ACT on Alzheimer’s Community:

Dr. Solomon Carter Fuller
(North Minneapolis)

Activities & Progress
As of May, 2015

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Executive Summary

The Dr. Solomon Carter Fuller ACT on Alzheimer’s® community located in North Minneapolis is one of 34 ACTion communities using the guided community engagement process and the ACT on Alzheimer’s Dementia Capable Communities Toolkit.

This report describes the progress made through this work in North Minneapolis, from early 2014 through early 2015. In that time, this ACTion community completed the “convening” phase (Phase 1), the “assessment” phase (Phase 2), and the “analysis” (Phase 3) of that work and began crafting its’ Action plan (Phase 4). The community has now begun its Phase 4 work.

The lead agency for this effort is NorthPoint Health and Wellness Center. The ACTion team includes representatives from churches, schools, community groups, health centers, the YMCA and various social services and advocacy/civic organizations.

Thus far, there have been two open-invitation ACTion community meetings and more than a dozen small-group team member working meetings which were held between March 2014 and May of 2015. From March to June 2014, there were approximately 12-15 individuals engaged in the monthly ACT working meetings. Additional individuals became involved after attending the kick-off event (September 18, 2014)—where there were 70+attendees.

Community assessments and facilitated conversations using questions from the Toolkit occurred from September through December, 2014. This was done by 9 ACTion team members. Forty-one assessments were completed. Following this assessment/conversation process, a small working group of ACTion team members reviewed the results. An intern was hired to input the data from the assessments.

On February 19, 2015, the ACTion team held a Community Forum to report its results and lead a “Call to Action.” Approximately 40 people attended. This Call to Action was organized to share what had been learned and also to facilitate a discussion on how to address the two top priority areas chosen: (1) raise community awareness, and (2) provide caregiver training and support. Some individuals agreed to sign Action Pledges indicating what action step they would make—either as a community member at large or as part of an organizational effort. The ACTion team has met following the February meeting to review the Pledges and see how individuals want to follow up. For example, one volunteer wants to raise awareness within the church community about what caregiving is and provide basic information about Alzheimer’s disease. The ACTion team as a whole is concentrating efforts on awareness building, education, and offering information about local resources.
Background on ACT on Alzheimer’s Initiative

ACT on Alzheimer’s® is a volunteer-driven statewide collaboration. It was organized to focus on 5 goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer’s disease and related dementias. 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.

In 2012 a Dementia Capable Communities Toolkit was developed by one of the leadership groups and other participants involved in ACT on Alzheimer’s.

The Toolkit provides a structured process for a community to assess its own dementia awareness and resources, as well as to determine priority areas for action. The toolkit offers four clear steps and processes:¹

1. Convene key community leaders and members to understand Alzheimer’s disease and its implications for your community. Then, form an Action Team.
2. Assess current strengths and gaps in meeting the needs that result from the disease and related dementias, using a comprehensive community assessment tool.
3. Analyze your community needs and determine the issues stakeholders are motivated to act on; then set community goals.
4. ACT Together to establish implementation plans for your goals and identify ways to measure progress.

Key elements of dementia capability were defined within the Toolkit, beginning with Awareness (see flowchart Figure 1).

Dr. Solomon Carter Fuller Community - Activities and Progress Report

Figure 1. Key elements of a dementia-capable community (Source: ACT on Alzheimer’s website: www.actonalz.org, Accessed April 15, 2015).
The process and Toolkit was piloted by four communities in Minnesota in 2012 and 2013 (finalized in 2013).²

In 2014 ACT on Alzheimer’s leadership secured outside funding to support and engage Minnesota communities in launching this community assessment and engagement process. As of April 2015, there were 34 ACTion communities within Minnesota who had responded to the request for grant proposals and were awarded funding. The ACT on Alzheimer’s® website summarizes the focus of this work as follows: “Community by community, we can create a supportive environment for everyone touched by this disease.”³ Additional information about specific goals of dementia-capable communities is provided in Attachment 1.

In 2014 the ACT on Alzheimer’s leadership also added the lens of health equity – and endorsed a call to action—to enhance the tools and work of the initiative across the 5 goal areas (See Figure 2).

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³ Source: www.ACTonAlz.org/realities accessed on December 20, 2013
Alzheimer’s disease and related dementias are increasing in prevalence as the population ages. According to the ACT on Alzheimer’s® website:\textsuperscript{4}

\textit{As more and more Minnesotans live with Alzheimer’s disease and other dementias, the costs and challenges can be overwhelming for them, their families, our communities and our state. Care costs for Americans age 65 and older with Alzheimer’s disease and other dementias are projected to increase from $203 billion in 2013 to $1.2 trillion by 2050 (in 2013 dollars).}

\textit{Many individuals with Alzheimer’s live alone and are at greater risk for inadequate self-care, malnutrition, untreated medical conditions, falls, wandering and accidental deaths.}

\textit{Nearly 250,000 Minnesotans care for family members with Alzheimer’s disease. These caregivers provide 277 million hours of unpaid care, valued at $3.4 million yearly. The physical and emotional impact on caregivers results in nearly $9 billion in increased healthcare costs annually, including $157 million for Minnesota caregivers.}

Alzheimer’s Disease in African Americans

The Alzheimer’s Association notes that “African Americans are two times more likely to develop late-onset Alzheimer’s disease than whites and less likely to have a diagnosis of their condition.” This, then, means that there is less time for treatment and planning. (Source: Alzheimer’s Association website \url{http://www.alz.org/africanamerican}; accessed April 15, 2015).

According to a study of 79 African-American patients and caregivers attending either an inner city clinic or a suburban memory assessment clinic, there are impediments to getting a timely diagnosis of Alzheimer’s disease, including lack of physical contact, belief that forgetfulness observed was a normal part of aging, and finding it difficult to discuss the problem with the patient, and/or to face the possibility that the cause was dementia. Reported lag time between noticing AD symptoms and consulting a physician was between 4 and 7 years.\textsuperscript{5}

\textsuperscript{4} Source: \url{www.ACTonAlz.org} accessed on December 20, 2013
Dr. Solomon Carter Fuller ACTion Community

Introduction
The Dr. Solomon Carter Fuller ACT on Alzheimer's® community located in North Minneapolis is one of 34 ACTion communities using the guided community engagement process and the ACT on Alzheimer's Dementia Capable Communities Toolkit. This community engagement process guides a community action team as it identifies current resources, strengths and gaps within its community and plans action steps, based on findings.

This report describes the progress made through this work in North Minneapolis, from early 2014 through early 2015. In that time, this ACTion community completed the “convening” phase (Phase 1), the “assessment” phase (Phase 2), and the “analysis” (Phase 3) of that work and began crafting its’ Action plan (Phase 4). The community has begun its Phase 4 work.

Data sources included:
- Key informant interviews (conducted in April and May, 2015)
- Meeting notes and progress reports
- YouTube videos of community meeting excerpts
- Assessment survey data
- The ACT on Alzheimer's® website (www.ACTonAlz.org)

Lead Agency/Coordinators
The lead agency for the Dr. Solomon Carter Fuller ACTion community is NorthPoint Health & Wellness Center.

NorthPoint Health & Wellness Center is: a multi-specialty medical, dental, and mental health center, and human services agency located in North Minneapolis. It is administered through a partnership between Hennepin County and a Community Board of Directors comprising NorthPoint’s patients and people who live and/or work in the community. (Source: NorthPoint website, accessed 5/2/2015 at: http://www.northpointhealth.org/AboutNorthPoint/tabid/72/Default.aspx)

Vanne Owens Hayes and Beverly Propes are the two Co-Coordinators for the Dr. Solomon Carter Fuller ACTion community. Both Vanne and Beverly have been active in the North Minneapolis community for many years. Vanne is a Cultural Consultant and Health Educator and formerly served as a Director of the Minneapolis Civil Rights Department and as a law school Assistant Dean. She is also active in the African American Leadership Forum—described as a movement of area African American...

Beverly was a licensed school nurse for North High School in Minneapolis and retired before joining the ACTion team. Beverly has a public health nursing background and is currently serving as a Nurse Consultant for a Charter School that serves 1200 families with children. Beverly was also on the Board of The Givens Foundation for African American Literature—the only organization in the Twin Cities that is exclusively dedicated to advancing and celebrating black literature and writers (see: The Givens Foundation website, http://www.givens.org/about-us/; Accessed May 15, 2015). Beverly has received several awards in recognition of her efforts to promote health in the African American community.

Vanne and Beverly are the point people who guide and manage the community engagement process as outlined in the ACT on Alzheimer’s Dementia Capability Toolkit, and shepherd and facilitate the priority actions of the community.

Community Profile
The Dr. Solomon Carter Fuller ACT community is made up of two zip code areas: 55411 (known as “Near North) and 55412 (known as “Camden). It is approximately bounded by the Mississippi River and West River Parkway to the East, 49th Ave to the North, Memorial Parkway to the West and 55 to the South.

The North Minneapolis community has many strengths as well as challenges. According to a 2007 report generated through community listening sessions funded by NorthPoint Health & Wellness Center, Hennepin County, and NorthWay Community Trust, the Northside is one of the most economically and ethnically diverse communities in Minnesota (See: North Minneapolis Community Listening Project: Complete Report). The Northside community has a large African-American, Hmong, Somali, and Caucasian population, with a rapidly growing Latino population. This report provides insight gathered from many small-group conversational/listening sessions held throughout North Minneapolis with over 476 people in 2005-2006.

Based on extrapolations of 2010 U.S. Census data, people age 65+ make up 7.8% of the resident population as compared to 13.9% for the state as a whole—thus the population is proportionately younger, with more children age 0-17 compared to the state as a whole. In addition to ethnic and racial diversity, there are also more foreign-born

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residents in the North Minneapolis community as compared to Minnesota as a whole (Table 1).

Profile of Dr. Solomon Carter Fuller ACT on Alzheimer’s Community

<table>
<thead>
<tr>
<th>Table 1. Dr. Solomon Carter Fuller ACTion Community Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Zip Code</strong></td>
</tr>
<tr>
<td>Population Size (estimated from 2010 U.S. Census)</td>
</tr>
<tr>
<td>% African American</td>
</tr>
<tr>
<td>% Foreign born</td>
</tr>
<tr>
<td>% Age 65+</td>
</tr>
<tr>
<td>% Age 18 or under</td>
</tr>
</tbody>
</table>

The community has a mix of single person and family households. There are portions of the community living in poverty, as well as portions that are solidly in the middle class economically. Median household income for residents of the Northside is lower than the state as a whole. Approximately 40% of residents living in the Near North neighborhoods (55411) report income below the poverty level. Approximately 24% of residents living in the Camden (55412) neighborhoods report income below the poverty level (Table 2).

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7 Source: [www.city-data.com](http://www.city-data.com) (uses 2010 Census Bureau data); accessed April 1, 2015.
Table 2. Household Data - Dr. Solomon Carter Fuller ACT on Alzheimer’s Community

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>55411</th>
<th>55412</th>
<th>Minnesota</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median Household Income</td>
<td>$28,193</td>
<td>$43,493</td>
<td>$56,954</td>
</tr>
<tr>
<td># Households</td>
<td>4,785</td>
<td>5,856</td>
<td>---</td>
</tr>
<tr>
<td>% 1 Person Household</td>
<td>21%</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>% Female Householder</td>
<td>40.5%</td>
<td>32.1%</td>
<td>16.9%</td>
</tr>
<tr>
<td>% Households with individuals 65+</td>
<td>15.5%</td>
<td>14.7%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Average Household size</td>
<td>3.18</td>
<td>2.71</td>
<td>2.48</td>
</tr>
<tr>
<td>Residents with income below poverty level (2011)</td>
<td>40.4%</td>
<td>24.1%</td>
<td>11.9%</td>
</tr>
</tbody>
</table>

According to the U.S. Census Bureau data (2010), there are approximately 10,641 households in the Northside within these two zip code areas. About 60% of these are family households—meaning there are two or more people living in the household who are related by birth, marriage, or adoption. Approximately 32-40% of households are headed by a female. The composition of these households tends to be younger and have more people, per household unit, than Minnesota statewide. In addition, proportionately fewer households have a person age 65+ living within them in the Northside, as compared to Minneapolis statewide.

Educational attainment for residents living in these Northside neighborhoods is lower than the average statewide. Data are shown in Table 3.

Table 3. Educational Attainment in zip codes 55411 and 55412

<table>
<thead>
<tr>
<th>ZIP</th>
<th>High School or Less</th>
<th>Bachelor or Associates Degree</th>
<th>Graduate Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>55411</td>
<td>30%</td>
<td>14%</td>
<td>4%</td>
</tr>
<tr>
<td>55412</td>
<td>22%</td>
<td>20%</td>
<td>5%</td>
</tr>
</tbody>
</table>

9 Source: [www.city-data.com](http://www.city-data.com) (uses 2010 Census Bureau data); accessed April 1, 2015; and [http://factfinder.census.gov/faces/tables services/jsf/pages/productview.xhtml?src=CF](http://factfinder.census.gov/faces/tables services/jsf/pages/productview.xhtml?src=CF)
Groundwork & Convening

The lead agency for the Dr. Solomon Carter Fuller ACTion community is NorthPoint Health & Wellness Center. NorthPoint is a valuable community resource with a long history of working in and for the community (see Appendix A). The chief executive office of NorthPoint, Stella Whitney-West, was involved in ACT on Alzheimer’s as a member of the Health Equity Leadership Group.

The Health Equity Leadership Group is one of several leadership groups formed under the ACT on Alzheimer’s initiative. Volunteer Leadership Group members work to “embed a set of principles and values” including embracing the richness of cultural diversity and reducing health disparities into the “operational lens of all ACT on Alzheimer’s work” (See ACT on Alzheimer’s website at: www.actonalz.org/sites/default/files/.../HEidentity-purpose-082714.docx )

As the Health Equity Leadership discussions continued, the group determined that there should be more focus on African-American and Latino communities, given the high risk data identified by the Alzheimer’s Association. That decision was explored in a conversation with Olivia Mastry and Emily Farah-Miller (ACT on Alzheimer’s leads), and Dawn Simonson (Metropolitan Area Agency on Aging). Vanne Owens Hayes, also a member of the Health Equity Leadership Group and a Cultural Consultant and Health Educator, agreed to initiate the first steps. She approached Stella Whitney-West and Beverly Propes, a public health nurse who is known for her advocacy around health issues affecting this North Minneapolis neighborhood to create an ACTion community for the North Minneapolis community. Stella agreed to have NorthPoint Health & Wellness Center serve as the lead agency for the effort. NorthPoint provides the infrastructure and serves as the fiscal agent, provides administrative.secretarial support, offers meeting space, and provides supplies (e.g., copying, mailing supplies).

Groundwork for this ACTion community began in 2014. In March of 2014 the Co-Coordinators for this action community (at that time called “North Minneapolis” ACTion community) were invited to be on the community radio station (KMOJ) to briefly describe the ACT on Alzheimer’s initiative and its importance to the African American community.

An important part of our initial groundwork was to follow the framework and approach of community-based participatory work. We brainstormed how we could get all levels and all ages involved. We talked about going to people where they are—not expecting them to come to us. We worked on getting the word out in many different ways.
Beverly and Vanne talked to the Minneapolis City Council President and, joined by Olivia Mastry, also talked to the Minneapolis Mayor’s policy aide to describe the initiative. Both offices indicated their support. The Co-Coordinators also approached other individuals and organizations already active in senior services and health issues affecting seniors in the Northside community.

All agreed that North Minneapolis, with a large concentration of African American residents, would be a prime area to begin to raise awareness of the disease and also to engage residents, businesses, churches, and local organizations in identifying gaps in resources and in setting a plan for action.

Estimating the number of people with Alzheimer’s Disease

A methodology provided in the Toolkit to estimate the number of people with Alzheimer’s disease. The estimate for this Northside community is shown below.

1. Estimate your population over the age of 65 years. Divide by 9 to estimate the number of people with Alzheimer’s and related dementias. For these two zip code areas (55411 and 55412) = 3,694 ÷ 9 = 410 people with Alzheimer’s

2. 1 in 7 people who have Alzheimer’s live alone. Estimate this population for your community. 410 ÷ 7 = 58 people living alone.

What makes our community unique is the strong leadership. We are willing to organize and address community issues. This is sometimes the only way. It is part of how we access resources.

Among the individuals stepping forward to work on this ACTion team effort were Henry Crosby from the Y at Heritage Park, Christina Kendrick from City of Minneapolis, Gayle Skoglund from Augustana Open Circle Adult Day Services, Rev. Leonard Thompson from Fellowship Missionary Baptist Church, Dr. Tamiko Morgan of Metropolitan Health...
Dr. Solomon Carter Fuller Community - Activities and Progress Report

Plan, Helen Jackson Lockett-El of Minnesota Council of Churches, and Evelyn LaRue from Minneapolis Public Housing/Heritage Park Senior Services Center.

This core group of individuals began working together as an ACTion community in April of 2014. Additional community members joined in the effort as well as time went on, including Samantha Mills from the Office of Senator Al Franken, Maren Levad from the Minnesota History Museum, Angela Williams of the Minneapolis Urban League, Rose McGee (a caregiver), Connie Rance (a community member), Famata King (nurse from the community), Ora Hokes (a community member) and Mamie Favor (a caregiver). The ACTion team was comprised of between 9 and 15 people who met monthly to develop their approach and a work-plan. This core team began their work by reviewing the Dementia Capability Toolkit and discussing how to engage the community at large.

Another partner was the YMCA—just 2 years ago they developed a senior center and they do the Silver Sneakers® program there.

The team working on this initiative re-named their group the Dr. Solomon Carter Fuller ACT team. The ACTion community is named after the African American psychiatrist who worked alongside Dr. Alois Alzheimer to identify the disease. Dr. Fuller was the first known black psychiatrist in America and a pioneer of research on the physical changes in the brain (See Alzheimer’s Association website at: http://www.alz.org/africanamerican/bios.asp).

When we began to seek out information about Alzheimer’s disease and the African American population, we learned about the work of Dr. Solomon Carter Fuller, who was a colleague of Dr. Alois Alzheimer and was integral in the discovery of the disease. This was significant. We knew then that we had a leading figure—and we therefore decided to name our ACTion community after Dr. Solomon Carter Fuller.
All of the ACTion team meetings were held at NorthPoint. Kate Houston from the Metropolitan Area Agency on Aging provided technical support, and participated in monthly meeting discussions.

We relied heavily on Kate from the Metro Area Agency on Aging. She has been very supportive of this community.

Kick-off
The ACTion Team decided to have a community-wide kick-off event. Each member of the ACTion Team was asked to notify their personal and professional networks to generate interest and invite them to come. The event was announced through local churches. Residents of Augustana were notified. The City of Minneapolis sent out information. One month before the community kick-off event, an article appeared in the Star Tribune about the work of Dr. Joseph, an African American researcher at Mayo Clinic. This helped generate interest in the effort as well.

This event was held on September 18, 2014 at Heritage Park Senior Services Center to officially launch the effort (See Appendix B and Appendix C for the program and YouTube videos of the event). Approximately 70 people attended.

Assessing
Beverly volunteered to facilitate the community engagement process. Nine members of the ACTion team said they would conduct community interviews to assess their community resources and determine high priorities for action. They reviewed the assessments in the Toolkit, which uses a sector-specific approach. Marsha Berry (Alzheimer’s Association) and Kate Houston (Metropolitan Area Agency on Aging) coached these team members on how to present basic facts about Alzheimer’s disease and about conducting interviews in the community, using the question sets and the Toolkit guided process.

The Toolkit has 13 sector surveys\(^\text{12}\) which vary (include questions specific to that sector)—but have a common format. Questions ask about the current level of activity on a specific issue or function or resource, and then ask the interviewee about his/her opinion whether than issue/function/resource should be a priority for action.

\(^{12}\) Note that this community did not like the term “surveys.” That term has negative connotations to the African American community. Instead, the ACTion team members talked about engaging the community through structured conversations using this Toolkit.
Table 4. Toolkit question structure and scale response

<table>
<thead>
<tr>
<th>Level of Current Activity</th>
<th>Priority for Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Strongly disagree</td>
<td>1. Strongly disagree</td>
</tr>
<tr>
<td>2. Disagree</td>
<td>2. Disagree</td>
</tr>
<tr>
<td>3. Neither agree or disagree</td>
<td>3. Neither agree or disagree</td>
</tr>
<tr>
<td>4. Agree</td>
<td>4. Agree</td>
</tr>
<tr>
<td>5. Strongly agree</td>
<td>5. Strongly agree</td>
</tr>
<tr>
<td>0. Do not know</td>
<td>0. Do not know</td>
</tr>
</tbody>
</table>

The Dementia Capable Community Toolkit had been piloted with communities that did not match the urban or ethnic/racial composition of the Northside community. Thus, the Co-Coordinators anticipated that some aspects of the Toolkit and process—including language within the Toolkit—might not fit them.

The Toolkit was such a good guide about the process for community engagement. It was great to have everything scripted out for us.

However, right away we felt that the word “survey” was not a good term to use. Historically African American communities have been harmed by surveys and research which were touted as for their benefit, but turned out not to be so. Therefore we started off using the term “community engagement process.” We also read the questions and felt that some of them could put people off. Thus, we modified our approach.

Members of the team were asked to identify 3 to 5 people to interview. They contacted the individuals and set up time to meet, or conducted the interview by phone.

We divided up the work. I (Vanne) took the legal/financial sector. Beverly took overall responsibility for the process and also did interviews with case workers at Minneapolis Public Housing. Gail did residential settings, Helen did churches, Tamika and Stella did clinics/doctors/hospitals. Christina did local government, and John did transportation. Connie did community members. . . . The hardest thing was scheduling.
Forty-one assessments were conducted from October through December 2014. Representatives from all 13 sectors participated, although some sectors only had one representative.

We found that it was important to give the interviewee a summary of what we’re trying to achieve first before asking any questions—why are we doing this? We explained that we really want to reduce the impact of this disease on individuals and families in our community.

Dr. Solomon Carter Fuller ACT Assessments Stats:

- 41 Surveys Completed across 13 Sectors
- 9 ACT team members
- 3-4 individuals participated in meeting(s) to discuss results

<table>
<thead>
<tr>
<th>13 Sectors</th>
<th>Represented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Day Programs (AD)</td>
<td>✓</td>
</tr>
<tr>
<td>Caregiver Supports (CS)</td>
<td>✓</td>
</tr>
<tr>
<td>Community Members (CM)</td>
<td>✓</td>
</tr>
<tr>
<td>Action Team (AT)</td>
<td>✓</td>
</tr>
<tr>
<td>Employers (E)</td>
<td>✓</td>
</tr>
<tr>
<td>Legal Council (LC)</td>
<td>✓</td>
</tr>
<tr>
<td>Local Government (G)</td>
<td>✓</td>
</tr>
<tr>
<td>Residential Settings (RS)</td>
<td>✓</td>
</tr>
<tr>
<td>Social Service Agencies (SSA)</td>
<td>✓</td>
</tr>
<tr>
<td>Transportation (T)</td>
<td>✓</td>
</tr>
<tr>
<td>Clinics (C)</td>
<td>✓</td>
</tr>
<tr>
<td>Home Health Agencies (HHA)</td>
<td>✓</td>
</tr>
<tr>
<td>Hospitals (H)</td>
<td>✓</td>
</tr>
</tbody>
</table>

Figure 6. Toolkit Coded Sectors
Some of the sector question sets were lengthy; especially the health care one. We had provided the questions to the providers beforehand. They completed what they could, then we met as a group to complete the assessment.

At our monthly Team meetings we brainstormed how to get some additional feedback from some of the less well represented groups—such as the business community and government. Those questions sets were long and they don’t have the time to sit down and fill out a long survey or be interviewed for a long time. There was too much detail.

Analysis

The ACTion team conducted an analysis of the results in January, 2015. At first, they worked on reviewing the results and tabulating by hand. This was too complicated/confusing. Then an intern was hired to enter the data and put them in the matrix.

It was a lot of information to deal with. We tried to aggregate using the online process. It was confusing. We hired an intern who was more familiar with data entry than I. She did that and put the results in the Toolkit matrix.
Then the Co-Coordinators sat down with Kate Houston to examine the results. The two priorities that emerged had to do with (1) increasing community awareness and (2) increasing referrals to community support services for caregivers.

**Action Planning**

Results of this work were showcased on February 19, 2015 with another community wide meeting and a Call to Action. The ACTion team had set up the meeting to include smaller group discussions for the community to be engaged in developing action strategies. The group first came up with the action steps and then individuals submitted their pledges to identify specific actions they would take.

![We included a Pledge and Call to Action at our February meeting to encourage community members to come forward to take action in a specific way. We hoped they would engage and get more involved now that the priorities were specified by the community.](image)

The Pledges were tallied following the February meeting (see Appendix D). The most frequent pledges were to pursue Dementia Friends or Dementia Champions training and to host a dementia educational/awareness session at a local church.

![The Health Ministry Team at Fellowship Missionary Baptist Church has been inspired to seek support for caregivers in their congregation and have volunteers who prioritized this work. Also, recently a member from Fellowship showed us a Book on Alzheimer’s for African-American Churches (2006) that looks like a promising educational tool. We plan to order it form our Action Phase. We are also receiving calls from community churches requesting presentations re: memory loss/dementia.](image)

**Key Supports**

In addition to the support and guidance provided by Kate Houston from Metropolitan Area Agency on Aging, other ACTion community team leaders also emerged as important in providing assistance and information. These included: the St. Paul Neighborhoods Action Community Team, and the team leads from St. Louis Park, Edina, and Roseville.
ACTion Community Results to Date

Thus far, the Dr. Solomon Carter Fuller ACTion team has included representatives from:

- African American Leadership Forum Health & Wellness Work Group
- Augustan Open Circle Adult Day Services of Heritage Park
- City of Minneapolis, Neighborhood and Community Relations
- Fellowship Missionary Baptist Church
- Heritage Park Senior Services
- Heritage Park YMCA
- Metropolitan Area Agency on Aging
- Metropolitan Health Plan
- Minneapolis Urban League
- Minnesota Association of Black Physicians
- Minnesota Council of Churches
- NorthPoint Health & Wellness Center
- Volunteers of America

The work of this ACTion community over one year (March 2014-May 2015) has included:

- Putting together a lists of names of local individuals and organizations and reaching out to request their involvement in this initiative
- Gathering information about Alzheimer’s disease and resources for the African-American community
- Creating the ACTion Team identity, providing the team with a culturally significant name, and launching the initiative
- Reviewing the ACT Toolkit and community engagement process as outlined in the Toolkit
- Making modifications to the language that was used in the Toolkit and modifying the process to fit the timeframe available for the work,
- Deciding how to talk about this within the community,
- Planning the open community meetings and events,
- Dividing up various functions between ACT team members,
- Working on the messaging and outreach to determine how to have the conversations (assessments) to gather information about gaps and priorities,
- Conducting the assessments/conversations,
- Determining how to analyze the information gathered (and doing so),
- Discussing the results as a small group,
- Drawing the community together to discuss results and priorities,
- Brainstorming with the community to identify possible action steps,
- Landing on the action steps to pursue and writing an Action Plan,
Beginning to pursue some of the activities that individuals pledged they would do, such as raising awareness through churches and providing additional caregiver support (through a new support group and referrals to three existing culturally competent support service providers).

**Lessons Learned/Advice**

The Co-Coordinators described the advantages of being part of a coordinated effort—part of the larger ACT on Alzheimer’s initiative. The Health Equity Leadership Group had led to the establishment of this ACTion community within the Northside community. Having the scripted community engagement process and the technical assistance and seed money through ACT was critical to initiating and then working through the Dementia Capable Community Toolkit—it provided some resources to do the work. In addition, the information and sharing from other ACTion community leads was also important for helping to address some of the challenges and short-cut or avoid bumps in the process.

Challenges have included the language and terminology used in the Toolkit, the lack of culturally relevant resources, the complexity of the assessment and analysis process, and the time commitment this process took.

Going through the process of synthesizing the data gathered from the CEP was truly a struggle – and time consuming. We have, of necessity, been on an aggressive timeline in order to get through the four phases by the end of 2015. Our coordinators have become volunteers as our resources have been exhausted.

The Co-Coordinators note that there is a heavy demand on many African American community based non-profit organizations and churches—coming from many agencies and from government. These larger organizations want to partner/collaborate, but there is an inequality of resources between the organizations—they have greater capacity and can hire or allocate existing staff time for special projects. However the smaller community-based organizations cannot. They have to continue to stretch existing time which is already stretched.
Communities such as ours don’t have the resources—staff time—available to donate to an effort such as this. Organizations leading this may or may not be able to do that. So a community such as ours starting this up would need to think through how they can have an all-volunteer force. One way to facilitate this would be to have a list of activities/tasks and time commitment associated with each one. Then each person knows what he/she is committing to and can make informed decisions.

The Co-Coordinators also remarked that they have found surprisingly few resources designed for African Americans regarding Alzheimer’s disease/dementia and caregivers of persons with the disease—especially few from the vantage point of various service sectors (e.g., business, faith community, government, health care).

Nationwide it is important for the African American community to know about this disease. We are interested in connecting with other African American groups, coalitions, organizations, or grassroots efforts that are focusing on this disease in the African American population. Finding what is going on across the country and learning from their work is a higher priority now as compared to when we started.

Despite these challenges, the Co-Coordinators say that the Dr. Solomon Carter Fuller ACTion team remains “on fire” and committed to addressing the impact of Alzheimer’s disease and dementia on the African American community living or working on the Northside of Minneapolis.
Appendix A: NorthPoint Health & Wellness History
Appendix B: Community Kick-off Event Program

Dr. Solomon Carter Fuller
ACT on Alzheimer’s

Action Team Members
- NorthPoint Health and Wellness Center
- Y at Heritage Park
- Heritage Park Senior Services Center
- Augustana Open Circle Adult Day Services
- Fellowship Missionary Baptist Church
- Minnesota Council of Churches
- Metropolitan Health Plan
- Minneapolis Urban League
- City of Minneapolis
- Minnesota Association of Black Physicians

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With support from:
ACT on Alzheimer’s
Alzheimer’s Association Minnesota-North Dakota
AALF Health & Wellness Work Group
Metropolitan Area Agency on Aging

Community Event
Thursday, September 18, 2014
6 pm to 8 pm
Heritage Park Senior Services Center
**About Dr. Solomon Carter Fuller**

- Born August 11, 1872 in Monrovia, Liberia to Americo-Liberians. His grandfather, a former slave, had purchased his freedom and moved the family to Liberia.
- At age 17 he came to North Carolina to attend college.
- He graduated in 1893 from Livingstone College then went on to study medicine at Long Island Hospital and Boston University School of Medicine where he received his M.D.
- First Black psychiatrist and neurologist in the United States.
- Worked with Dr. Alois Alzheimer and contributed to the growing clinical knowledge of Alzheimer’s disease.
- Associate Professor at Boston University’s School of Medicine for over 30 years.
- Boston University’s mental health facility officially known as the Dr. Solomon Carter Fuller Mental Health Center.
- American Psychiatric Association honors Black pioneers with an award in his name for ‘providing significant benefit to the quality of life for Black people’.

**Program ~ 6pm to 8pm**

I. Welcome and Introductions - Rose McGee, Emcee

II. About the Dr. Solomon Carter Fuller ACT on Alzheimer’s Action Team

III. What is Alzheimer’s/Dementia? Memory Loss?

IV. Video ‘B. Smith and Her Diagnosis of Alzheimer’s’

V. Local family story

VI. ACT on Alzheimer’s - Olivia Mastry, Executive Lead

VII. Questions and Answers

VIII. Invitation to Join Us
Appendix C: Community Kick-off Event (September 18, 2014) Videos:

- Full Video: http://youtu.be/dnsMRKawO-w
- Creating Action Team Identity: http://youtu.be/6IwxwlP4zAg
- What Dementia Friendly Is and Is Not for One Community: http://youtu.be/DSh9yiYPPrc
- Acting Together In Ways That Have Meaning for Us: http://youtu.be/1pjSJJmVD3k
Appendix D: February 2015 Call To Action Community Meeting Pledges

**TALLY RESULTS**

I am willing to support the efforts of the Dr. Solomon Carter Fuller ACT on Alzheimer’s Action Team to address the impact of Alzheimer’s in north Minneapolis.

- I will mow my neighbor’s lawn, or shovel their snow, to help with chores
- I will take them on a MN Historical Society tour for people with memory loss
- I will volunteer at an adult day program for people with dementia 1
- I will mow my lawn, or shovel their snow, to help with chores
- I will take them on a MN Historical Society tour for people with memory loss
- I will become a Dementia Champion and host a Dementia Friends session (or many!) 1
- I will provide respite (one hour, overnight, or anything in-between) for a family member who is caring for a spouse or parent so they can rest, run an errand, or go out to dinner 1
- I will plan a Dementia Friends session in my living room, at the local coffee shop, or at my place of business and ask a trained Champion to host
- I will become a Dementia Champion and host a Dementia Friends session (or many!) 1
- I will help research culturally-appropriate resources for educating others about the disease 1
- __ Other (please indicate)

I will get my organization ________________ to support the efforts of the Dr. Solomon Carter Fuller ACT on Alzheimer’s Action Team by doing one of the following:

- __ Host a Dementia-Friends Training session 1[Grandparents Raising Grandchildren];
- __ Organize a Caregiver Support Group 1
- __ Host Alzheimer’s/dementia awareness Sunday at church 111[U Care Skyway Senior Center]
- __ Sponsor an Alzheimer’s Walk during the Longest Day Walkathon this June 1
- __ Host a community information series re Alzheimer’s/dementia 1
- __ Have members of my organization receive Dementia-Friends Training. 111
- __ Help raise funds to sustain the efforts of the Dr. Solomon Carter Fuller ACT on Alzheimer’s Action Team 1
- __ Other [please indicate] Receive dementia training: 11
  * Participate in Alzheimer’s awareness Sunday at church: 11
  * Make materials, e.g. 10 Signs, available at clinic: 1