follow-up; satisfaction of caregivers

Evaluation - Methods/Sources

- Electronic surveys of ACT participants; community representatives
- Key informant interviews – State, AAAs, implementing organizations, ACTion community reps
- Focus group of care partners
- Secondary data review
Appendix I: ACT “Early Adopter” E-Survey Instrument

The survey was created as a SurveyMonkey® instrument by Deborah Paone¹ of Paone & Associates, LLC. The URL link was included in an electronic communication to all individuals who were listed on any of the groups organized through ACT on Alzheimer’s. It was assumed that these participants were “early adopters” who would be using the ACT-developed tools and resources personally, professionally, or both. There were eleven questions in the survey. The survey was conducted between February and May, 2014. It was e-mailed to 159 people and 92 responded (58% response rate).

This survey is designed to capture information about three things:
1. The nature and level of your involvement with ACT on Alzheimer’s to date
2. How you have used or are using the ACT information, tools, resources, website, networking or other aspects of your involvement with this collaborative in your personal or professional life
3. What tools, information, etc., have been adopted at your organization.

Your Involvement

Identify the time period that you are using to base your responses—that is, from the beginning of the entire effort (June 2011) to the present time, or in an alternate time period (e.g., the last 3 months or last 6 months, etc.)

Time Period:
1. I am using the following time period to answer this survey: from: ____ to: ____

OR X # of months (approximate)

Type of Involvement:

2. My major activity(ies) with ACT on Alzheimer’s has been: (check all that apply, or write in others)

  □ I participated in one or more Leadership Groups or Committees:
    ____________________________ (name of group)
    ____________________________ (name of group)
    ____________________________ (name of group)

  □ I worked on developing one or more of the ACT tools or resources (Clinical Provider Practice Tool, EMR Decision Support Tool, Care Coordination Practice Tool, Community-Based Service Provider Tool, Mid-Late Stage Tool, Dementia Curriculum, Dementia Training for Direct Care Staff grid)

  □ I worked on the After A Diagnosis consumer brochure

  □ I worked on the Dementia Capable Communities Toolkit

  □ I provided input into the development of the economic modeling of caregiver interventions.

  □ I developed content for or gave feedback on the ACT on Alzheimer’s website

  □ I worked on the communication and visibility efforts, including helping identify the logo and branding

¹ Deborah is an embedded researcher, having participated in the ACT on Alzheimer’s initiative as a volunteer participant since November 2011, and currently serving under contract to conduct a formative evaluation for ACT.
□ I am a part of an Action Community using the ACT on Alzheimer’s Dementia Capable Communities Toolkit
□ Provided advice, or participated in the “behind the scenes” work for the ACT collaborative
□ I worked to build awareness for the effort and assisted in getting the word out to local colleagues
□ I brought in new participants to be part of the ACT on Alzheimer’s collaborative
□ I worked on attracting funding sources for the effort
□ I provided input into the dementia capability training for Minnesota’s Senior LinkAge® Line staff and Caregiver Consultants.
□ I provided input into www.MinnesotaHelp.info®.
□ I reviewed and downloaded resources available through the ACT on Alzheimer’s website
□ I participated in educational outreach about ACT on Alzheimer’s, such as conferences, workshops, seminars, etc.

Other:

Other:

Other:

Level of Involvement:

Think about how extensive your involvement has been in the work of ACT on Alzheimer’s. *(We recognize there are peaks and valleys in terms of time—consider what you’ve spent as an average over the time period you’ve selected)*

3. Check the category that most closely represents your level of involvement in terms of time commitment for the ACT work:
   □ Extensive – more than 8 hours per month
   □ Moderate – between 4 and 8 hours per month
   □ Modest – between 4 and 12 hours a quarter
   □ Light – about an 1 hour a month
   □ Minimal – a few hours a year

If you would like to provide more specifics about your involvement, we welcome that. Describe:_____

4. Are you still participating in the ACT on Alzheimer’s work?  □ Yes     □ No

Explain: ______________________________________________________________

Making Use of the ACT Initiative:

5. How are you making use of your participation in the ACT on Alzheimer’s collaborative? (check all that apply, or write in others)

□ In my personal life with friends, families or self
□ Professionally
  ○ To build general awareness about the issue of Alzheimer’s disease and dementia capability within my organization [educational focus]
  ○ Strategically, with the leadership of my organization to discern impact on our direction/future [strategic focus]
ACT Evaluation Appendix & Instrument Repository

- To champion use of one or more practice tools that were developed by ACT on Alzheimer’s [operational focus]
- To modify current efforts and incorporate some or all of the ACT practice guidelines [operational/practice focus]
- To review how my organization or department addresses/serves people with dementia [evaluative focus]
- To raise awareness about Alzheimer’s disease in my community and foster interest in working together to become more “dementia capable” [collaborative focus]
- Other:

☐ I am not currently making use of my participation. Explain:

Resources Viewed/Used from ACT on Alzheimer’s:

6. I have viewed or used the following resources in my organization or in my work (put a check ✓ in the column or in both columns, indicating whether you have only viewed the resource, or have used it in your work in some way).

<table>
<thead>
<tr>
<th>ACT on Alzheimer’s® Resource</th>
<th>Viewed this Resource</th>
<th>Used this Resource</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Provider Practice Tool</td>
<td></td>
<td></td>
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<tr>
<td>Care Coordination Practice Tool</td>
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<tr>
<td>Community Based Service Provider Practice Tool</td>
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<tr>
<td>EMR Decision Support Tool</td>
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<tr>
<td>Dementia Training for Direct Care Staff grid</td>
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<tr>
<td>Dementia Curriculum Modules</td>
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<tr>
<td>After a Diagnosis</td>
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<tr>
<td>Dementia Capable Communities Toolkit</td>
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<tr>
<td>PowerPoint presentations about ACT work</td>
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<tr>
<td>Website (general info about ACT)</td>
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<tr>
<td>Social Media tools (YouTube, Facebook, Twitter)</td>
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<tr>
<td>Reports on the website (name of report):</td>
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<tr>
<td>Links and resources of other organizations found on ACT website</td>
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<tr>
<td>Other:</td>
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<td>Other:</td>
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</table>

Collective Action Approach: The ACT on Alzheimer’s® collaborative is structured as a voluntary, inclusive, collective effort that is not owned by one organization. As such, the collective (team/coalition/group) function and group process is important for achieving goals. Please consider your experience with ACT on Alzheimer’s in the time period you mentioned in the first page of this survey.
Directions: Think about how you have experienced this unique collaborative. Then, read each statement below. Choose your response to the right of the statement that most closely matches your opinion, based on your experience with ACT on Alzheimer’s to date. If you don’t know, check the box to the far right.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>Always</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>No Never</th>
<th>1</th>
<th>Don’t Know</th>
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</thead>
<tbody>
<tr>
<td>1. Purpose/Focus</td>
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<tr>
<td>I am clear on the purpose and goals of ACT on Alzheimer’s.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
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<tr>
<td>2. Organization/Structure of the Team’s work</td>
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<tr>
<td>The structure supporting this work by participants/volunteers (such as myself) has been effective.</td>
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<td>4</td>
<td>3</td>
<td>2</td>
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<td>3. Resources</td>
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<tr>
<td>a.) This initiative has the right resources to accomplish its work.</td>
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<td>4</td>
<td>3</td>
<td>2</td>
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<td>b.) Resources available are used appropriately.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
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<tr>
<td>1. Group Participation &amp; Decision-Making</td>
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<td>There is an openness and opportunity for involvement in meetings and decisions within this collaborative.</td>
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<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<td>5. Communication</td>
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<tr>
<td>a.) The existing communication channels and methods are sufficient in providing information about the activities and progress.</td>
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<td>b.) I feel informed about ACT on Alzheimer’s work</td>
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<td>6. Outreach</td>
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<td>There has been good representation of people and organizations involved in ACT on Alzheimer’s.</td>
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<td>7. Effectiveness</td>
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<tr>
<td>a.) The activities are yielding useful resources and plans that we can act upon together.</td>
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<td>3</td>
<td>2</td>
<td>1</td>
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<td>b.) I believe our collective work is having an impact.</td>
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<td>8. Collaborative Group Strength</td>
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<tr>
<td>This is a collaborative that does not depend on one person or organization for sustaining the momentum.</td>
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<td>9. Commitment</td>
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<tr>
<td>I am committed to staying involved in the ACT on Alzheimer’s work as it moves forward.</td>
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<td>10. Confidence</td>
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<tr>
<td>I am confident that ACT on Alzheimer’s will make progress in the next year toward stated goals.</td>
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<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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</table>
Impact
ACT on Alzheimer’s will continue its work in 2014 and 2015 as a collective. Please think about the overall impact that the ACT on Alzheimer’s collaborative action has had in Minnesota in each of the following areas to date.

<table>
<thead>
<tr>
<th>IMPACT TO DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is the overall impact of this initiative to date?</strong> If you don’t know or don’t have an opinion, check the box to the far right.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinicians</th>
<th>Enhanced skills of clinical professionals practicing in the field for detecting, treating and managing Alzheimer's disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Coordination &amp; Links to Community</td>
<td>Enhanced the coordination and continuity of care for persons with Alzheimer’s disease and their care partners</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Community Services</td>
<td>Enhanced linkages to community resources following detection of Alzheimer’s disease</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Supported caregivers by increasing access to effective support resources</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Communities</td>
<td>Assisted communities to build capacity and increase their support for persons with Alzheimer’s disease and their families and care partners</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Education/Training</td>
<td>Enhanced educational content of professionals in training</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
<tr>
<td>Awareness</td>
<td>Raised awareness of the issues and needs of persons with Alzheimer’s disease and their families/care partners within Minnesota</td>
</tr>
<tr>
<td></td>
<td>Very Strong</td>
</tr>
</tbody>
</table>

To clarify your answers above, give more information here:

Are there other results or impacts you have observed? Please describe:

What is the MOST valuable aspect of ACT on Alzheimer’s, in your opinion?

Paone & Associates, LLC
Appendix J: Evaluator’s Framework for Examining ACTion Communities

As developed by D. Paone, September, 2013 and shared with ACT leads (revised December 2013).

This framework for examining the ACT Communities is based on the work of Butterfoss and Francisco as well as Wandersman and Goodman (see references) - These last two researchers are very well known in the world of implementation research, particularly around coalitions and communities. The evaluation approach does NOT assume that ALL ACTion communities studied would have moved through ALL of the following steps within 2014 to early 2015, although I think the expectation is that the SPN-ACT will have done so, and maybe one of the original 4 communities. Any community, whether part of the formal evaluation or not could conduct a self-assessment.

The steps followed under the ACT on Alzheimer’s process are:
- convened a group that defines itself as a collective with some permanent members
- conducted an assessment involving others across sectors
- synthesized the information
- landed on priorities through a group process
- focused action through a written implementation plan, and
- carried through on one or more action item

There are three discernible phases that I anticipate ACTion Communities will move through:

(1) **Level 1 – Process evaluation focus** – This roughly corresponds to the convene, assess, and synthesize stages, and into the prioritization as well as setting up a plan for action – a written plan. The evaluation would focus on documenting what was done. Use of the ACT infrastructure, tools and technical assistance—essentially process measures in what and how things got done using the Toolkit.

(2) **Level 2 – Implementation evaluation focus** – This moves to a focus on implementing a specific written workplan with lead accountabilities for various action steps. This requires organized project management for a coalition working group that sees itself as a collective working toward defined goals. The evaluation focuses on process measures (what was done, when, did the group meet its’ milestones & markers), as well as on the group itself – they perform a self-assessment using a simple tool to help them identify areas of strength/need for support. The focus is also on identifying the effects of the output in some way—measures dependent on the focus of the effort.

(3) **Level 3 – Proximal outcomes, Community changes/impact** - What did the coalition accomplish in the timeframe that is seen as community impact? This may focus more on the creation of new relationships and shared work efforts across organizations, as well as the embedding of dementia capability components, such as training, services, policy, environmental changes, public education, ongoing core funding, etc. We would be looking for sustainability of effort if that is important, or the accomplishment of a goal (e.g., public awareness messages on Alzheimer’s now part of regular PSAs within the local cable or news channels). The community could look at a population health measure target such as CDC does with Healthy People 2020 etc. -- such as “By (time period) our community will have NO individuals with memory loss who are reported missing for more than 2 hours” (example). It would be up to the community to
come up with a health status measure that is meaningful to them. I could see assisted living facilities, for example, saying: "Our building will have NO elopements of persons with memory loss who get out of the building unsupervised."

**Sample Questions & Suggested Methods**

1. **Did the Community ACTion Team Engage the full 4 Step Process? How/What?** - What were the key markers in the Convening, Assessing, Synthesizing and Action planning steps for this Community? How did this Community move through these steps? (Descriptive with same participation data, documented largely by the coalition itself, checklist for the plan itself, key informant interviews provide richness, context)

2. **Did the Community move into to Implementation? How/What?** As the Community moved into the Implementation phase for their ACTion plan, what were the characteristics of the project management, communication, decision-making, and reporting/feedback that the coalition put into place? (Descriptive with some Likert scale self-assessment surveys, key informant interviews, review of documents)

3. **Did the Community set itself up for Evaluating its’ progress? How/What?** As the Community set up their ACTion plan, did it set for measures, a timeline, and a process for self-evaluating progress and results? (Descriptive, review of the plan, key informant interviews, checklist)

4. **Did the Community achieve its targets?** Was the result/impact documented in a systematic way such that another observer could replicate or verify the conclusions/assessment of results? (Use the Community marker and determine how met the mark)

5. **Did the Community report back to stakeholders?** Were the results reported back to the community at large and to other stakeholders? (Review communication, presentation documents, checklist)

6. **Did the Community determine sustainability, continuity or conclusion?** What is the natural or discernible end point for the Community ACTion – or how will it continue? How will it be sustained? (Descriptive with some Likert scale self-assessment surveys, key informant interviews, review of documents)

The self-assessment tool I have drafted measures/assesses some of the common elements that are typically found to be important in coalition, voluntary, community engagement work such as:

- clarity of vision/goals
- leadership
- project organization
- communication
- feedback loops
- quality of inputs (e.g., human resources, information, expertise, etc.)
- collaborative nature and process
- level of participation

*Paone & Associates, LLC*
To get through all three levels the Community would have implemented an action or two and kept it going through a coalition kind of way to its conclusion/result.

Comment re: coalition transitions across levels/phases - It seems to me that a critical phase/transition in the life of these ACT coalitions will be after they’ve picked a priority and defined a plan. There may need to be a reforming of the team/coalition with clear ownership and resources committed with strong leadership around the newly created ACTion Plan that is not the same composition of the organizations or individuals that facilitated the assessment. That would mean the evaluation process shifts focus too to a different set of players. So who moved successfully into level 2 and then level 3 and why/how they did so would be part of the evaluation.

Resources, References
The following figures, references and models provide helpful examples from the literature and from other community coalition efforts that have many parallels to the ACT on Alzheimer’s Community ACTion coalition/team work.


**Fig. 3.** Overview of the development of a community coalition.
Fig. 1. Community Coalition Partnership Programs for the Prevention of Teen Pregnancy evaluation logic model. This logic model was developed to assist in the evaluation of the CCPP and describes the process of building community capacity to prevent teen pregnancy. This model is based on a conceptual framework developed by the CDC in the early years of the program; however, it is not intended as a step-by-step description of what the partnership projects were expected to do. Although the logic model is presented as linear, it represents a process that is dynamic and sometimes circuitous.
Appendix K: ACTion Communities Interviews - Key Informant Protocol

Key Informant Question Set #1 - Focusing on an ACT on Alzheimer’s Community

We are interviewing the Community Coordinator and up to 3 other individuals from each selected community. Thank you for providing your insights, experience, lessons learned, and concrete information about the process your community used. This question set will guide the interview. If you are able to provide additional notes or information to the Evaluator, such as meeting minutes, records of attendance, and work-plans, etc., this will greatly help us correctly document the process, methods, and lessons learned from this effort. Please contact Deborah Paone, DrPH, MHSA – deborahpaone@paoneandassociates.com cell: 952-200-6810 if you have additional questions about the Evaluation. During this interview, (suggested time length is a little over an hour) we will ask you to describe/discuss:

(1) Assumptions – 5-10 minutes
   a. What were the starting assumptions you and key leadership within your community had about why this (Alzheimer’s disease and caregivers) is important in your community?
   b. Were you surprised by anything regarding assumptions you or others had made?
   c. Are there specific aspects of your community that you feel make it unique?

(2) Start-up – 5 minutes
   a. How did you begin embarking on this ACT on Alzheimer’s community engagement process?
   b. Who (people, organizations) were the important players involved?
   c. What resources were needed?

(3) Process & Methods for Convening – 5-8 minutes
   a. How did you go about forming & convening an ACTion Team? Did people reach out to their own personal and professional networks? Were notices put up—what worked best?
   b. How were the logistics handled—meeting locations, notes, materials, communication before/after?
   c. How was the broader community informed/involved? What was important in this?

(4) Toolkit & Process – 15 minutes
   a. Talk to me about the Dementia Capable Community Toolkit and guided process overall - what worked? What didn’t? At a broad level...
   b. Surveys - Did you use the surveys as they are and have community members gone out and survey those from different sectors? How did this go? Were there any barriers? Did the language/wording work? What would you change?
   c. Compiling the results – How are/were the results from your community surveys compiled/gathered together? What kind of picture emerged/is emerging from them?
   d. Interpreting the results/Analysis - How did ACTion team members work through the analysis phase to identify priorities? Did this involve small and large group activities? How was the community as a whole engaged?
(5) Action Planning – 10 -15 minutes
   a. Have you created one or more action plans?
   b. Are these written action plans with key activities, lead accountabilities, timeframes, and measures or milestones to gauge progress?
   c. Who are the leads in the Phase 4 action steps effort (organization and/or individual)? Is this different from those who led the assessment process?
   d. Are there other stakeholders in the community that you intend to engage?
   e. What is the measure and marker that will indicate your community is making progress toward its goals?
   f. How will you be evaluating the success of this?
   g. How visible is this effort in your community? What are the intentions around continued community involvement?

(6) Lessons/Findings (so far) - 15 minutes
   a. What are your lessons learned so far?
   b. What are the constraints/barriers? Can you give an example?
   c. What are the facilitators—what makes this easier? Can you give an example?
   d. What emerged/is emerging as top priority areas for your community?
   e. What were the major successes in this effort? Were there “side benefits” that resulted from this effort?
   f. What advice do you have for other communities starting this process?
   g. Do you have tips or suggestions for making this easier?

FINAL Question: Do you have any other observations that would be helpful to the ACT on Alzheimer's leadership regarding the process, methods, tools, and support to help ACTion Communities assess and increase their dementia capability?

Thank YOU!

Please call or email if additional material - Deborah Paone, DrPH, MHSA – deborahpaone@paoneandassociates.com cell: 952-200-6810
NOTE: We are interviewing the Community Coordinator and up to 2 other individuals from each selected community. Thank you for providing your insights, experience, lessons learned, and concrete information about the process your community used. This question set will guide the interview. If you are able to provide additional notes or information to the Evaluator, such as meeting minutes, records of attendance, and workplans, etc., this will greatly help us correctly document the process, methods, and lessons learned from this effort. Please contact deborahpaone@paoneandassociates.com if you have additional questions about the Evaluation.

Assumptions
What were the starting assumptions you and key leadership within your community had about why this (Alzheimer’s disease and caregivers) is important in your community?

Were you surprised by anything regarding assumptions you or others had made?

Are there specific aspects of your community that you feel make it unique?

Start-up
How did you begin embarking on this ACT on Alzheimer’s community engagement process?

Who (people, organizations) were the important players involved?

Did you notice any particular demographic segment (gender, ethnicity, culture, economic level, employment type, etc.) of your community that was missing? If so, who were they?

What resources were needed?

Were resource needs met?

Process & Methods for Convening
How did you go about forming & convening an ACTion Team? Did people reach out to their own personal and professional networks? Were notices put up—what worked best?

How were logistics handled—meeting locations, notes, materials, communication before/after?

How was the broader community informed/involved? What was important in this?

Was anyone missing?
How did you accommodate for differences within your audiences (e.g. gender, ability to hear, see, move around, culture, etc.)?

What strategies and/or tactics did you use that fostered participation by everyone?

**Toolkit & Process**

Talk to me about the Dementia Capable Community Toolkit and guided process overall - what worked? What didn’t? At a broad level...

Surveys - Did you use the surveys as they are and have community members go out and survey those from different sectors? How did this go? Were there any barriers? Did the language/wording work? What would you change?

Compiling the results – How are/were the results from your community surveys compiled/gathered together? What kind of picture emerged/is emerging from them?

Interpreting the results/Analysis - How did ACTion team members work through the analysis phase to identify priorities? Did this involve small and large group activities? How was the community as a whole engaged?

**Action Planning** –
Has your community created one or more ACTion plans?

Are these written action plans with key activities, lead accountabilities, timeframes, and measures or milestones to gauge progress?

Who are the leads in the Phase 4 action steps effort (organization and/or individual)? Is this different from those who led the assessment process?

Are there other stakeholders in the community that you intend to engage?

What is the measure and marker that will indicate your community is making progress toward its goals?

How will you be evaluating the success of this?
How visible is this effort in your community? What are the intentions around continued community involvement?

Have you noticed that a particular demographic segment or type of community member was missing?

If so, what are the intentions around involve those missing community members?
Lessons/Findings (so far)

What are your lessons learned so far?

What constraints/barriers did you experience? Can you give an example?

Did something or someone (facilitators/catalysts) improve the overall experience? Can you give an example?

What emerged/is emerging as top priority areas for your community?

What were the major successes in this effort? Were there “side benefits” that resulted from this effort?

What advice do you have for other communities starting this process?

Do you have tips or suggestions for making this easier?

Besides money, what other supports do you feel are needed for your ACTion community plan to be successful?

If you are making progress in building a demographically diverse dementia friendly community, what tips would you offer other groups who are starting out?

Is there anything unique about your community that you think would be important for someone reading this report to know and understand?

FOR AFFINITY GROUPS (Ethnic, Faith, Cultural, IDD)

In what ways do you feel that your affinity group will be better able to deal with Alzheimer’s and related dementia?

What unique experiences did you have that demonstrated the benefits of a culturally/affinity-based effort versus a broader geographic community-wide effort?

What if anything remains to be done?

FINAL Question: Do you have any other observations that would be helpful to the ACT on Alzheimer’s leadership regarding the process, methods, tools, and support to help ACTion Communities assess and increase their dementia capability?
Appendix L: Self-Assessment E-Survey for Community ACTion Team (Used by St. Paul Neighborhood Community ACTion Team)

Background:

This self-assessment tool was developed by Paone & Associates, LLC for Community Action Teams conducting a collective work effort to build dementia capability through using the ACT on Alzheimer’s Community Toolkit and process (see www.ACTonalz.org).

This self-assessment tool is based on the work of many researchers\(^2\) who have contributed to the understanding of how community coalitions work and what factors or characteristics enable progress and enhance effectiveness. These researchers have evaluated progress and provided ongoing support to many types of community coalitions.

ACT on Alzheimer’s Dementia Capable Community Team (Coalition) Work

The tool is intended to be used at key points in the life of the team/coalition, as that community team moves through its phases of work (at its own pace). In each phase, the players/participants may change—thus those who are completing the instrument would also change. Natural phases in the life of the ACTion communities include:

- After the convening, assessing, synthesizing and action steps have been completed [first phase to identify priorities]
- After the action planning around the top priority area(s) is done, with a workplan generated that includes action steps and leads, timeframe, and measures or markers for gauging progress [second phase to plan action]
- After the community has initiated one or more action steps, involving collective action by individuals and organizations in a coordinated way, and have finished/completed those steps [third phase to implement action]
- During a collective review or final evaluation process.

The best use of this tool is by the collective—to take stock and make mid-course corrections as a whole. Therefore the tool is simple to complete (envisioned as an online survey taking less about 5 minutes to complete) and the results should be aggregated and provided back to the whole group to discuss in a timely way.

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\(^2\) Researchers include: Francisco, Schlutz, Fawcett, Becker, Wandersman, Goodman, Butterfoss, Green, McKnight, Chervin, Katz, and others. See list of references in other evaluation materials provided.
St. Paul Neighborhood ACTion Community Self-Assessment (E-Survey)

[This group self-assessment tool was designed by Deborah Paone, Evaluator, to highlight the key elements of an effective coalition. It was distributed electronically and responses were aggregated and shared with the team.]

Instructions: Please take a minute and think about your experience with the SPN-ACT community action team and this St. Paul initiative focusing on building toward a dementia-capable community. List the time period that you are using to base your responses, as either from the beginning (February 2013 launch) to the present time, or in an alternate time period (e.g., the last 3 months or last 6 months, etc.) Also please indicate what your major activities have been with regard to the SPN-ACT team. Thank you for your participation in this group effort! - Deborah

Time Period for my review: 

My major activities with SPN-ACT: (check all that apply, or write in others)

☐ Attended the group meetings to learn
☐ Attended the group meetings to participate in the decision-making and work
☐ Conducted community surveys
☐ Analyzed information and provided feedback to group
☐ Brought in new group participants
☐ Marketed/built awareness for SPN-ACT and assisted in getting the word out
☐ Found funding source for the work

Other:

_________________________________________________________________________________

<table>
<thead>
<tr>
<th>Purpose/Focus</th>
<th>Yes Always</th>
<th>No Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>I am clear on the purpose for the St. Paul Neighborhood ACTion Community work.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organization/Structure of the Team’s work</th>
<th>Yes Always</th>
<th>No Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>The organization and structure supporting the team’s work for SPN-ACT is effective.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resources</th>
<th>Yes Always</th>
<th>No Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>a.) The SPN-ACT initiative has the right resources to accomplish its work.</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>b.) Resources available are used wisely.</td>
<td>6 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Always</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>--------</td>
</tr>
<tr>
<td>2.</td>
<td>Group Participation &amp; Decision-making</td>
<td>There is an openness and opportunity for involvement in meetings and decisions within the SPN-ACT initiative.</td>
</tr>
<tr>
<td>5.</td>
<td>Communication</td>
<td>a.) The existing communication channels and methods are sufficient in providing information about SPN-ACT activities and progress.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b.) I feel informed.</td>
</tr>
<tr>
<td>6.</td>
<td>Outreach</td>
<td>There has been good representation of people and organizations involved in SPN-ACT.</td>
</tr>
<tr>
<td>7.</td>
<td>Effectiveness</td>
<td>a.) The SPN-ACT work and activities are yielding plans that we can act upon together.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b.) I believe our collective work is having an impact.</td>
</tr>
<tr>
<td>8.</td>
<td>Collaborative Group Strength</td>
<td>This is a collaborative that does not depend on one person or organization for sustaining the momentum.</td>
</tr>
<tr>
<td>9.</td>
<td>Commitment</td>
<td>I am committed to staying involved in the SPN-Act work as it moves forward.</td>
</tr>
<tr>
<td>10.</td>
<td>Confidence</td>
<td>I am confident that our group will make progress in the next year toward our goals.</td>
</tr>
</tbody>
</table>

Appendix M: Area Agency on Aging Technical Assistance E-Survey (March, 2015)

The evaluator conducted an electronic survey of these AAA key contacts regarding their technical assistance to the 34 ACTion communities (N=12, 100% response rate). This provides both the questions and the responses.

Q1. How many ACTion communities are you assisting?

<table>
<thead>
<tr>
<th># Communities the AAA is assisting</th>
<th>Response</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>33%</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>42%</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>6+</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Q2. For each ACTion community you are supporting, choose the relevant characteristics that describe the community.

<table>
<thead>
<tr>
<th>Culturally diverse</th>
<th>Affinity Group</th>
<th>Primarily rural</th>
<th>Primarily urban</th>
<th>Primarily suburban</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>5</td>
<td>13</td>
<td>5</td>
<td>6</td>
<td>31</td>
</tr>
</tbody>
</table>

Q3. For each ACTion community your are supporting, indicate what types of support you’ve provided to them—in their community engagement process for ACT. Check all that apply.

- a. Understanding the ACT Initiative
- b. Orientation to the Toolkit
- c. Info on community resources
- d. Info on Alzheimer’s disease
- e. Help convening a team
- f. Facilitating meetings
- g. Help conducting surveys
- h. Help with analysis (of surveys)
- i. Putting together an ACTion plan
- j. PR or communications

<table>
<thead>
<tr>
<th>a</th>
<th>b</th>
<th>c</th>
<th>d</th>
<th>e</th>
<th>f</th>
<th>g</th>
<th>h</th>
<th>l</th>
<th>j</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>18</td>
<td>14</td>
<td>7</td>
<td>12</td>
<td>11</td>
<td>14</td>
<td>15</td>
<td>22</td>
<td>3</td>
</tr>
</tbody>
</table>
Additional comments:
- Attended all meetings (x2)
- Completed a survey with a provider
- Participated as part of data analysis group (x2)
- Participated in discussion on the objectives, priorities, action steps (x3)
- Helped with initial discussions about ACT and what it was
- Provided survey implementation training (x3)
- Offered help on several occasions but limited involvement
- Provided TA on ACT website
- Non-traditional communities needed much more assistance
- Team leaders have used us as a sounding board at many points along the way; especially related to identifying possible action steps under their priorities.

Q4. Given that each community is unique and on a different timeframe in the process, have you seen any tangible results to date in the communities you've been supporting? Describe. (Open-ended)

Summary:
- Progress on the phases/Toolkit process observed for many communities
- Many point to priority around raising awareness, community education
- Getting cross-sectors/disciplines together in one community has value
- Energy and commitment observed
- # of surveys completed, and analyses done that moved to action prioritizing and planning

Comments as written:
All 3 communities completed their analysis at the end of 2014, held their Action Team Meetings to identify the priorities, convened their community meetings in January and identified the goals for Phase IV application.
Roseville has submitted application for Phase 4 and received grant. Well on their way to implementing Phase 4 activities
Well-organized group with work groups for various pieces.
Great leadership from CENTRO staff, strong connection to community.
CENTRO - great job on completing 117 surveys - good process for selecting goal areas and activities.
Should be ready to submit application by deadline.
Each of these communities is at a point where they are determining the action they will be taking to implement their goals.
Sauk Rapids-Good Shepherd Community commitment is a definite asset to the initiative.
Becker-This community has a small, but talented Action Team and the passion to make it work.
The ACT effort has strengthened the relationships among gov’t, business, education, elders, & aging services providers for the benefit of Becker’s future.
All community assessments are showing priority goals in community education awareness, ways to support caregivers and providing printed materials about local community resources.
There has definitely been interest in raising awareness but I don’t believe the community has had any tangible results yet.
Great to get different disciplines together to discuss major impact of Alzheimer’s disease on a community. All plan and work together.
Yes - despite challenges, Phases 1 to 3 have yielded learning and good discussions among action teams in all communities.
Edina is well poised to have good results for action plans - no concerns there.
Hopeful for other three communities
Team members are energized and feeling empowered by the process. Physician champion has emerged for better screening/diagnosis.
Caregivers voices have been heard about the need for more respite.
Fair number of surveys completed, data input, analysis
Q5. Considering ALL of the communities you’ve supported (total) approximately how many hours per month have you spent (average/usual month) providing ACT on Alzheimer’s Dementia Capable Communities support?

<table>
<thead>
<tr>
<th>Range</th>
<th># Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 hours</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3-5 hours</td>
<td>3</td>
<td>28%</td>
</tr>
<tr>
<td>6-9 hours</td>
<td>6</td>
<td>55%</td>
</tr>
<tr>
<td>10-15 hours</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>16-20 hours</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>More than 20 hours/month</td>
<td>1</td>
<td>9%</td>
</tr>
</tbody>
</table>

Additional comments:
Most TA is being provided to the lead agency staff in Mankato/N. Mankato, Marshall & Redwood Falls is via email - I receive their team minutes.
Most recently I’ve recommended resources/activities related to their goals.
Timely communication and prompt responses to questions and/or concerns are essential.
Successful guidance and mentorship are time-consuming but worth the effort.
Lots of "windshield time" getting to them.
Have used Skype for Walker as a way to attend their meetings.
Time commitments ebb and flow - so this is average over last 9 months.
Much more intensive help needed for analysis phase with 3 communities, as well as selection process for Phase IV.
Probably have underestimated time, if I factor in travel time.

Q6. What resources (in addition to time) have you needed to provide the technical and other support to the communities? (Gave examples: information about the ACT collaborative; information needed about Collective Action; training on the Toolkit; refresher in meeting facilitation skills; access to ACT staff; travel; materials; supplies)… Open ended comments:

Connected multiple times with Emily to locate documents on the website, discuss approaches to communities who had struggles, and clarify expectations for Phase IV
TA on data analysis and use of matrix. Use website resources regularly.
The best and most effective method of support has come through the ACT learning collaborative workshops.
Team leads have felt it very beneficial to discuss and share experiences with other community leaders
I have had the resources I needed but the website is overwhelming because of the scope of information. Could we evaluate its efficacy? Could it be more user-friendly?
All of the above as well as sharing materials developed from the communities as they implement their priority goals.
Travel time.
Access to survey training materials Kathy Gilbride developed was very helpful - though not used in my communities.
Provided an approach to adapt.
All of the Act materials have been very helpful, and needed to "seed" information and ideas for action teams.
Would suggest investment in streamlined data collection/analysis tools - these were a challenge and time consuming for communities without time/skills.
Helped to have funds to pay for someone - but they are still clunky to use. Also, more explanation of how to transfer matrix data into priority worksheet, would be helpful.
Discussion among projects about how they made decisions about how they classified matrix data in that spreadsheet.
Interesting to note that while communities survey 13 sectors, most have selected awareness goals, and/or caregiver support goals - the other 11 sectors are less of a priority the first time around, and with the time constraint of 8-9 months.

ACT staff access, travel, toolkit training.
All of the above, except supplies.
Have appreciate the great support from ACT staff and the trainings organized.
Information about the ACT collaborative, training or clarification on the toolkit, helping the community understand "community engagement"
Access to ACT staff, travel and copies.
Just staying on top of the contents of the Toolkit.

Q7. What more would be helpful to you in your role of providing technical support to the ACTion communities? Check any that apply or write your own.

<table>
<thead>
<tr>
<th>Answer Choice Responses Given</th>
<th># Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>More background/orientation to the Toolkit</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Better understanding of principles of community engagement</td>
<td>3</td>
<td>27%</td>
</tr>
<tr>
<td>Time with other AAA mentors/key contacts to share learned experiences</td>
<td>4</td>
<td>36%</td>
</tr>
<tr>
<td>Repository of helpful tips, practices, advice for using and training others on the Toolkit and process</td>
<td>6</td>
<td>55%</td>
</tr>
<tr>
<td>Coaching or ideas on how to best support the local ACTion team Coordinator</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Opportunity for me to provide support via video stream/other live media - to cut down on my travel time</td>
<td>2</td>
<td>18%</td>
</tr>
<tr>
<td>Assistance with helping communities set up metrics/measures for evaluating their progress</td>
<td>5</td>
<td>45%</td>
</tr>
<tr>
<td>Help with PR/Communications</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Nothing, I had everything I needed</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Additional Comments:
The development of a tool for assisting with the analysis of the surveys. It is very labor intensive.
A Communication Plan template would be helpful.
Keeping up with ACT tools and resources on the website as it grows. Example: I have a difficult time accessing the ACT brochures and notecards easily and quickly.

Q8. How likely would it be for your AAA to provide support to NEW communities in your region who elect to use the ACT on Alzheimer’s Dementia Capable Toolkit beyond 2016?

<table>
<thead>
<tr>
<th>Response Choices</th>
<th># Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely</td>
<td>8</td>
<td>73%</td>
</tr>
<tr>
<td>Not Sure-Considering</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Unlikely</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Can’t Answer/Don’t Know</td>
<td>2</td>
<td>18%</td>
</tr>
</tbody>
</table>

Additional Comments:
We have not had internal discussions but I am sure we would consider depending on the resources we have and the other projects assigned.
I am aware of at least 2 communities that are considering including the ACT initiative in their LWAH proposals.
I am already doing this.
Our E.D. supports the initiative and sees the lasting benefits of establishing new relationships in each community.
We are bought in - and seeing more interest - but there will be limits to how much and how many communities we could work with on an annual basis without more TA staff/funds.
Defer this question to our AAA Director.
We have already been contacted by two more communities in our region that would like to move forward.

Q9. Is there anything else that you feel we should know regarding the technical support that you provide to ACTion Communities in your region? (Open ended)

Comments:
Successful communities had great leadership and those that struggled did not.
It has been a great opportunity to learn about the full ACT process. Has also created an opportunity to more directly engaged with work in the Latino community through CENTRO.
I've appreciated the learning experience in participating in the TA role.
Support form ACT staff is integral to our work and much appreciated.
Not at this time. We are able and willing to continue supporting and consulting with ACT or new communities.
ACT and Alzheimer's staff have provided great support for the project
This was my first time through this process. I was on a learning curve, too. I worked with very competent team leaders. It was sometimes hard to tell when/ if they wanted support. Often, they felt comfortable going right to state ACT staff with questions. Where I sensed they valued AAA participation most was in processing possible action steps under the priorities they identified. Providing TA to communities going forward will be easier now, having had this first experience.
Not that I can think of right now.
Not at this time.
No.
Nothing at the moment.
Appendix N: ACTion Communities’ Learning Collaborative, June 2015 – Post Session Survey (conducted by the Minnesota Board on Aging)

A post-session evaluation of participants in the June Learning Collaborative (N=20) provided information from ACTion community coordinators and team leads. The four questions shown address: (1) about what they thought were the top accomplishments of the ACTion communities, (2) what technical assistance was important, (3) what they would do differently, and (4) what more they wanted to do. This information was analyzed to capture the common themes and is shown in the four following tables. Note that the questions were open-ended, write-in, so that more than one response could be given by the participants. In many cases, the participants offered several comments for each question.

Q: How would you describe your top 5 accomplishments?

<table>
<thead>
<tr>
<th>Themes that emerged:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community engagement; involvement of people, organizations, sectors</td>
<td>17</td>
</tr>
<tr>
<td>Education and community awareness-building actions</td>
<td>7</td>
</tr>
<tr>
<td>Action plan development and follow-through</td>
<td>6</td>
</tr>
<tr>
<td>Identifying the community’s top needs</td>
<td>4</td>
</tr>
<tr>
<td>Dementia Friends training</td>
<td>3</td>
</tr>
</tbody>
</table>

Q: What kinds of technical assistance do you think a grantee (new program site) would need and how much of it?

<table>
<thead>
<tr>
<th>Similar comments were grouped as follows:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA support and guidance as they have done</td>
<td>7</td>
</tr>
<tr>
<td>Help with marketing, communications</td>
<td>4</td>
</tr>
<tr>
<td>Admin support, including with survey data</td>
<td>3</td>
</tr>
<tr>
<td>Specialized knowledge, e.g, health care, policy/advocacy, Alzheimer’s info</td>
<td>3</td>
</tr>
<tr>
<td>Evaluation</td>
<td>2</td>
</tr>
<tr>
<td>Community organizing strategies</td>
<td>2</td>
</tr>
</tbody>
</table>
Q: Knowing what you know now, describe what you would do differently if you could do it all over again.

Table x. **What Would Do Differently (N=20)**  
[note that individuals could list more than one thing]

<table>
<thead>
<tr>
<th>Similar comments</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orient more volunteers, get more involved at the beginning, more partners</td>
<td>7</td>
</tr>
<tr>
<td>Less time on surveys and/or different surveys</td>
<td>7</td>
</tr>
<tr>
<td>Better foundation/understanding of ACT and more peer learning before launch</td>
<td>3</td>
</tr>
<tr>
<td>Grant writing, funding</td>
<td>2</td>
</tr>
<tr>
<td>Too many priorities chosen – so would choose fewer</td>
<td>1</td>
</tr>
<tr>
<td>Would research what options we could consider more before deciding</td>
<td>1</td>
</tr>
<tr>
<td>No changes</td>
<td>3</td>
</tr>
</tbody>
</table>

Q: What work would you like to accomplish if you had additional time and/or funding?

Table x. **What to Accomplish Next (N=20)**  
[note that individuals could list more than one thing]

<table>
<thead>
<tr>
<th>Similar comments</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create more services and supports for persons with AD and their caregivers, e.g., meaningful engagement, caregiver outreach, adult day, etc.</td>
<td>13</td>
</tr>
<tr>
<td>Community educational and awareness efforts, e.g., films, conferences, etc.</td>
<td>4</td>
</tr>
<tr>
<td>Additional partners, sectors</td>
<td>3</td>
</tr>
<tr>
<td>Funding, sustainability</td>
<td>3</td>
</tr>
<tr>
<td>Marketing, visibility, PR</td>
<td>2</td>
</tr>
<tr>
<td>Culturally relevant resources and information</td>
<td>1</td>
</tr>
<tr>
<td>A paid community resource person</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix O: Proposed Community Self-Assessment, Post “Phase 4”

This self-assessment instrument was designed to be used by ACTion communities following their “Phase 4” action steps. It was not utilized, but is offered as an example.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes, Completely</th>
<th>Most of Time</th>
<th>Sometimes</th>
<th>Few/Not Often</th>
<th>None/Never</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall ACTion Community Purpose &amp; Goals</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, we achieved our ACT on Alzheimer’s Dementia-Capable community purpose and goals</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Organization/Structure of the ACTion Team and Work</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The way we structured the ACTion team and the way we conducted the work was effective.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Resources</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.) We had the right resources to accomplish our work.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b.) A few people and organizations provided most of the resources.</td>
<td>7 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Workplan &amp; Activities</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.) We followed through on our workplan as written.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b.) We overcame barriers we faced.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Communication</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.) The communication channels and methods were sufficient to make progress and continue community engagement.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>b.) I felt informed as a member of the ACTion community team.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Outreach</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>We were able to reach our community of interest.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>7. Timeframe, Progress</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.) The timeframe (amount of time we had) for our collective action was sufficient.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>b.) We have ways to measure our progress.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>8. Evaluation, Impact</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.) We have defined measures to show change or impact in the community.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Commitment</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>We have a core group of individuals and organizations that have committed themselves to staying involved in this ACTion work.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Confidence</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We are confident we will make progress in the next few years toward building dementia-capability within our community.</td>
<td>5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix P: Caregiver Focus Group Question Set

ACT on Alzheimer’s Evaluation – Caregiver Focus Group Confirmation

Hello! Thank you for agreeing to participate in our caregiver focus group/discussion to capture insights from knowledgeable caregivers like yourself. Each person has been selected and invited by the ACTion Community team Coordinator (from your ACT on Alzheimer’s community) as a person who has been involved in the ACTion community meetings/work and also as a person with experience in caring for a person with Alzheimer’s disease or dementia in your community. So we will tap into that knowledge and experience. Several communities are represented by the group of caregivers who will attend that day.

I am Deborah Paone, Evaluator for ACT on Alzheimer’s overall—and have been involved in the initiative as a volunteer since June of 2011 and also now a consultant.

Caregiver Focus Group – May 7th, 2015 from 2:00-3:30
(Introductions at 2:00 and start by 2:10 with finish by 3:15 and wrap up if any lingering questions)

Location: Edina Library, 5280 Grandview Square, Edina, MN 55436 (see attached directions location info)

Facilitator & Key Contact: Deborah Paone, Evaluator - Phone: 952-200-6810

The focus areas for our group discussion will include such topics as:

1) What do you see is different in your community as a result of the ACT on Alzheimer’s Action team work? (Give an example of a “before” and “after”)

2) Are caregivers supported differently now in your community? How? How can you tell changes have happened?

3) In your experience, have you had the access and availability to “meaningful and dementia-specific resources” that you and your partner wanted/needed?

4) What was your pathway in your community to getting the resources/help you needed? Do you think this pathway would be different for newly diagnosed individuals now?

5) ACTion communities would like to measure impact on caregivers and persons with dementia related to the services and programs and care available in their community. How do you think communities can best measure this impact? How would you like your community to do that?
Appendix Q: Leadership Group Chairs Telephone Interviews - Key Informant Instrument

Key informant interviews were conducted between late October and December of 2014 with the ACT Leadership Group Chairs or Co-Chairs (N=10). Interview questions were mailed prior to the interview. All were conducted by telephone. The interviews generally took 1 hour each. The focus of the questions was on the outputs/results that had been achieved by the initiative and by the Leadership Group, lessons learned about implementation, what more needed to be done, and how to measure results. The evaluator typed responses from each key informant and shared them with that individual to ensure accuracy and completeness. Most informants added a few additional comments, but changes were minimal. The responses were analyzed for common themes. A report capturing both individual comments and common themes was provided as an evaluation report and made available to all.

Q1: Overall, how would you evaluate the work of ACT?

Q2: Regarding your Leadership Group work, what were the top outputs of this Leadership Group?

Q3: What have you learned works in terms of implementation or dissemination? (If your group was not responsible for implementation or dissemination of a particular work product, then comment on ACT as a whole.)

Q4: How would you measure results and impact?

Q5: Do you have ONE example related to a change you have seen — that you can share?

Q6: Where do things go from here?

Q7: What are your overall lessons learned for the ACT on Alzheimer's initiative as a whole?
Overview
We have carefully documented the implementation experience and lessons learned of several ACTion communities. We have some information from the perspectives of these communities themselves.

1. You have had the role of fostering the process across all of the communities. From your perspective, what are the key take-aways you have learned about what it takes for communities to engage in collective action around this goal—creating dementia-friendly communities?

2. As an overall assessment of the 34 ACTion communities’ experiences here in MN (starting in 2013 to the present day 2015)—Talk to me about the Dementia Capable Community Toolkit and guided community engagement process overall—

   What worked? What didn’t? At a broad level…

   a. Any particular successes stand out (by community or with a specific approach)?

   b. Any particular challenges stand out (by community or given a component of the Toolkit that proved difficult for more than one community)?

   c. With regard to the successes—how could these be “bottled” for others to take advantage of this approach to accelerate their own success?

   d. With regard to the challenges—how could these be better addressed to flatten out the “bumps” or help communities be more prepared to address the challenge?

3. There are four phases in the Toolkit for ACTion communities to follow:
   - Convene –
   - Assess –
   - Analyze –
   - Action Plan -

For those communities who have reached Phase 4—Action plan—what is the next step following that work—where are communities going from there? What are they asking for to
help them continue or sustain this work—or move to the next phase around building a dementia-friendly community?

4. Drawing from the literature, we see that having a structure for collective action, strong leadership, technical support/guidance, effective communication/feedback loops, and specific evaluation plan to measure progress/impact are five components that coalitions need. Can you comment on each one of these 5 components from an overall perspective across the 34 communities you’ve observed?
   1- Structure/Plan
   2- Leadership
   3- Technical support
   4- Communication
   5- Evaluation/measurement – to turn into continuous improvement – e.g., Plan Do Check Act

5. What kind of overall infrastructure is needed—the behind the scenes work and resources—to guide this kind of collective action process across a state or even a larger region? What are key components to that infrastructure?

6. Technical support and guidance around the Toolkit and process was provided by the AAAs. Can you comment on the methods, strategies, resources deployed by the AAAs that seemed to be most effective in supporting the ACTion communities?

7. Anything else to add for us to capture your wisdom/knowledge around the experience in MN to engage and support 34 ACTion communities?
Appendix S: Implementation of Health Care Provider Practice Tools – Case Example Key Informant Question Set

1) Describe the implementation activities since January 2014--so about the last 18 months--within your organization (briefly/summary version).

2) What practice tools were/were not implemented? How far did this implementation go throughout your network of providers/clinics?

3) What were the successes?

4) What were the barriers?

5) Implementation science research typically identifies the following as key factors in implementation success. Can you comment on each of these briefly with regard to this implementation experience within the organization?
   a. Internal Champion(s)
   b. Visible Leadership Support
   c. Perceived Value of the Program/Practice
   d. Program/Practice-to-organization "Good Fit"
   e. Potential financial incentives/funding
   f. Robust Technical support/training resources
   g. Culture/Climate

6) Considering this organization's implementation experience what would you say where the top lessons learned regarding implementation of ACT practice tools?

7) What are baseline "readiness" characteristics or criteria?

8) What were successful strategies?

9) What evidence of effectiveness can you offer as a result of the implementation?

10) What advice would you give to others seeking to implement these practice tools?
Appendix T: Health Summit Agenda, 2015

Health Leadership Summit on Adoption of Optimal Dementia Care Practices

Thursday, February 26, 2015- 7:30 a.m.-12:00 p.m.

University of Minnesota, St. Paul Student Center
North Star Ballroom -- 2017 Buford Ave., St. Paul, MN 55108

MEETING AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 a.m.</td>
<td>Check In and Breakfast</td>
</tr>
<tr>
<td>8:00 a.m.</td>
<td>Welcome and Acknowledgment of Champions for Work — Marvin J. Lofquist, Ph.D., Chemistry Associate Dean of the Weinberg College of Arts &amp; Sciences at Northwestern University in Evanston, Illinois – Retired Olivia Mastry (Executive Co-lead, ACT on Alzheimer’s)</td>
</tr>
<tr>
<td></td>
<td>• Why do this and why do it now?</td>
</tr>
<tr>
<td></td>
<td>• Who has come together to support adoption effort?</td>
</tr>
<tr>
<td></td>
<td>• What do we hope to achieve today?</td>
</tr>
<tr>
<td></td>
<td>• What led up to the work?</td>
</tr>
<tr>
<td></td>
<td>Introductions (participants and speakers)</td>
</tr>
<tr>
<td>8:30 a.m.–9:30 a.m.</td>
<td>Setting Context</td>
</tr>
<tr>
<td></td>
<td>• Environmental Landscape and the Case for Adopting Optimal Dementia Practices — Jennifer Lundblad (President and CEO, Stratis Health), Cally Vinz (VP of Clinical Projects and Strategic Initiatives, Institute for Clinical Systems Improvement)</td>
</tr>
<tr>
<td></td>
<td>• ACT on Alzheimer’s Provider Tools and Training Orientation — Terry Barclay, PhD (Clinical Director, HealthPartners Neuropsychology), Michelle Barclay (Executive Co-lead, ACT on Alzheimer’s), Steve Waring, PhD (Senior Research Scientist, Essentia Institute of Rural Health), Nancy Lee (Sr. Project Consultant, Department of Human Services, Aging and Adult Service Division/ Minnesota Board on Aging)</td>
</tr>
<tr>
<td></td>
<td>• Perspectives from a Caregiver — Carol Shapiro, Spousal Caregiver and ACT on Alzheimer’s Community Volunteer</td>
</tr>
<tr>
<td></td>
<td>Questions and Answers</td>
</tr>
<tr>
<td>9:30 a.m.</td>
<td>Discussion and Brainstorming:</td>
</tr>
<tr>
<td></td>
<td>1) Issue identification: What are the principal barriers unique to adoption of optimal dementia practices?</td>
</tr>
<tr>
<td></td>
<td>2) Organizational Priorities: Given what we have talked about today, the barriers we have discussed, and what you now know is available to you from ACT on Alzheimer’s, what would it take for your organization to make dementia a priority within the context of chronic disease management?</td>
</tr>
<tr>
<td></td>
<td>3) Community Strategies: At a community level, what would support your organization in making progress on this issue?</td>
</tr>
<tr>
<td></td>
<td>4) Next Steps: What should/could we do next to support the spread of optimal dementia practices in MN?</td>
</tr>
<tr>
<td>11:30 a.m.</td>
<td>What Did We Learn; Immediate Next Steps, Future Follow Up, Willingness to Take Action</td>
</tr>
<tr>
<td>12:00 p.m.</td>
<td>Adjourn</td>
</tr>
</tbody>
</table>
Appendix U: Health Equity Leadership Group Call to Action

Preamble

The promise of our nation is that all men are created equal and that we have certain unalienable rights that include life, liberty and the pursuit of happiness. This promissory note throughout our history has been compromised by the concurrent growth of structural racism, discrimination, inequality of opportunity, and lack of access to resources and services to those who are marginalized and disenfranchised because of their race, ethnicity, culture, language, sexual orientation, gender identity, mental illness, sensory, intellectual, or physical disability, economic status, or geographic location. The lack of equity [social, health, environmental] impacts the health and well-being of all and creates health disparities. On behalf of people living with Alzheimer’s in all communities, we must act.1

Health Equity Call to Action

Alzheimer’s disease touches every community. According to the Alzheimer’s Association, 5.2 million people in the United States are known to be living with the disease. As we explore pathways to reduce the economic, social, and spiritual impact of Alzheimer’s, we know that some groups are at greater risk of developing the disease. Two cases in point: Data of the Alzheimer’s Association indicates that the prevalence of Alzheimer’s is disproportionately higher for the African-American and Latino communities;2 and a study by Johns Hopkins University states that persons who are hard of hearing are at greater risk of developing the disease.3 These facts indicate a health disparity.

The health disparity of Alzheimer’s is the health equity call to action of ACT on Alzheimer’s.4 As we act to address Alzheimer’s disease and other dementias, our efforts will be enhanced by the following equity-based vision, rationale, principles, and practices and we will work more usefully together.

Vision: “An inclusive health and social system that treats people equitably and creates conditions in which all people can achieve optimal health ...” [National Partnership for Action to End Health Disparities].

Rationale: The context and content of our work is rooted in addressing the social determinants of health and the alignment of priorities, policies, practices and resources toward achieving health equity and reducing/eliminating Alzheimer’s-related health disparities.

1 This preamble speaks to the values and principles the Health Equity Leadership Group seeks to embed in all the work of ACT on Alzheimer’s.
2 Alzheimer’s Association, 2014 Alzheimer’s Disease Facts and Figures. African-Americans are about twice times more likely and Latinos about one and one-half times more likely to have Alzheimer’s and other dementias compared with white adults.
3 Study by Johns Hopkins and the National Institute on Aging, published in the Archives of Neurology, February 2011.
4 Minnesota ranks, on average, among the healthiest states in the nation. But the averages do not tell the whole story. Too many people in Minnesota are not as healthy as they could and should be, and the health disparities that exist are significant and persistent and cannot be explained by bio- genetic factors. Minnesota has these disparities in health outcomes because the opportunity to be healthy is not equally available everywhere or for everyone in the state. [MDH 2014 Advancing Health Equity Report to the State Legislature]

August 27, 2014
Principles
We will:
• Be fair and just.
• Work on our own intercultural competence.
• Be open to the perspectives of those whose world lens may be different from our own.
• Recognize, honor and respect the heritage, value and contributions of diverse communities.
• Be inclusive and transparent in our decision-making process.
• Transform the rhetoric of diversity into the template of inclusiveness as we reflect the racial, cultural, language, and gender diversity of the populations touched by ACT on Alzheimer’s.
• Be a champion for ethnic and cultural competency.
• Be engaged in the efforts of the communities we are trying to engage.
• Share findings with communities and involve them in decisions impacting their lives.

Practices
We will:
• Build equitable partnerships with communities disproportionately affected by Alzheimer’s and who are underserved.
• Embrace collaboration and synergy. [HHS Action Plan to Reduce Racial and Ethnic Health Disparities; and MDH 2014 Advancing Health Equity Report to the State Legislature, 2014]
• Expand health access, data collection, and the use of promising practices and evidence-based interventions contributing to health equity for vulnerable populations that are characterized by income, geography, disability, sexual orientation or other important characteristics. [HHS Action Plan to Reduce Racial and Ethnic Health Disparities]
• Promote integrated approaches, evidence-based programs and promising practices to reduce disparities and stigma. [HHS Action Plan to Reduce Racial and Ethnic Health Disparities]
• Apply the Health in All Policies\(^3\) approach in the context and content of our work.
• Continuously assess the impact of all policies and programs on racial, ethnic and other key disparities.
• Expect and achieve clinical excellence, support, inclusion, compassion and good stewardship of financial resources for everyone touched by Alzheimer’s disease.
• Promote robust and intentional public engagement that actively informs and involves people and communities.
• Develop and implement communication and promotion strategies that are culturally appropriate.

Our success is premised on being consistent in applying and implementing our principles while sustaining our efforts to build and maintain dementia-friendly communities.

Roles: We believe that we all [ACT on Alzheimer’s organizations, leadership groups, community action teams, and staff] have a role in building health equity as we address Alzheimer’s and other dementias. The Health Equity Leadership Group’s role is to:

\(^3\) Healthy Minnesota 2020 Framework for Health in All Policies (HiAP)

August 27, 2014
• Champion inclusiveness, equity, and transparency
  o Develop a process for the Leadership Council to enhance inclusiveness and cultural sensitivity
  o Develop a process for engaging leadership groups and clinical providers to discuss necessary changes to provider practice tools
  o Provide learning support for action teams to aid them in becoming more inclusive and culturally sensitive – an initial building block in laying the foundation for health equity
• Be a resource and guide in the development and presentation of information offered through the learning collaboratives for action communities
• Assist our overall collaborative in aligning priorities and actions with principles in the preamble as we aid in the development of policy and strategy

Health Equity Lens in ACTion
As we work on building cultural competence and health equity in our activities to address Alzheimer’s, we should ask ourselves the following:
• What lens am I looking through?
• Am I listening? Hearing? Communicating effectively?
• Who needs to be involved in the process? Are we engaged “with” the community?
• Is this process inclusive?
• How will the community benefit? Are needs being met?
• What has been the community’s experience? Am I [Are we] prepared?
• What will be the outcome? How will “success” be defined?
• Is it sustainable?

Background, Terms, Definitions
Health equity – Health equity means that all people have the opportunity to attain their highest level of health possible. To do so, people must have: access to political, economic and educational opportunity; the capacity to make decisions and effect change for themselves, their families, and their communities; and social and environmental safety in the places they live, learn, work, worship and play. For people in Minnesota of American Indian, African American, Latino, Asian, Pacific Islander, Middle Eastern, and African descent, these opportunities are limited by structural inequities that are rooted in historical and individual racism, as well as inequities due to culture, language, sexual orientation, gender identity, mental illness, intellectual or physical abilities, hearing or other sensory differences, economic status or geographic location, whether intended or not.

Social determinants of health – Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. [HHS Healthy People 2020]

Structural racism – Structural racism is the normalization of an array of dynamics — historical, cultural, institutional and interpersonal — that routinely advantage white people while producing cumulative and chronic adverse outcomes for people of color and American Indians and other people who experience inequitable treatment.

August 27, 2014