

Wisconsin's Journey with Dementia

2018 Public Survey Results



WISCONSIN DEPARTMENT OF HEALTH SERVICES
DIVISION OF PUBLIC HEALTH
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Table of Contents

Executive Summary.....	2
Background	3
Survey Methods	3
Survey Results	5
Closed-Ended Questions	5
Respondent Group: People with Cognitive Concerns.....	5
Respondent Group: Family Caregivers.....	5
Respondent Group: Professionals.....	6
Respondents’ Additional Suggestions for Dementia-Related Goals.....	6
Respondent CHARACTERISTICS.....	8
Respondent Group: People with Cognitive Concerns.....	8
Respondent Group: Family Caregivers	9
Respondent Group: Professionals.....	10
Conclusion.....	10
APPENDIX 1: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY INDIVIDUALS WITH COGNITIVE CONCERNS	12
APPENDIX 2: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY FAMILY CAREGIVERS	13
APPENDIX 3: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY DEMENTIA PROFESSIONALS	15
APPENDIX 4: 2014 SYSTEM REDESIGN TOPICS RATED AS BOTH NEEDING MORE WORK AND A HIGH PRIORITY.....	17
APPENDIX 5: RESPONSE KEY FOR THE OPEN-ENDED PRE-SUMMIT SURVEY QUESTION.....	19

EXECUTIVE SUMMARY

The Wisconsin Department of Health Services (DHS), in collaboration with planning partners and other community stakeholders around the state, will be developing a new state plan for Alzheimer's disease and related dementia (ADRD) in 2018. A planning summit will be held on March 15-16, 2018 to identify priorities to include in the new plan. The plan will be completed and published in 2018, and will be implemented between 2019 and 2023.

In preparation for the summit, DHS and partners conducted a survey to obtain public comment and input on progress since the publication of the [Wisconsin Dementia Care System Redesign Plan](#) in February of 2014. The survey included multiple choice questions as well as an open-ended question through which respondents could make recommendations in their own words for the focus of the new plan. DHS linked to the survey on its website, and the link to the survey shared widely by DHS, its planning partners and other stakeholders.

Over 1,600 people responded to the survey, including 61 people with self-identified cognitive concerns, 474 family caregivers, and 1,153 professionals who provide care to people with dementia or their families. The open-ended question was answered by 817 survey respondents, which was approximately 50% of all respondents.

Overall, the survey indicates that the top priorities of respondents include:

- Improving assistance available for a person with dementia experiencing a crisis.
- Improving the quality of dementia care in assisted living residences and nursing homes.
- Increasing public awareness and understanding of brain health and dementia.

The top three topics provided by respondents in open-ended questions include:

- Increasing staff training and skill level in long-term care facilities.
- Educating family caregivers on providing care and utilizing resources.
- Increasing timely diagnosis and improving basic physician education.

The results from this public survey will give a voice to stakeholders and other concerned citizens who, as a result of space and other logistical limitations, are unable to attend the planning summit.

BACKGROUND

DHS published the [Wisconsin Dementia Care System Redesign Plan \(Redesign Plan\)](#) in February 2014 based on input provided by key stakeholders at a dementia summit held in October 2013. The focus of that summit was to identify and prioritize goals and strategies to include in a plan to redesign the system of dementia care in the state. The resulting Redesign Plan contained approximately 50 initiatives under five main categories: community awareness and services; facility-based long-term care; care for those with significant challenging behaviors; dementia care guiding principles and training; and research and data collection. DHS and partners have since worked to implement the strategies outlined in the Redesign Plan. Highlights of some of the resulting accomplishments have been published on the DHS [Dementia-Capable Wisconsin website](#).

In early 2017, a planning team that included DHS, the three chapters of the Alzheimer's Association of Wisconsin, the Alzheimer's and Dementia Alliance of Wisconsin, and the Wisconsin Alzheimer's Institute, agreed that the time was right to assess the progress made to date and identify priorities for the coming years. The planning team proposed to convene another summit of stakeholders and partners from across the state to identify the priorities of the new state plan to address dementia. The title of the new summit is: "Wisconsin's Journey with Dementia: Priorities for the Next Five Years" (referred to in this report as the 2018 Dementia Summit).

The planning team agreed that conducting a pre-summit survey and sharing the results with participants in the 2018 Dementia Summit would help broaden stakeholder input into the development of priorities for a new state plan. The remainder of this report describes the survey methods and results.

SURVEY METHODS

The pre-summit survey was intended to allow stakeholders who would otherwise not be able to attend the summit to offer their views and suggestions for developing the plan. The online survey sought input from three distinct audiences: people who self-identify as having cognitive difficulty, people who are providing care to someone with dementia in their family or social group (referred to in this report as family caregivers), and professionals who work with people or families living with dementia or with systems that serve people with dementia (referred to in this report as professionals). The survey questions and wording were tailored to these audiences. This resulted in three versions of the survey, although some questions were common to all versions. As the survey did not involve random sampling, the results cannot be interpreted as representing the views of all residents of the state of Wisconsin. However, the results do reflect the priorities of Wisconsin residents who chose to respond.

The survey was posted on the DHS Dementia-Capable Wisconsin website, and the link to the survey was distributed broadly by planning team and other stakeholders. The survey was available to potential respondents from December 1, 2017 to January 5, 2018.

Most of the survey questions were developed around the topics included in the 2014 Dementia Care Systems Redesign Plan. Respondents were asked how much progress they feel has been made on each topic (possible responses were sufficiently addressed or needs more work) and whether they feel continuing work on that topic is a high, medium or low priority. The table below shows the possible combination of responses for these questions.

Questions asked of pre-summit survey respondents for each topic		Highlights
How do you think your community is doing with this goal?	What level of priority would you give this goal now?	Priority level for future efforts
Needs more work	High priority	Highest
	Medium priority	Medium to low
	Low priority	
Sufficiently addressed	High priority	
	Medium priority	
	Low priority	

The findings discussed in this report focus only on the issues which respondents rated as needing more work *and* being a high priority, as shown in the table above. The planning team considered those topics to have the highest priority for future efforts. For more details on the rankings of topics by each group of respondents, see Appendices 1, 2 and 3 for results for people with cognitive concerns, family caregivers, and professionals.

Through an open-ended question, survey respondents also had the opportunity to describe in their own words additional concerns or suggestions for change related to care for individuals with dementia.

Finally, all survey respondents were asked several questions about their own experience as a person with cognitive concerns, a family caregiver, or a professional working with individuals with dementia.

The following sections summarize the key findings from the survey, and offer an overview of characteristics of the survey respondents, based on general information requested in the survey.

SURVEY RESULTS

A total of 1,688 survey responses were submitted by 61 individuals with cognitive difficulty, 474 family caregivers, and 1,153 professionals. The open-ended question at the end of the survey received 819 total responses in all, with 29 from people with cognitive difficulty, 281 from family caregivers, and 507 from professionals offering responses to that item.

Closed-Ended Questions

The figures shown in parentheses in the following discussion reflect the percentage of individuals in each respondent group reporting that a particular topic needs more work **and** is high priority.

Respondent Group: People with Cognitive Concerns

The survey for individuals with a cognitive issue or other dementia focused on their experience. The topics these respondents most often rated as both needs more work and high priority included:

1. Increasing public awareness and understanding of brain health and dementia (54%).
2. Increasing availability of community-based programs for people who have cognitive impairment or dementia (49%).
3. Improving the quality of dementia care in assisted living residences and nursing homes (46%).
4. Improving assistance available for a person with dementia experiencing a crisis (43%).

Respondent Group: Family Caregivers

Six topics in total made the top ratings among family caregivers.

1. Improving assistance available for a person with dementia experiencing a crisis (62%).
2. Improving the quality of dementia care in assisted living residences and nursing homes (62%).
3. Increasing availability of community-based programs for people who have cognitive impairment or dementia (61%).
4. Increasing appropriate diagnosis of cognitive impairment and dementia to help families plan for the future (55%).
5. Increasing availability of respite services to support family caregivers (55%).
6. Increasing the number of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia (55%).

Respondent Group: Professionals

Among the 752 responses from dementia professionals, there was a clear top choice, which matches one of the two top choices among family caregivers. Both professionals and family caregivers prioritized improving assistance available for a person with dementia experiencing a crisis. Professionals identified five additional topics as top issues.

1. Improving assistance available for a person with dementia experiencing a crisis (67%).
2. Improving the quality of dementia care in assisted living residences and nursing homes (59%).
3. Increasing the number of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia (58%).
4. Increasing the number of assisted living residences and nursing homes that will accept people under an emergency protective placement (57%).
5. Increasing availability of respite care services to support family caregivers (57%).
6. Increasing availability of community-based programs for people who have cognitive impairment or dementia (57%).

For a table comparing the percentages in each respondent group that rated a topic as a high priority needing more work, refer to Appendix 4.

Respondents' Additional Suggestions for Dementia-Related Goals

In addition to the responses to multiple choice survey questions, referenced above, the survey included the following open-ended question:

If there could be one or two additional service areas created or improved over the next five years, in addition to the goals shown above, what would you want it to be?

This question was asked at the end of the survey, and a total of 819 respondents replied.

The answers to the open-ended question were reviewed and grouped into six broad categories, including the following:

- Support for people with dementia, family caregivers, and the community
- Medical
- Facility care
- Dementia-related crisis
- Education
- Miscellaneous

Within these categories, more detailed topic labels were also established as needed to reflect the nature of the comments received. A total of 84 different topics were identified. A list of the topics can be found in the open-ended question response key in Appendix 5.

When the open-ended responses for all three target audiences were combined, two topics stood out above the others: 126 respondents asserted a need for more skills and training for facility-based staff, and 102 respondents mentioned the need for greater availability and utilization of training and education for family caregivers.

The separate respondent groups reported somewhat different concerns:

Twenty-nine people with **cognitive concerns** answered the open-ended question, and these individuals had a clear leading issue, with education receiving more than twice the number of comments of other categories. Education was mentioned 18 times in all. Specifically, most of these responses mentioned education of the general public. Understanding where to find resources and education for caregivers, stigma reduction, and education in schools were also mentioned more than once by respondents with cognitive concerns.

The top issue for the 289 **family caregivers** who responded to the open-ended question was education and training for family caregivers, with 42 comments. Other topics commonly mentioned by caregiver respondents included:

- Physician education and earlier diagnosis is needed (30 comments).
- Out-of-pocket cost of care is too high or is a financial hardship (29).
- Staff members of facility-based long-term care need more skills and training (29).
- Greater availability of respite care is needed (27).
- Support for dementia-friendly communities (21).
- The need to provide education to the general public (20).
- The need for greater access to a variety of types of support groups (18).
- The need for greater access to adult day care (16).

The responses from the 507 **dementia professionals** who completed the open-ended question included 318 comments in the category of facility care, with the top comment indicating the need for more training and skill among facility-based staff, which was mentioned by 96 respondents. Other topics commonly mentioned by dementia professionals included:

- The need for education and training for family caregivers (57 comments).
- Support for dementia-friendly communities (50).

- The need for physician education related to early diagnosis (49).
- The need for greater availability of respite care (39).
- The belief that Medicaid nursing home reimbursement rates are too low (37).
- The need for greater availability of crisis beds and/or designated facilities (37).

RESPONDENT CHARACTERISTICS

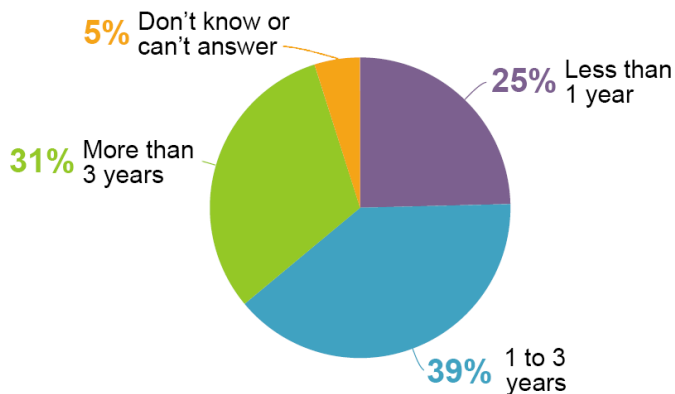
Respondent Group: People with Cognitive Concerns

Sixty-one respondents self-identified as **people with cognitive concerns or a dementia diagnosis** and completed the portion of the survey for people with cognitive difficulty. These individuals may have been assisted by a caregiver or other person to complete the survey.

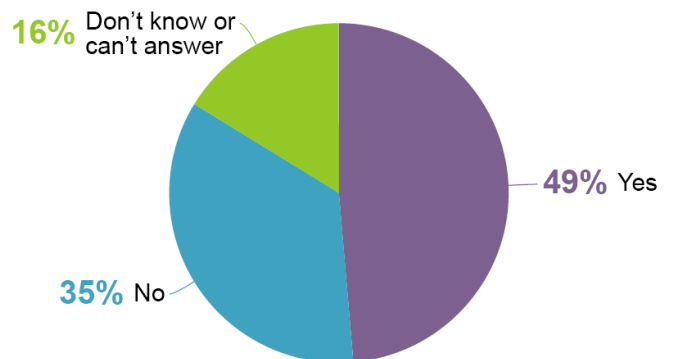
One-quarter of these respondents have been concerned with their cognitive health for less than one year, 39% have had such concerns for one to three years, and 31% have had concerns for more than three years.

Approximately half indicated they have received a diagnosis of dementia or cognitive issues. Of those individuals, 62% felt that their primary medical provider has helped them to understand and manage their condition.

How long have you been concerned about your memory or brain health?



Has a doctor diagnosed cognitive issues or dementia?



Relatively few of the survey respondents with cognitive concerns appear to have obtained formal support or services from providers within the dementia care system. Only 15% of the respondents in this group reported that they participate in Family Care, IRIS, or the Community Options Program; just over a third, 38%, reported having used any programs or services from an

aging office, Aging and Disability Resource Center, or senior center; and 28% had used programs or services from an Alzheimer's and dementia organization.

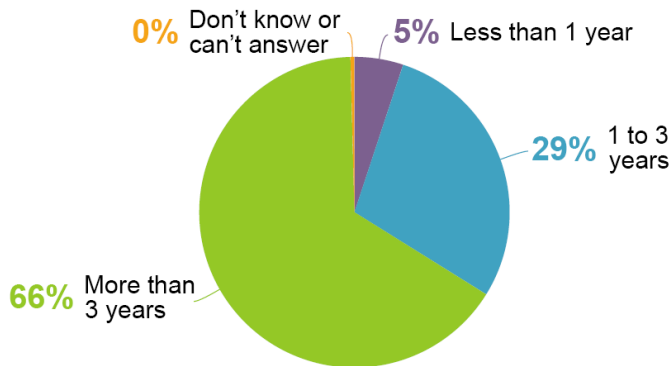
Respondent Group: Family Caregivers

The 474 respondents to the family caregiver portion of the survey self-identified as **family and other informal caregivers for people with cognitive concerns or a dementia diagnosis**.

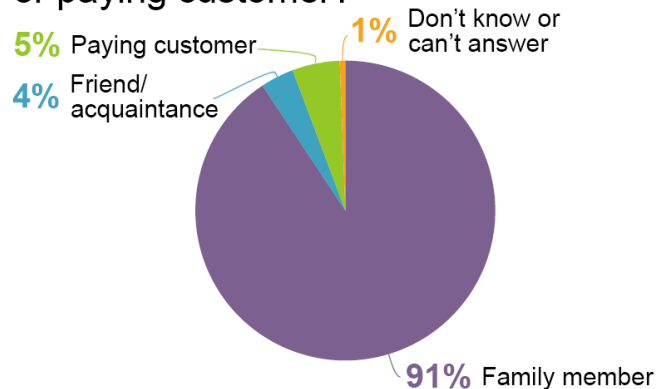
Some respondents to the open-ended question in this survey discussed their roles as both a family caregiver and a professional, but it is unknown how many respondents to the family caregiver survey are also professionals.

Two-thirds of respondents to the family caregiver survey have been providing care for more than three years, and more than 90% of the caregivers reported that the person they assist or take care of is a family member.

How long have you been assisting or caring for a person with brain health concerns or dementia?



Is the person you assist or take care of a family member, friend or acquaintance, or paying customer?



Almost two-thirds do not live with the person they provide care to, and 93% say the person has a diagnosis of cognitive issues or other dementia. Of those caregivers, 57% felt that the person's primary care provider helped them to understand and manage the condition.

Mental health issues such as depression were reported by 66% of respondents, with physical health issues reported by 57% and financial strain by 45%.

Family caregivers reported providing the following types of assistance on at least a weekly basis: performing household chores; running errands and taking the person out; and making decisions about money, medical care, and where to live.

Of the respondents, 22% reported that the person to whom they provided care was enrolled in Family Care, IRIS or the Community Options Program. Respondents also reported getting support from various other sources: 64% had used programs or services from an aging and disability resource center; 42% had used programs or services from an Alzheimer’s and dementia agency; 69% had attended information, training, or support programs; and 31% of the caregivers had used respite care.

Respondent Group: Professionals

Respondents to the third portion of the survey self-identified as **professionals working in the field of cognitive health or dementia** and came from a variety of backgrounds. At 19% each, health care professionals and aging and disability resource center staff were the most common affiliations.

Professional Affiliation	Percent of Respondents
Aging and disability resource center or aging unit staff	19.0%
Healthcare professional	18.8%
Community-based service provider	16.1%
Managed care organization staff	15.8%
Residential care facility staff or service provider	13.9%
All others	16.4%

CONCLUSION

The survey described in this report was designed as a pre-summit survey to gather input to share with participants at the 2018 Dementia Summit. The online survey sought participation from three audiences, including people who self-identify as having cognitive difficulty, family caregivers of people with dementia, and professionals who work with people with dementia and their families. Overall trends from the survey indicate that respondents’ top priorities include:

- Improving assistance available for a person with dementia experiencing a crisis.
- Improving the quality of dementia care in assisted living residences and nursing homes.
- Increasing public awareness and understanding of brain health and dementia.

The 2018 Dementia Summit is the next step in establishing priority goals to include in a statewide plan for improving care and support for people with dementia, their families, and their communities across the state. This plan will be developed in partnership with dementia stakeholders and implemented through collaborative efforts across the state. Individuals, agencies, and other interested organizations are welcome and encouraged to participate in

working towards the goals outlined in the plan, which will be finalized and published by the end of 2018. For future information on the new state plan and dementia-related issues, please sign up to [receive email updates](#) on the [DHS Dementia-Capable Wisconsin website](#).

APPENDIX 1: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY INDIVIDUALS WITH COGNITIVE CONCERNS

There were 61 respondents in this group.

	Sufficiently addressed	Needs more work	Don't know or can't answer	High priority	Medium priority	Low priority	Don't know or can't answer
Increase public awareness and understanding of brain health and dementia.	4 (7%)	44 (72%)	13 (21%)	40 (66%)	16 (26%)	0 (0%)	5 (8%)
Improve community-based programs for people who have cognitive impairment or dementia.	5 (8%)	43 (73%)	11 (19%)	37 (62%)	17 (28%)	0 (0%)	6 (10%)
Improve assistance available for a person with dementia experiencing a crisis.	4 (7%)	46 (77%)	10 (17%)	33 (54%)	18 (30%)	3 (5%)	7 (11%)
Increase the number of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia.	10 (17%)	37 (62%)	13 (22%)	28 (47%)	18 (31%)	4 (7%)	9 (15%)
Improve the quality of dementia care in assisted living residences and nursing homes.	5 (8%)	38 (63%)	17 (28%)	35 (58%)	14 (23%)	1 (2%)	10 (17%)
Encourage assisted living residences and nursing homes to include design features that are inviting and comfortable for people with dementia.	7 (12%)	36 (60%)	17 (28%)	30 (51%)	17 (28%)	3 (5%)	9 (15%)

APPENDIX 2: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY FAMILY CAREGIVERS

There were 474 respondents in this group.

	Sufficiently addressed	Needs more work	Don't know or can't answer	High priority	Medium priority	Low priority	Don't know or can't answer
Increase public awareness/ understanding of brain health, dementia, and resources to help support people with brain health concerns.	58 (12%)	370 (78%)	45 (10%)	303 (64%)	140 (30%)	14 (3%)	15 (3%)
Increase availability of community-based programs for people who have cognitive impairment or dementia.	53 (11%)	387 (82%)	33 (7%)	329 (70%)	115 (24%)	15 (3%)	12 (3%)
Increase availability of respite services to support family caregivers.	40 (9%)	365 (78%)	65 (14%)	294 (63%)	126 (27%)	16 (3%)	32 (7%)
Increase appropriate diagnosis of cognitive impairment and dementia to help families plan for the future.	70 (15%)	342 (72%)	60 (13%)	305 (65%)	109 (23%)	23 (5%)	34 (7%)
Develop dementia care guiding principles for family caregivers and professionals providing care for people with dementia.	57 (12%)	361 (77%)	52 (11%)	288 (61%)	120 (26%)	34 (7%)	28 (6%)
Develop educational opportunities for family caregivers providing care for people with dementia.	99 (21%)	329 (70%)	43 (9%)	252 (54%)	159 (34%)	35 (7%)	24 (5%)

	Sufficiently addressed	Needs more work	Don't know or can't answer	High priority	Medium priority	Low priority	Don't know or can't answer
Develop training opportunities for professionals providing care for people with dementia.	57 (12%)	312 (66%)	101 (21%)	295 (63%)	100 (21%)	23 (5%)	50 (11%)
Improve assistance available for a person with dementia experiencing a crisis.	18 (4%)	349 (74%)	102 (22%)	337 (72%)	61 (13%)	10 (2%)	58 (12%)
Increase # of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia.	67 (14%)	330 (70%)	73 (16%)	291 (62%)	94 (20%)	36 (8%)	48 (10%)
Improve the quality of dementia care in assisted living residences and nursing homes.	41 (9%)	346 (74%)	81 (17%)	325 (69%)	65 (14%)	20 (4%)	58 (12%)
Encourage assisted living residences and nursing homes to include design features that are inviting and comfortable for people with dementia.	49 (10%)	317 (68%)	103 (22%)	269 (57%)	107 (23%)	26 (6%)	67 (14%)
Clarify procedures for emergency protective placement (court-ordered emergency residential services) for people with dementia.	28 (6%)	263 (56%)	180 (38%)	215 (46%)	84 (18%)	26 (6%)	139 (30%)
Increase the number of assisted living facilities and nursing homes that accept people under emergency protective placement.	14 (3%)	254 (54%)	201 (43%)	233 (50%)	68 (14%)	14 (3%)	155 (33%)

APPENDIX 3: RATINGS OF 2014 SYSTEM REDESIGN TOPICS BY DEMENTIA PROFESSIONALS

There were 1,153 respondents in this group.

	Sufficiently addressed	Needs more work	Don't know or can't answer	High priority	Medium priority	Low priority	Don't know or can't answer
Increase public awareness and understanding of brain health and dementia.	165 (14%)	950 (83%)	35 (3%)	617 (54%)	479 (42%)	41 (4%)	13 (1%)
Increase availability of community-based programs for people who have cognitive impairment or dementia.	139 (12%)	985 (86%)	26 (2%)	720 (63%)	367 (32%)	41 (4%)	15 (1%)
Increase availability of respite services to support family caregivers.	125 (11%)	945 (83%)	75 (7%)	720 (63%)	309 (27%)	64 (6%)	52 (5%)
Increase appropriate diagnosis of cognitive impairment and dementia to help families plan for the future.	163 (14%)	891 (78%)	93 (8%)	621 (54%)	373 (33%)	85 (7%)	63 (6%)
Develop dementia care guiding principles for family caregivers and professionals providing care for people with dementia.	263 (23%)	810 (71%)	69 (6%)	531 (47%)	426 (37%)	134 (12%)	50 (4%)
Develop educational opportunities for family caregivers providing care for people with dementia.	261 (23%)	828 (72%)	60 (5%)	555 (48%)	446 (39%)	102 (9%)	45 (4%)
Develop training opportunities for professionals providing care for people with dementia.	273 (24%)	836 (73%)	38 (3%)	588 (51%)	388 (34%)	139 (12%)	30 (3%)

	Sufficiently addressed	Needs more work	Don't know or can't answer	High priority	Medium priority	Low priority	Don't know or can't answer
Improve assistance available for a person with dementia experiencing a crisis.	83 (7%)	983 (86%)	77 (7%)	828 (72%)	217 (19%)	47 (4%)	53 (5%)
Increase # of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia.	202 (18%)	871 (76%)	72 (6%)	704 (62%)	235 (21%)	137 (12%)	66 (6%)
Improve the quality of dementia care in assisted living residences and nursing homes.	145 (13%)	920 (80%)	83 (7%)	732 (64%)	267 (23%)	80 (7%)	66 (6%)
Encourage assisted living residences and nursing homes to include design features that are inviting and comfortable for people with dementia.	189 (16%)	849 (74%)	109 (10%)	478 (42%)	412 (36%)	169 (15%)	85 (7%)
Clarify procedures for emergency protective placement (court-ordered emergency residential services) for people with dementia.	129 (11%)	840 (73%)	174 (15%)	621 (55%)	279 (24%)	89 (8%)	150 (13%)
Increase the number of assisted living residences and nursing homes that will accept people under an emergency protective placement.	64 (6%)	880 (77%)	205 (18%)	706 (62%)	204 (18%)	62 (5%)	166 (15%)

APPENDIX 4: 2014 SYSTEM REDESIGN TOPICS RATED AS BOTH NEEDING MORE WORK AND A HIGH PRIORITY

	Grand Total (n=1,688)	Grand Total %	Individuals (n=61)	Caregivers (n=474)	Professionals (n=1,153)
Improve assistance available for a person with dementia experiencing a crisis.	1,091	65%	43%	62%	67%
Improve the quality of dementia care in assisted living residences and nursing homes.	999	59%	46%	62%	59%
Increase availability of community-based programs for people who have cognitive impairment or dementia.*	972	58%	49%	61%	57%
Increase the number of assisted living residences and nursing homes that provide care for people with behavioral symptoms of dementia.	950	56%	39%	55%	58%
Increase availability of respite services to support family caregivers.	921	55%	NA	55%	57%
Increase the number of assisted living facilities and nursing homes that will accept people under an emergency protective placement.	853	51%	NA	41%	57%
Increase public awareness and understanding of brain health and dementia.*	829	49%	54%	53%	47%
Increase appropriate diagnosis of cognitive impairment and dementia to help families plan for the future.	827	49%	NA	55%	49%
Develop training opportunities for professionals providing care for people with dementia.	768	45%	NA	51%	46%
Clarify procedures for emergency protective placement (court-ordered emergency residential services) for people with dementia.	750	44%	NA	38%	50%

	<i>Grand Total (n=1,688)</i>	<i>Grand Total %</i>	<i>Individuals (n=61)</i>	<i>Caregivers (n=474)</i>	<i>Professionals (n=1,153)</i>
Develop dementia care guiding principles for family caregivers and professionals providing care for people with dementia.	715	42%	NA	53%	40%
Encourage assisted living residences and nursing homes to include design features that are inviting and comfortable for people with dementia.	695	41%	36%	49%	38%
Develop educational opportunities for family caregivers providing care for people with dementia.	690	41%	NA	44%	42%

* Statement worded slightly differently in the individual surveys

APPENDIX 5: RESPONSE KEY FOR THE OPEN-ENDED PRE-SUMMIT SURVEY QUESTION

Support for People with Dementia & Family Caregivers/Community (Home)		
	Topic	Comments
1.	Increase dementia-friendly communities activities	73
2.	Increase access to respite care, overnight respite, and home and facility settings	66
3.	Increase access to adult day care	45
4.	Increase the number of dementia care specialists	26
5.	Provide more and varied support groups	24
6.	Increase access to quality home care services	20
7.	Home care services need to become dementia-capable	16
8.	Provide transportation	16
9.	Increase the use of volunteers (respite and other)	10
10.	Improve the timeliness of eligibility for financial support	10
11.	Increase access to early-stage support	8
12.	Increase emergency support for caregivers	7
13.	Provide more services specific to young onset	5
14.	Provide culturally appropriate care	4
15.	Provide assistance with legal decisions or /paperwork	3
16.	Increase Medicaid reimbursement for home care	2
17.	Increase workforce availability of home care workers	2
	TOTAL HOME	337

Medical		
	Topic	Comments
1.	Increase timely diagnosis and /improve basic physician education	79
2.	Physicians should provide referrals to supports and services	17
3.	Improve hospital and emergency room care	15
4.	Increase availability of geriatricians and geropsychiatrists	15
5.	Increase memory screening by physicians	10
6.	Support more research	8
7.	Provide physician home visits for care	7
8.	Increase involvement of physicians in care and caregiver support	6
9.	Improve support for completion of advance planning	5
10.	Increase coordination of medical care between providers and settings and provide health care navigators	5
11.	More awareness and provision of dementia care for individuals with intellectual and developmental disabilities	2
12.	Increase access to dementia-capable dental care	1
	TOTAL MEDICAL	170

Facility Care		
	Topic	Comments
1.	Increase staff training and skill level	126
2.	Increase staff pay and decrease turnover	46
3.	Increase nursing home reimbursement and Family Care rates	45
4.	Not admitting or retaining people with dementia-related behavior	38
5.	Higher standards for memory care units	27
6.	Keep residents busy	24
7.	Not enough staff on a shift to meet resident needs	19
8.	Workforce shortage	19
9.	Need for improvements to the physical environment and associated funding	13
10.	Reduce the use of anti-psychotic medications	10
11.	Increase oversight and surveys of facilities to improve quality	10
12.	Regulation is a hindrance	9
13.	Increase external support for behavior management in assisted living	7
14.	Needs of the intellectual and developmental disability population	6
15.	Increased access to adult family homes	6
16.	Need assistance in selecting a facility	5
17.	Access to outside behavioral support for residents diagnosed with both dementia and a mental illness	4
18.	Use more non-pharmacological interventions	2
	TOTAL FACILITIES	416

Dementia-Related Crisis		
	Topic	Comments
1.	Develop more crisis beds and designated facilities for Emergency Protective Placement	39
2.	Need improved response	38
3.	Increase pre-crisis planning in facilities	3
4.	Increase crisis prevention efforts	3
5.	Allow use of Chapter 51 Emergency Detentions	2
	TOTAL DEMENTIA-RELATED CRISIS	92

Increase Education		
	Topic	Comments
1.	For family caregivers on providing care and using resources	102
2.	To the general public	59
3.	In schools	17
4.	Law enforcement and first responders	16
5.	Lifestyle interventions to lower risk	11
6.	Stigma reduction	10
7.	Awareness of palliative care and power-of-attorney forms	7
8.	Awareness of resources	5
9.	Awareness and use of assistive technology	1
	TOTAL EDUCATION	228

Miscellaneous		
	Topic	Comments
1.	Out-of-pocket costs for needed care are too high	36
2.	More services in rural areas	23
3.	More funding for all dementia related efforts	13
4.	Pay family to provide care	13
5.	Need collaboration between systems	8
6.	Directly involve IRIS staff in efforts	6
7.	Shortage of all forms of resources and services	4
8.	Use the Virtual Dementia Tour	4
9.	Provide options to access support remotely and telehealth	4
10.	Improve non-English service availability	4
11.	Assistance with a timely process to stop driving	4
12.	Need consistency of service availability across state	3
13.	Tiny home communities and Dementia village	3
14.	New nursing home level of care for dementia behaviors	2
15.	Health care system too fragmented	2
16.	Promote care cooperatives	2
17.	Consider the Iowa pay-for-performance Medicaid model	1
18.	Explore the Court-Appointed Special Advocates volunteer model from the youth system	1
19.	People should move to care facilities sooner	1
20.	Utilize a dementia passport	1
21.	Make the use of hyperbaric chambers available	1
22.	Intergenerational care settings	1
23.	Improve services for people with dementia living alone	1
	TOTAL MISCELLANEOUS	131