



Survey of Participants as “Early Adopters”

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Executive Summary

ACT on Alzheimer's is a volunteer-driven, statewide collaboration focusing on five goals: (1) sustain caregivers, (2) raise awareness and reduce stigma, (3) invest in promising approaches, (4) increase detection and improve care, and (5) equip communities. The initiative launched in June 2011.

A survey of collaborative participants was conducted between February and May, 2014. The survey's purpose was to capture information on how the ACT on Alzheimer's initiative impacted individuals who have been active in it—as participants in the Leadership Groups, Leadership Council/Executive Committee, Management Steering Committee, and other sub-Committees or working groups. It is assumed that these participants are “early adopters” who are using the ACT-developed tools and resources personally, professionally, or both.

The survey was mailed to 159 people and 92 responded (58% response rate). Results showed that most respondents had been involved for two years or more and 91% were still involved as of the survey. Most had served on Leadership Groups or Committees (84%) and participated in various other initiative activities.

Many were using the ACT tools and resources both personally and professionally. The website was used most frequently (by 74% of respondents). Most respondents indicated strong commitment to the initiative and were clear about its purpose.

Overall, responses around impact to date were largely positive. The respondents indicated strong support (66%) for the statement that this initiative had *raised awareness of the issues and needs of persons with Alzheimer's disease (AD) and their care partners in MN*. There was also strong support (62%) for the statement that ACT had *assisted communities to build capacity and increase their support of persons with AD and caregivers*. However, a sizeable minority (38%) of the respondents said they did not know whether ACT had *enhanced skills of clinical professionals practicing in the field for detection and management of Alzheimer's disease*, or if ACT had *enhanced coordination and continuity of care for persons with AD* (35%). The latter two statements focus on disease detection and management and the follow-up from the clinic setting to other settings and to community resources.

Respondents were asked to write in comments as to what they thought was the most valuable aspect of the ACT on Alzheimer's work. Most frequent responses were about building awareness and the collaborative nature of the work itself. Many also said the tools were very important and had been valuable, particularly in moving toward a standard or consistent approach.

This report provides information from the survey findings that yields a solid picture of engaged individuals committed to the *ACT on Alzheimer's* initiative and who have provided time, content expertise, and energy toward developing and using the resources generated by the initiative, as well as bringing others into the work and making the work known.

Survey Purpose

The purpose of this survey was to capture information on application of the *ACT on Alzheimer's* initiative in the lives of individuals who have been active in it—as participants in the Leadership Groups, Leadership Council/Executive Committee, Steering Committee, and other sub-Committees or working groups. We call these individuals “early adopters,” a term used by Everett Rogers in defining different phases of diffusion for innovation (Rogers, 2003).

The individuals surveyed were very involved in the *ACT on Alzheimer's* initiative—which was designed to function as a grassroots coalition for collective action around five defined goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer's disease and related dementias (ARD). The goals include: (1) sustain caregivers, (2) raise awareness and reduce stigma, (3) invest in promising approaches, (4) increase detection and improve care, and (5) equip communities. The initiative was launched in June 2011.

The individuals surveyed discussed the challenges and shared ideas about addressing the issue of stigma and lack of awareness in the general public about the disease. They also discussed the issues of detection, quality and nature of follow-up after a diagnosis, how care coordination can be linked to community resources and caregiver education, and caregiver support. They created tools and materials, including educational curriculum, provider practice tools, a “Dementia-Capable Community Toolkit,” and other resources. They worked with a consultant group to create and test an economic model around one evidence-based program focused on Alzheimer's caregivers. They rebranded the initiative and worked on the messages and communication to raise the visibility of initiative—either in front or behind the scenes. They also helped create a robust website that serves as a repository and communication vehicle for the initiative and to the general public.

These individuals were also involved in advising state and Area Agency on Aging staff about dementia content in the health care home certification standards, health care home learning collaborative sessions, Senior LinkAge Line® training, and www.MinnesotaHelp.info® database components. They also helped foster the dementia-capable health care home initiatives within the state, such as through the Community Services/Service Development request for proposals.

It is assumed that these participants are a set of “early adopters” who are using the tools and resources either personally or professionally, or in both ways. Through their actions of volunteering their time and expertise to the initiative they have demonstrated their commitment to the issue. We assume they are the most knowledgeable individuals in the State of Minnesota regarding the work and resources of *ACT on Alzheimer's*, and therefore, most likely to utilize the resources and materials generated by this effort.

The information probed in this survey focused on the following:

- Length of time the person had been involved with the *ACT of Alzheimer's* initiative
- Type of involvement
- Time commitment
- How the person is using the work and resources of ACT
- What resources he/she is using
- The person's perspective about the group itself (e.g., structure, cohesion, communication, representation, activities)
- The impact of the effort to date
- The person's opinion about the most valuable aspect of the initiative to date

Methods

The survey was created as a SurveyMonkey® instrument by Deborah Paone¹ of *Paone & Associates, LLC*, providing healthcare and aging services research. She has authored this report.

A URL link was provided to participants to click on and participate. There were eleven questions in the survey. The URL link was included in an electronic communication to all individuals who are listed on any of the groups organized through *ACT on Alzheimer's*.

Individuals were notified about the survey by Mary Ek, Project Manager, *ACT on Alzheimer's*. The first communication to all members of the Leadership Groups and Committees occurred in February where the survey was included in a longer message that included other updates for the groups. This request included a message from the Leadership Council chair, Mary Lenard, asking for response to the survey. This generated 70 responses out of 159 people (the author of the survey excluded herself from the pool of respondents).

A second request was sent in early May under the subject heading: "Plea from Olivia Mastry, Re: Survey response for *ACT on Alzheimer's*." This message focused solely on the Adopter Survey and generated an additional 22 responses for a total of 92 responses, or 58% response rate.

The first respondent completed the survey on February 8 and the last respondent completed the survey on May 8. The time to complete the survey online ranged from a low of 2 minutes to a high of 20 minutes. Generally, respondents took between 5 and 9 minutes to complete the survey. The survey provided an option to include the respondent's name. Thirty people did so.

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*.

Findings

Length of time & current involvement

Most respondents had been involved for two years or more. Half (46 people) had been participating since November 2011 or earlier and another 22 people had been participating about two years, for a total of 68 individuals or 74%. Only 3 people had been involved six months or less. Most (91% or 84 people) said that they were still involved in *ACT on Alzheimer's*. Eight people said they were no longer involved.

Type of involvement

Everyone responding indicated that they were or had been involved in a variety of activities for the ACT on Alzheimer's effort. This included:

- Participating in one or more of the Leadership groups or committees (84%)
- Building awareness for the effort and getting word out to colleagues (61%)
- Developing one or more of the ACT tools or resources (61%)
- Participating in educational outreach, such as in conferences or workshops (35%)
- Working on the Dementia Capable Communities Toolkit (34%)
- Bringing in new participants to be part of the ACT collaborative (34%)
- Developing content or giving feedback on the ACT website (29%)
- Providing advice or participating “behind the scenes” for the ACT collaborative (29%)
- Participating as a part of a specific ACTION community using the Dementia Capable Communities Toolkit (22%)

In addition 10-11 people responded that they had provided input into the *Senior LinkAge Line*[®] and caregiver consultants training, the MinnesotaHelp.info[®] resource, and/or the economic modeling work. Nine people responded that they had worked on the communication and visibility efforts for ACT, including helping to identify the logo and branding, and five people said that they assisted with attracting funding sources.

Time commitment

The following question was posed regarding the amount of time people spent on ACT activities:

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).

Check the category that most closely represents your level of involvement in terms of time commitment for the ACT work:

- | | |
|---|--|
| <input type="checkbox"/> Extensive – more than 8 hours per month | <input type="checkbox"/> Modest – between 4 and 12 hours a quarter |
| <input type="checkbox"/> Moderate – between 4 and 8 hours per month | <input type="checkbox"/> Light – about an 1 hour a month |
| | <input type="checkbox"/> Minimal – a few hours a year |

The most frequent response option chosen was that their time commitment was “modest.” Thirty-five percent (32 people) said they spend between 4 and 12 hours per quarter (up to 4 hours a month). However, about one-fifth of these respondents (19 people) said they had spent more than 8 hours per month on the effort (“extensive”), and another 22% (20 people) said they spent between 4 and 8 hours per month (“moderate”). The remaining 23% (21 people) said they spend from 1 hour a month to just a few hours a year.

How the person is using the ACT work & involvement

Individuals were asked how they are making use of their participation in the ACT on Alzheimer’s collaborative. They were given response options and an open-ended text box to add additional responses and describe their answers more completely. Individuals could select multiple options—categories were not mutually exclusive.

Table 1 provides the responses.

Table 1. How I am using ACT on Alzheimer’s work	%
In my personal life, with family, friends, or self	42%
Professionally - I am using the information strategically, with leadership within my organization	52%
Professionally - I am championing the use of one or more of the practice tools or resources internally	46%
Professionally - The resources and tools from ACT are being used to review current practice and to educate staff	35%
In my Community - I am using the resources to raise awareness about Alzheimer’s disease within my community	41%
I am not making use of participation	1%

What resources are being used

Many individuals responded that they are/had been using more than one of the ACT resources. The resource reported as being used by most (74%) of this group was the ACT website. The next most frequent resource used was the Dementia Capable Communities Toolkit (41%) and the “After a Diagnosis” consumer brochure (39%). Table 2 provides detail on the resources used.

Table 2. Resources Used	%
Care Coordination Tool	34%
Community Based Service Provider Practice Tool	26%
EMR Decision Support Tool	22%
"After a Diagnosis" consumer brochure/resource	39%
Mid-Late Stage Tool	16%
Dementia Training for Direct Care Staff (grid/table)	25%
Dementia Curriculum Modules	27%
Dementia Capable Communities Toolkit	41%

Reports on the www.ACTonAlz.org website (please name report)	10%
PowerPoint presentations about ACT work	35%
Website (general info about ACT)	74%
Social media tools (YouTube, Facebook, Twitter)	14%
Links to other resources found on the ACT website	28%

Perspective about the group and the collective action process itself

Respondents were asked to consider the structure and process of the *ACT on Alzheimer’s* collective itself, and to choose from pre-set response options to indicate how they had experienced the group—probing a set of elements that have been shown to be important in the research literature on group functioning and cohesion. This is the question that was posed:

The ACT on Alzheimer’s[®] collaborative is structured as a voluntary, collective effort—not owned by one organization. As such, how the collective functions is important for achieving goals. Please consider how you have experienced this unique collaborative. Choose the response for each question that most closely matches your opinion/experience to date.

[Ratings used: Yes, Always / Most of the Time / Sometimes / Not Usually / No, Never]

Statement
Purpose - I am clear on the purpose and goals of ACT on Alzheimer's
The structure supporting this work by participants has been effective
This collaborative has the right resources to accomplish its work
Resources are used wisely
There is an openness and opportunity for involvement in meetings
The existing communication methods are sufficient to provide information about progress
I feel informed about the ACT on Alzheimer's work
There has been good representation of people and organizations involved
The activities are yielding useful resources and plans that we can act upon together
I believe our collective work is having an impact
This is a collaborative that does not depend on one person or one organization for sustaining the momentum
I am committed to staying involved in the ACT work as it moves forward
I am confident that ACT on Alzheimer's will make progress in the next year toward stated goals

The response options given and the results are shown in Table 3.

Table 3. ACT collaborative structure, function, and process					
Statement	Yes, Always	Most of the Time	Sometimes	Not Usually	No, Never
Purpose - I am clear on the purpose and goals of <i>ACT on Alzheimer's</i>	63%	33%	4%	0	0
The structure supporting this work by participants has been effective	48%	50%	2%	0	0
This collaborative has the right resources to accomplish its work	41%	46%	13%	0	0
Resources are used wisely	63%	33%	4%	0	0
There is an openness and opportunity for involvement in meetings	70%	26%	2%	1%	0
The existing communication methods are sufficient to provide information about progress	48%	43%	8%	1%	0
I feel informed about the ACT on Alzheimer's work	52%	43%	4%	1%	0
There has been good representation of people and organizations involved	60%	32%	8%	0	0
The activities are yielding useful resources and plans that we can act upon together	61%	32%	7%	0	0
I believe our collective work is having an impact	64%	29%	8%	0	0
This is a collaborative that does not depend on one person or one organization for sustaining the momentum	43%	40%	15%	1%	1%
I am committed to staying involved in the ACT work as it moves forward	60%	30%	10%	0	0
I am confident that <i>ACT on Alzheimer's</i> will make progress in the next year toward stated goals	68%	27%	4%	0	0

Impact of the effort to date

[Author's Note: With the caveat that it is very difficult to assess or measure impact (especially statewide) along variables such as "enhancing skills of professionals," "enhancing linkages to community resources," or "assisting communities to build capacity," –this survey asked respondents about their beliefs about impact of the initiative in a number of areas. The areas chosen were directly tied to the work efforts and tools that had been undertaken. The assumption was that these early adopters were/are an important group – to capture their perspectives about impact. These are the people who are most likely to describe and disseminate these tools and promote the work of ACT. Therefore, their opinions as stakeholders are important in assessing impact.]

Overall, responses around impact of the effort to date were largely positive, with a sizeable number of people also reporting that they just did not know what the impact had been yet.

The group indicated strong support for the statement that this initiative had "Raised awareness of the issues and needs of persons with AD and their care partners in MN." Sixty-six percent of the respondents said there had been "Strong" or "Very Strong" impact in this area. There was also strong support for the statement that ACT had "Assisted communities to build capacity and increase their support of persons with AD and caregivers." Sixty-two percent of the respondents indicated they felt that there had been "Strong" or "Very Strong" impact in this area.

There was moderate to strong agreement that the ACT work had "Enhanced linkages to community resources following detection of AD" and that it had "Enhanced educational content of professionals in training. There was some agreement that ACT had also "Supported caregivers by increasing access to effective support services," but 7% of the respondents said this had been minimal and another 20% of the respondents didn't know if there had been impact.

There were a number of statements to which a sizeable number of people indicated they did not know what the impact had been. Thirty-eight percent of the respondents said they did not know if ACT had "Enhanced skills of clinical professionals practicing in the field for detection and management of Alzheimer's disease." Thirty-five percent of respondents said that they did not know if ACT had "Enhanced coordination and continuity of care for persons with AD." Both of these statements focus on the detection and follow-up from the clinic setting to other settings and to community resources.

The set of responses is shown in Table 4.

Table 4. Impact to Date - Statements						
Statement	Very Strong Impact	Strong Impact	Moderate Impact	Minimal Impact	None, No Impact	Don't Know
Enhanced skills of clinical professionals practicing in the field - for detection and management of Alzheimer's disease	12%	14%	27%	9%	0%	38%
Enhanced coordination and continuity of care for persons with AD	12	14	33	7	0	35
Enhanced linkages to community resources following detection of AD	17	30	30	6	0	16
Supported caregivers by increasing access to effective support services	7	33	33	7	1	20
Assisted communities to build capacity and increase their support of persons with AD and caregivers	20	41	25	1	0	13
Enhanced educational content of professionals in training	17	32	24	8	0	20
Raised awareness of the issues and needs of persons with AD and their care partners in MN	31	35	24	2	0	8

Most valuable aspect

Respondents were asked to write in comments related to what they thought was the most valuable aspect of the ACT on Alzheimer's work. The entire set of narrative comments is offered in Table 5 (Appendix). Most frequent responses centered around building awareness and the collective, collaborative nature of the work itself, which respondents described as mobilizing individuals and organizations. There were also many who said the tools were very important and had been valuable, particularly in moving toward a standard or consistent approach.

Discussion

This survey yielded a solid picture of engaged individuals who were committed to the *ACT on Alzheimer's* initiative and had provided time, content expertise, and energy toward developing and using the resources generated by the initiative, as well as bringing others into the work and making the work known.

Involvement. Most individuals had been involved for two years or more. While this speaks highly of them and their commitment, a question might be raised about how long this commitment can continue and what avenues there are for new participants to become involved. Given that the initiative as currently structured will complete its work in the Fall of 2015, this may not be a problem. The leadership groups, councils, and committees may be working toward greater outreach and involvement of others in new structures or through ongoing efforts—for example that may be happening at the community level. Almost 60% of the respondents (55 people) said that they are committed to staying involved in the ACT work as it moves forward.

Use of Tools, Resources. Participants are using the tools and resources generated by ACT—most particularly the website and the Toolkit. The use of the “After a Diagnosis” tool was also high—with 36 people saying they have used it. This could indicate that the respondent is learning more about what he/she should do after a patient or client is diagnosed. The respondent may be providing this material to newly diagnosed individuals/families. Why certain tools are being used and how they are being used may be worth exploring in more depth.

Other resources that were often mentioned were the Care Coordination Tool (31 persons) and the Community-based Service Provider Practice Tool (24 persons). It may be useful to ACT to get additional information on how individuals are using these materials and whether they are being used throughout their organizations or for personal education and reference. Finally, with only 9 people responding that they are using the reports on the website (those generated from ACT)—this may indicate that the reports are either hard to find, not known, or not useful. Perhaps a publications button would help people find these reports more easily.

Structure, Process. The responses to the way that the collective is operating were largely very positive. There is strong positive response to knowing the purpose for the initiative and feeling there are opportunities to be involved in meetings. The two areas noted for examination or clarification included: (1) communication methods and feeling informed, and (2) dependence on one person or organization for sustaining the momentum.

Impact. Many respondents indicated that *ACT on Alzheimer's* has had an impact on raising awareness of the disease and its effects on individuals and communities. Many point to the tools and Toolkit as important resources for people and organizations throughout the state. The collective is also valued for bringing people and organizations together to work on this issue. The narrative responses and agreement on impact statements offered indicate a belief that this is making a difference in Minnesota. The challenge is how to measure the impact and trace the use of tools or resources. This may be worth additional examination. #

NOTE: Please contact Emily Farah-Miller or Olivia Mastry for more information on the ACT on Alzheimer's initiative. For clarification on the survey or the report, contact Deborah Paone.

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References

ACT on Alzheimer's website: www.actonalz.org

Rogers, E. M. (2003). *Diffusion of innovations*, 5th Ed., New York: Simon and Schuster.

Appendix

Table 5. Narrative Comments on the most valuable aspect of ACT on Alzheimer's N=92

A true grass roots collaborative by people energized by others dealing with this disease.
The ability to take the issues related to Alzheimer's to a larger body of decision makers at provider, payer, and legislative arenas. Providing tools that are useful and demonstrate outcomes.
The toolkits
Raising awareness and the importance of educating the community and health providers on actionable steps
I'm sorry I don't think I can pick just one, but I can bring it down to two. The first being education of the public getting a better understanding and acceptance of this disease and those living with it. Which leads into the second most valuable aspect of the project and that is making sure our Alzheimer's/dementia residents world stays open and as big as possible for as long as possible. One of the side effects for an Alzheimer's client and their caregivers is that because of the lack of acceptance and/or education on the disease people don't know how to act or react and I believe patients and caregivers find it to hard to go out so their world gets very small very fast. That is never good!
Awareness
To date, the professional and thoughtful materials and educational opportunities.
Raising awareness of Alzheimer's disease and the resources available to help those living with the disease
The collaborations of people and organizations
Tool development
The development of the Dementia Capable Communities Tool Kit
Raising community awareness.
The development of the ACT guidelines, EMR tool and the work to embed these guidelines in health systems
Making a difference
The increased awareness of the disease and how communities can help.
I think the most valuable impact and aspect of ACT is bringing together large diverse service groups, businesses for community change.
The collaborative nature of this effort from stakeholders across the state.
Building professional awareness and connections to work on this issue
Collective movement
Providing comprehensive resources and tools
Increasing awareness, education and resources
To bring hope and resources to those affected with Alzheimer's and other dementias
Building momentum about all things Alzheimer's-related by involving such a wide group of constituents from so many different agencies, government sectors, private industry, etc. I have never seen another collaborative effort that reaches across organizations be so successful.
The awareness that has been brought to the state about the need to address Alzheimer's disease and related dementia's and to support those caring for individuals with dementia.
Its voluntary and collective nature.
Tools that provide a clear, structured framework that use best practices. Also the opportunity for collaboration and interaction with other organizations and systems who are working with persons with AD and care partners.
Creating awareness in the professional and non professional communities

Informing the medical professionals.
Hard to say only one. Building and sustaining a dementia capable community is probably the most valuable because it includes all aspects of the work being done.
Raising awareness on every front.
The practice parameters!
Education and caregiver support
Gaining momentum in each community
The collaborative efforts of individuals from many disciplines
So many different professionals and entities working together to impact Alzheimer's Disease
The collaboration across organizations, sharing of learning and successful strategies
Collaboration for action
Developing resources and materials that have buy-in from a range of stakeholders, and using the group as a launching point for disseminating those resources.
It is truly remarkable how much work has gone into the website and the development of resources.
An ongoing forum to support and enhance activities that are within participating organization roles but would not be as robust without ACT.
Multi organization collaboration
General visibility
The collaborative infrastructure that has developed
Early ID tools for health care professionals
The commitment of those involved gives me hope.
Building Awareness about needed changes in how we deal with dementia and providing resources and support for caregivers
Broader recognition of the community and financial impact and the need to develop effective alternatives to the current system
Representation from all stakeholders enhances both the depth and breadth of focus areas.
Strong foundation and potential for replicability in other communities
the collaboration itself; tools that have been developed that can last beyond the collaborative
Raising awareness of the issues and resources available to individuals with AD and supports available to care givers
Influencing public attitudes and policy
Dementia communities expansion
I believe it is the work of the leadership groups that move the work along and it could not happen without them.
The opportunity to work together for a common cause has powerful and lasting effects in the ACT-communities. Relationship building is very strong and evident during the assessment process and sets the stage to ACT together on identified community gaps through a formalized problem solving method.
That TOGETHER we are working on this!
Demonstration of the ROI benefit of the interventions
Community, grassroots focus of the work - impressed by significant role and involvement of the community
the collaborative nature of the project and the tools that have been produced
Raising awareness
Drawing attention to a disease that affects so many.
The excellent tools and resources available to all users.
Increasing awareness about the disease and community resources

The collaboration between many organizations passionate about improving dementia care around the state.
Building awareness.
The collective impact/awareness in the community and the excellent tools available to professionals and communities to continue the work. It is an impressive coalition of passionate people that has garnered resources to advance the work.
Broad mobilization of individuals and organizations across the state
Community engagement at the local level
Cohesive approach with communications systems.
The visible effort.
Collaboration across organizations, communities and sectors.
Community based
It has guided us in extremely valuable work that needs to be done in each community.
Building capacity and awareness across diverse stakeholders
ACT reveals the depth and breadth of commitment of people and organizations to improving dementia care.
I cannot hone it to one aspect; all are equally important, in my opinion. I am directly affected by the valuable tools being developed for providers, and this is my bias...but I believe all aspects have equal weight.
The collective collaboration of so many organizations & individuals working together each willing to share their expertise.
Improving the awareness of the general public and practicing health care professionals
Standardizing a process for community awareness efforts by developing the toolkit and making it readily available.
Demonstration of the ROI benefit of the interventions
Raising awareness and impact