

Minnesota Aligning Forces for Quality (AF4Q) Consumer Engagement Workgroup

Final Report: November 2006 – April 2011

I. Background and Introduction

Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's (RWJF) signature effort to lift the overall quality of health care in targeted communities, reduce racial and ethnic disparities, and provide models for national reform, www.forces4quality.org. AF4Q asks the people who get care, give care, and pay for care to work together toward common, fundamental objectives to lead to better care. The \$300 million commitment to improve health care in 15 communities, that together cover 11 percent of the US population, is the largest effort of its kind ever undertaken by US philanthropy.

Each of the 16 Aligning Forces communities throughout the country has built its initiative around a core, multi-stakeholder leadership alliance working to advance the goals and activities of AF4Q at the local level. These alliances include participation from physicians, nurses, patients, consumers and consumer groups, purchasers, hospitals, health plans, safety net providers and others to improve the quality of health care through public reporting of health care data, provider quality improvement, and consumer engagement.

AF4Q in Minnesota

MN Community Measurement (MNCM) leads the AF4Q initiative in Minnesota. The Minnesota AF4Q initiative is guided by a broad stakeholder group forming the AF4Q Leadership Team. Organizations represented on the AF4Q Minnesota Leadership Team include: the American Cancer Society, Buyers Health Care Action Group, Institute for Clinical Systems Improvement (ICSI), Minnesota AARP, MN Community Measurement, Minnesota Department of Human Services, Minnesota Hospital Association, Minnesota Medical Association, Stratis Health, plus health plans, consumers, clinics, hospitals, physician and nursing leadership, and more. The Minnesota AF4Q initiative is also furthering consumer engagement through its Consumer Engagement Workgroup.

With the award of the initial Robert Wood Johnson Foundation grant for the AF4Q initiative in Minnesota, the Minnesota AF4Q Consumer Engagement Workgroup (CE Workgroup) was launched and held its first workgroup meeting on November 10, 2006. The charge to the workgroup at the time of project launch was to analyze best practices for engaging consumers to access and utilize provider performance data, such as the materials produced by MNCM, as a way to further engage with their health care provider and more fully participate in their care.

The current AF4Q Consumer Engagement Workgroup will disband when Phase III of the grant begins in May, 2011. The goals of this report are to document Minnesota AF4Q CE Workgroup efforts over the five years of the workgroup's existence, assess the results and learnings, and initiate an action agenda for future consumer engagement work, including both within the next iteration of the AF4Q initiative and other community efforts.

Minnesota AF4Q Consumer Engagement Workgroup Meetings and Membership

To carry out its work, the CE Workgroup has met on a monthly basis since the inception of the project. The meetings were on a structured schedule – second Monday of each month, by telephone for one hour, and every quarter, in-person for two hours.

Jennifer Lundblad, CEO at Stratis Health, was appointed Chair of the CE Workgroup, and the original members included:

Michelle Ferrari, MN Community Measurement (Staff)
Donna Anderson, Public Health Consultant/Consumer
Matt Flory, American Cancer Society, Midwest Division
Kristina Milinkovich, Stratis Health
Anne McGeary Snowden, MN Community Measurement
Kris Soegaard, Buyers Health Care Action Group
Ellie Strock, Park Nicollet International Diabetes Center

Over time, the membership has changed and expanded, and the composition of the workgroup in 2011 included:

Laura Bloom, MN Community Measurement (Staff)
Donna Anderson, public health consultant/consumer representative
Hugh Curtler, Medica
Matt Flory, American Cancer Society, Midwest Division
Jennifer Lundblad, Stratis Health (*Chair*)
Larry Morrissey, Stillwater Medical Group
Jan Pearson, Park Nicollet International Diabetes Center
Chris Schaefer, American Diabetes Association, Minnesota Area
Kris Soegaard, Buyers Health Care Action Group

This final report is organized into the following sections:

- **Understanding and Defining Consumer Engagement**
- **Focusing on Diabetes**
- **Reaching out to Cultural Communities**
- **Building Bridges with other Minnesota Consumer Engagement Efforts**
- **Synthesizing Key Learnings**
- **Formulating an Action Agenda**

II. Understanding and Defining Consumer Engagement

Literature Review

To launch and guide the CE Workgroup, we conducted a brief review of the research and literature in 2006, focusing on three areas:

- Connection between consumers' use of performance data and subsequent interaction with their providers
- Self-management of chronic conditions
- Decision-support tools

While the research and literature was sparse at the time, largely driven by the work of researchers Judith Hibbard, Dale Shaller, and Sheila Leatherman, it served as an initial guide to our work and a source of some evidence-based strategies and ideas. See Appendix A to access the literature review.

“Minnesota model” for Consumer Engagement

The workgroup spent substantial time at the start of its work discussing the various definitions of consumer engagement. The group discussed the distinctions between consumer audiences (i.e., the general public) versus a patient audience (i.e., those seeking information about specific care they require). The workgroup recognized the multiple audiences with multiple needs, and that no one message or message vehicle would fit for all. As a result, the workgroup initially focused on a targeted, highly motivated/educated population (e.g., patients with diabetes), with plans to expand as knowledge grew.

The discussions of the definition and focus led the CE Workgroup to clarity of purpose and intention within the scope of the AF4Q initiative, and the development of the visual depiction of the “Minnesota model” of how the consumer engagement component of AF4Q intersects with the public reporting and quality improvement components. The model, AF4Q “Sweet Spots” (depicted on the following page) served as a useful tool throughout the life of the CE Workgroup. In particular, the use of the model helped the Workgroup focus on:

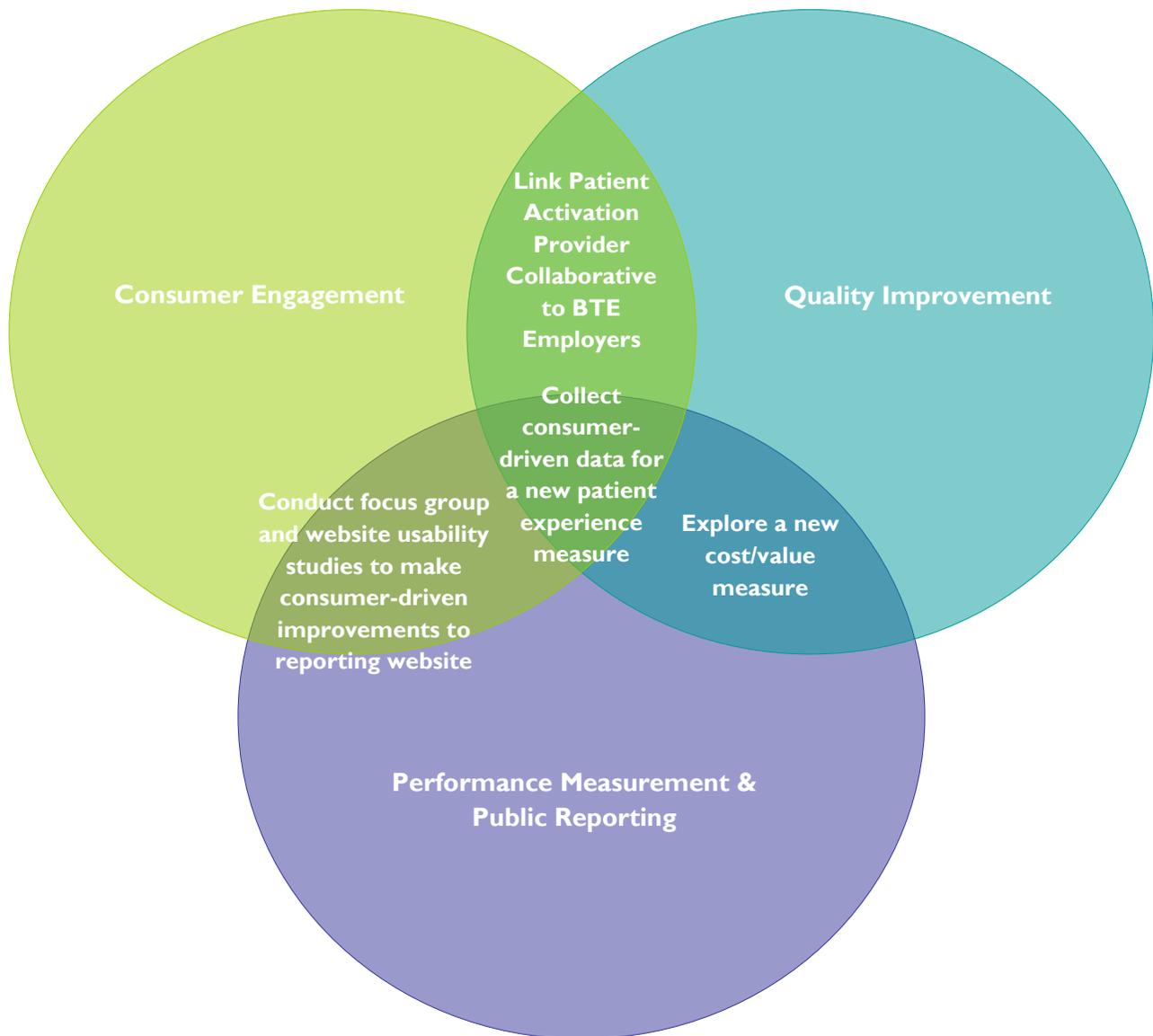
- a singular disease focus – diabetes – with the goal to delve deeply into one chronic condition and then spread the learnings to other diseases and conditions, which we hope will now materialize with the next iteration of AF4Q and the added clinical topics areas
- an activity focus on those areas reflected in the model.

As a result, our Minnesota AF4Q Consumer Engagement Workgroup vision, reviewed and approved by the Minnesota AF4Q Leadership Team, has been, “Consumers make informed decisions about their healthcare by actively using quality information.” Our workgroup aim has been,

We will work to engage consumers in the quality and management of their care by making information relevant and understandable and by highlighting the information at opportune decision making points.

Aligning Forces for Quality (AF4Q) Consumer Engagement “Sweet Spots”

Philosophy: Our best bets for engaging consumers are where the three areas of AF4Q overlap.



Focusing on Diabetes

Diabetes Patient Focus Groups

In May 2007, the CE Workgroup conducted a series of three focus groups with 28 employed people with diabetes. The objectives of the study were to learn how consumers – specifically, employed people with diabetes – engage in their health care, to what level they are aware of health care quality and information about health care quality, their reaction to the health care quality information provided by MNCM on its public reporting website and how the MNCM Web site and overall consumer engagement in health care might be improved.

The goals for the focus groups were defined as:

- a) Understanding baseline consumer engagement levels, in terms of how consumers define healthcare quality, whether or not they are aware of differing levels of quality among healthcare providers, and to what degree they are aware of and utilize healthcare quality information;
- b) Barriers people experience in understanding and utilizing healthcare quality information, specifically those materials produced by MNCM; and
- c) Opportunities to increase consumer engagement, in terms of how MNCM materials can be improved upon, as well as broader ideas on how to increase awareness of healthcare quality information.

Key findings of the focus group study, which were shared widely in the community via presentations by CE Workgroup members and MNCM staff, were:

- Consumers with diabetes generally are very engaged in the management of their conditions.
- Consumers with diabetes accept responsibility for their health status and thus do not believe that only health care providers are accountable for a patient's health outcomes.
- Consumers with diabetes value a physician's "soft" skills and perceived level of knowledge about diabetes.
- Consumers with diabetes perceive that health care quality is not uniform.
- Consumers with diabetes currently rely on subjective resources to find good care.
- The quality of institutional support for consumers with diabetes is not uniform.
- Awareness of the MNCM public reporting website among consumers with diabetes is very low.
- The MNCM public reporting web site is fairly easy to understand and navigate.
- Consumers are inherently suspicious of statistics, as well as the motivations of organizations that publish statistics.
- The measures published on the MNCM public reporting web site do not provide a complete or trusted picture of the quality of care for consumers with diabetes.
- Consumers believe what is measured is managed.
- Consumers with diabetes are not ready to use outcomes data to make health care decisions.
- Employed consumers with diabetes prefer to learn about MNCM's public reporting web site via the annual open enrollment period for their employee benefits plan.
- Consumers with diabetes are receptive to messages about health care quality information from trusted, objective sources.

The focus group findings served as foundational guidance for much of the subsequent work of the CE Workgroup. See Appendix B to access the complete focus group report.

Development and Launch of “The D5”

Based largely on the results of the focus groups, the CE Workgroup developed and launched a micro-site in the fall of 2007 devoted exclusively to MNMCM’s optimal diabetes care measure – the birth of “The D5.”

The D5 is a website and a set of related tools to support patients and their care team in the treatment and management of diabetes, and is found at www.thed5.org. It was created to make it easier for people with diabetes and their health care providers to work together to set and achieve goals to better manage the disease. The D5 goals are based on clinical guidelines developed by the Institute for Clinical Systems Improvement, and are similar to goals promoted by the American Diabetes Association.

The D5 focuses on the five goals that have the greatest health impact. For instance, people who achieve the D5 greatly reduce their risk of heart attack, blood vessel damage and other cardiovascular diseases. Patients achieving the D5 also experience fewer problems with their kidneys, eyes and nervous system. In addition to the D5, it is also important to receive other regular care like foot and eye exams. The D5 home page appears as follows, as of March 2011.



Minnesota’s D5 efforts and materials have been upheld as a best practice in several national studies and publications, including the following:

Hibbard J, Sofaer S. *Best Practices in Public Reporting No. 2: Maximizing Consumer Understanding of Public Comparative Quality Reports: Effective Use of Explanatory Information*. AHRQ Publication No. 10-0082-EF, May 2010, Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/qual/pubrptguide2.htm> (specific section: Recommendation No. 2)

Dudley RA, Hibbard JH, Shaller D. *Model Public Report Elements: A Sampler*. Rockville, MD:

Agency for Healthcare Research and Quality; 2010. AHRQ Publication No. 10-0088.
<http://www.ahrq.gov/qual/value/pubrptsampler.htm> (specific section:
<http://www.ahrq.gov/qual/value/pubrptsampl2c.htm#Consumer>)

Meeting Consumers Halfway: Context-Driven Strategies for Engaging Consumers to Use Public Reports on Health Care Providers (Dale Shaller, MPA, David Kanouse, PhD and Mark Schlesinger, PhD) A Paper Commissioned for the AHRQ National Summit on Public Reporting.

D5 Supporting Tools

A variety of communication tools and resources were developed in late 2007 for the D5 website. The goal of developing these tools was to have resources available for providers to help disseminate messages about the five important goals for optimal diabetes care and as a way to more actively engage patients in the management of their diabetes. These tools included:

- D5 Scorecard (since renamed the Health Tracker)
- D5 Appointment Card (since consolidated with the updated Health Tracker)
- D5 Recipe Card (discontinued in 2011)
- D5 Magnet (discontinued in 2011)
- D5 Poster and Flyer, and
- D5 Diabetes Notebook

In 2010, the CE Workgroup, through MNMCM, commissioned an evaluation study of the D5 website and printable tools to better understand the usefulness of the D5 strategy and apply lessons learned in the development of other patient engagement resources. This study consisted of a series of semi-structured telephone interviews held with stakeholders who had previously downloaded one or more of the D5 tools over the previous two years. The majority of the interviewees worked within a clinic setting and included physicians, nurses, care coordinators, managers and quality improvement specialists. The results of the study provided many insights into how to make the D5 tools more effective, which D5 tools get used the most frequently and how, and recommendations for future improvements.

This study also led to a number of additional suggestions such as:

- Development of a guide to using the D5 tools for diabetes
- A Spanish language translation of the Health Tracker
- Elimination of some of the less utilized tools
- Expanded awareness campaign of the D5 website and communication tools

All of the tools and materials can be found on the web site.

A snapshot of recent access and use of the D5 website shows the volume of web page views and downloads:

D5 Web Analytics

2009 (3/16/09 – 12/31/09)	2010 (1/1/10 – 12/31/10)	2011 (through 3/31/11)
4,339 visitors	4,857 visitors	1,488 visits

15,797 pageviews 2:54 average time on site 3.64 average pages per user	16,447 pageviews 2:39 average time on site 3.39 average pages per user	4,987 pageviews 2:37 average time on site 3.35 average pages per user
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The frequency of tools downloaded is listed here, from most frequent to least:

HealthTracker/Scorecard	23.1%
Flyer	21.0%
Poster	18.3%
Notebook	16.5%
Postcard	13.0%
Logo	6.5%
Recipe Card	1.1%
Magnet	0.5%

Users who downloaded tools from the website included individuals with diabetes, clinic/medical groups, health care organizations, public health agencies, employer groups and health plans.

It is also important to note that participants in the evaluation study were supportive of MNCM developing D5-like tools for other chronic conditions as well. This may be a strategy to pursue for the added focus areas in Phase 3 of the RWFJ AF4Q grant.

Diabetes Expo and other Outreach

The Diabetes EXPO is an annual event sponsored by the American Diabetes Association and attended by approximately 8,000 people per year during the six hour event. It offers speakers, fitness and healthy food demonstrations, an Ask the Expert Area, free screenings (eye, foot, blood pressure, sleep apnea, A1C, cholesterol, kidney function, BMI, hearing depression, etc.), and over 75 vendors of diabetes supplies and services. It includes everything for diabetes under one roof. The majority of attendees have type 2 diabetes, but many have pre-diabetes, type 1, or gestational diabetes and often bring their families and friends. This event is offered free to the public and transportation in the metro area as well as from many rural areas is provided free or at a nominal cost. The D5/AF4Q has been a part of the EXPO to provide information about its D5 website and materials. Members have been available to answer questions and offer these items as additional resources for help in managing diabetes.

III. Reaching Out to Cultural Communities

In 2008, the CE Workgroup expanded its focus to include racial and ethnically diverse populations, congruent with the expansion of the AF4Q program focus on this topic.

Learning Circles with Cultural Communities in Minnesota

The CE Workgroup, through MNCM, contracted with the Cultural Wellness Center (CWC) in an effort to engage diverse communities on the topic of achieving high quality diabetes care and understanding race/ethnicity/language data collection from the consumer perspective. The CWC is a community-initiated organization that mines and synthesizes experience-based knowledge to both explain problems and deliver solutions. The work of the Cultural Wellness Center is about carrying out its mission, “to unleash the power of citizens to heal them-selves and to build community.”

In fall of 2009, the CWC conducted six listening circles with the African American, East African, European American, Hmong and Latino communities on the topic of high quality diabetes care and the collection of race/ethnicity/language data. Approximately 40 community members participated in this series of six different listening circle meetings. Upon completion of the listening circles, CWC welcomed about 35 people from across all six of the focus group participants from different cultural groups (African American, East African, European American, Hmong, Latino, and Native American) to a dinner and conversation to discuss the findings. Each of the listening circles addressed these questions:

1. What does a good relationship with your health care provider look like?
2. What are the best ways to communicate information about diabetes for your (or health information in general)?
3. What is the best way for a provider to ask you to identify your cultural group and language preference?

The information is rich and deep, with common themes, variations in kind of responses identified, and specific suggestions recorded. To further illuminate the examples and specify the themes, the CWC was asked in 2010 to bring together the same cultural groups to review the findings from 2009 and make recommendations to health care providers. On September 27, 2010, CWC convened a community forum with 45 participants, many of whom had attended the previous year. To engage diverse communities in identifying key messages and actions that would assist health care providers, health plans, coalitions and other stakeholders in two endeavors:

- a. Help patients from traditionally underserved populations achieve goals associated with the optimal diabetes care performance measure.
- b. Collection of race, ethnicity, and language (R/E/L) data.

The specific findings and recommended action steps which emerged from the cultural communities are described as follows (see Appendices C and D to access the complete reports).

What are the best ways to communicate information about diabetes for you (or health information in general)?

1. People want more information on how to prevent diabetes in their cultural community.
Action Steps for health care providers and stakeholders:
 - 1) Flood the media with information to help prevent diabetes.
 - 2) Expose young children to diabetes education early in their schooling.

2. It is important that information on diabetes, both for prevention and management, be delivered in culturally appropriate ways.
Action Steps for health care providers and stakeholders:
 - 1) Provide diabetes education information in different languages.
 - 2) Train people in the cultural communities so they can spread diabetes information to their community and people can ask them questions.
 - 3) Provide diabetes education information at cultural gatherings, celebrations, and events.
 - 4) Hire people who know the cultural ways that affect healthy lifestyle, such as cultural foods and cooking and eating practices.
 - 5) Incorporate cultural healing practices into a diabetes care plan.
 - 6) Emphasize that diabetes does not have to define a person, but that people with diabetes can lead healthy lives if they take an active part in their care.

3. Utilizing the power of interpersonal relationships.
Action Steps for health care providers and stakeholders:
 - 1) View the patient's family support system as a crucial resource in their care plan. Meet with, and be welcoming to, the whole family to educate them about diabetes so they can better support the patient.
 - 2) Encourage people with diabetes to support each other in group meetings, classes, and listening circles.

4. The preferred way for people to get health information is from their doctor, usually the most trusted person in the clinic.
Action Steps for health care providers and stakeholders:
 - 1) At diagnosis, give the doctor time to explain all the resources available for their specific condition(s).
 - 2) Give people time to ask questions and explain what is working and not working for them.
 - 3) Create a care plan in which both providers and patients have contributed their knowledge and experience.
 - 4) Other venues that people find useful: community gatherings, celebrations, breakfasts, feasts, give-aways; videos; the internet; classrooms and workshops; phone calls; media (PSAs); and grocery stores.

Collecting Race/Ethnicity/Language (R/E/L) Data

1. It is important for people to know why the data is being collected.
 - People are generally not clear about what those reasons are.
 - In terms of direct patient care at a personal level, the collection of R/E/L data is seen as a benefit to help providers give culturally appropriate care. Immigrant groups and Native Americans, in particular, feel it is important for providers to understand their culture to give good care.
 - On the other hand, the reasons regarding the benefits of publicly reporting R/E/L data are not completely or clearly understood.

- Participants fear that giving that information may cause discrimination, stereotyping, or make people feel unwelcome, uncomfortable, and “diminished.” “Why should the R/E/L question be asked when the “rules” state that no one should be discriminated against because of their race?”

Action steps for health care providers and other stakeholders:

- 2) Educate yourself about the communities you serve.
- 3) Hire employees from cultural communities.
- 4) Establish a relationship with patients. Greet people and make them feel welcome before asking questions.
- 5) Show you care about the person and respect their culture. Building trust is very important.
- 6) More needs to be done to clearly communicate the benefits of public reporting. The relevance to the patient should be clear.

2. There is variation in the way people wish to receive information about R/E/L data collection. Many wanted the information in written form, many wanted it in both verbal and written form, and some preferred it in verbal form.

Action Steps for health care providers and other stakeholders:

- 1) Provide written information on R/E/L data, including reasons for collecting it, and an example of how the data is useful.
- 2) Ask patients if they would also like someone to verbally explain the reasons for collecting the data to them.

3. It is important how the R/E/L data collection questions are asked.

- The relationship between the health care provider and the patient is a crucial factor in how the R/E/L data collection questions will be interpreted. In cross-cultural interactions, the context in which a question is asked is as important as the question itself. People want to feel that the provider is trustworthy and respectful of their culture/race/ethnicity. A welcoming environment is essential.
- Most people prefer that the doctor ask the question. Since the question is one which requires trust, people focus on the doctor as the most important relationship for establishing trust.
- It is better to ask than guess, and to ask outright than to guess out loud.
- People have different opinions about whether the question should be asked by handing patients a form or by asking the question verbally. Some prefer to be handed a form to check a box, while others (particularly immigrant groups) prefer to be asked verbally.
- The quality of interpretation services can affect how well the patient understands the question and the reasons for it.

Action Steps for providers and other stakeholders:

- 1) Make sure the patient feels welcome.
- 2) Non-verbal, body language is very important.
- 3) A health care provider with whom the patient has built trust and/or a person of the same culture as the patient is the ideal person to ask the question.
- 4) Don't ask questions based on assumptions.
- 5) Ask about R/E/L first before you ask about medical problems. (This can be part of getting to know the patient.)

- 6) Use the patient's preferred language, if possible.
 - 7) Ask the patient if he or she would prefer to fill out a form or to be asked verbally. For most people from immigrant groups, asking verbally is best.
 - 8) Offer to answer any questions or concerns about the collection of R/E/L data.
 - 9) If English isn't the patient's preferred language, talk slowly and don't give too much information without checking in to make sure the patient understands.
 - 10) If you are using an interpreter, ask the patient how the interpretation is going, and if he or she is satisfied with the information they are getting.
4. The categories and terms used to describe cultural groups in R/E/L data collection are problematic and for some people, offensive. Some people want to be able to self-identify and/or to be able to identify themselves as multi-racial or multi-cultural. For example:
- Some people of Native American heritage find the term "American Indian" offensive.
 - Some Native Americans prefer to use their tribal name, e.g. Dakota or Ojibwe.
 - Many want more specificity, e.g. African American, born in such and such a place, or Hmong, Korean, or Chinese – not Asian.
 - Some people want to check as many boxes as the cultures represented by their known ancestors.
 - Some people want identity categories by nationality, others by a broader sense of culture.
 - Some want to identify themselves as "European American" instead of "White," because they see this category as fostering racial identity and therefore, racism.
- Action Steps for providers and stakeholders:
- 1) Expect some complaints about the R/E/L data collection categories.
 - 2) Explain that the categories are determined by the federal government and are attempting to be relevant across the entire country for many communities.
 - 3) If the person is upset by the questions and/or categories, provide them an address and/or phone number where they can register their concerns or complaints.

IV. Building Bridges with other Minnesota Consumer Engagement Efforts

Inventory of Patient/Member/Consumer Committees

In early 2009, the Consumer Engagement Workgroup, via MN Community Measurement, contracted with Stratix Health to conduct a survey to develop an inventory of existing patient/member/consumer committees that exist in Minnesota, sponsored by health care delivery organizations, health plans, and other health-related consumer organizations.

Stratis Health contacted 28 organizations that were asked to complete an on-line survey about any standing committees at their organization. The survey identified 12 existing consumer/patient/member panels or committees:

- 100% interact with patients (or members, residents, clients)
- 66.7% interact with other consumers
- 58.3% interact with families of patients (or members, residents, clients)

This information provides a rich source of communication avenues through which AF4Q and other consumer education/outreach initiatives can reach a wide range of patients and consumers.

Organization Name	Committee Name	Does your organization have a standing committee through which you interact with:		
		Patients*	Families of patients*	Other consumers
AARP	AARP - Member Engagement	Yes	Yes	Yes
Abbott Northwestern	No response	N/A	N/A	N/A
American Cancer Society	Minnesota State Leadership Team	Yes	Yes	Yes
American Diabetes Association, Minnesota Area	No committee	No	No	No
Blue Cross Blue Shield of MN	No committee	N/A	N/A	N/A
Citizens League	No response	N/A	N/A	N/A
Fairview Ridges Hospital	No response	N/A	N/A	N/A
Fairview Southdale Hospital	Women's Advisory Board	Yes	No	No
Fairview University Hospital	No response	N/A	N/A	N/A
FirstPlan of Minnesota	FirstPlan Blue Basic Stakeholder Committee	Yes	No	No
HCMC	No committee	N/A	N/A	N/A
HealthPartners	Do not complete outside surveys	N/A	N/A	N/A
Medica	The Center For Health Aging: Senior Advisory Council	Yes	No	Yes
Medica	Member Advisory Committee	Yes	Yes	Yes
Medica	State Public Programs: Community Advisory Council	Yes	No	Yes
Mercy/Unity Hospitals	No committee	N/A	N/A	N/A
Methodist Hospital	No response	N/A	N/A	N/A
Metropolitan Health Plan	No response	N/A	N/A	N/A
Minnesota Department of Health	Health Care Homes Consumer Family Advisory Council	Yes	Yes	Yes
North Memorial Hospital	No committee	N/A	N/A	N/A

Park Nicollet Health Services	Park Nicollet Health Services	Yes	Yes	No
PreferredOne	No committee	No	No	No
Regions Hospital	Patient and Family Advisory Council	Yes	Yes	No
St. John's Hospital	No response	N/A	N/A	N/A
St. Joseph's Hospital	No response	N/A	N/A	N/A
Stratis Health	Stratis Health Community Outreach Committee	Yes	No	Yes
UCare	No response	N/A	N/A	N/A
United Hospital	No response	N/A	N/A	N/A
Woodwinds Health Campus	Woodwinds Community Advisory Board	Yes	Yes	Yes

When asked which of the following best describes the purpose(s) of the committee, the following responses were reported:

- 91.7% To share information and updates between our organization and patients/families/consumers
- 75.0% To get feedback on health care programs or benefits we offer
- 75.0% To get feedback on patient/family/consumer education materials
- 75.0% For patients/families/consumers to have a voice about health care programs**
- 75.0% For patients/families/consumers to have an opportunity to inform policy and practices
- 50.0% To develop and/or respond to state or federal health care policy issues
- 25.0% Other: to support fundraising, to learn about issues “on the ground;” to participate in development HCH (health care home) program
- 16.7% For patients/families/consumers to resolve complaints or concerns

**Access, satisfaction, or service delivery

Forging Linkages to Other Consumer Engagement Efforts in Minnesota

An aspect of the CE Workgroup strategy was to be playful and deliberate about the linkages between the AF4Q Consumer Engagement work and other consumer engagement efforts in Minnesota, to learn and share, and to avoid duplication. Examples of these linkages include:

- *Minnesota Bridges to Excellence (BTE)*: The Buyers Health Care Action Group (BHCAG) manages the MNBTE program, an employer-led pay-for-performance initiative and Kris Soegaard served as the liaison to the AF4Q CE Workgroup. Diabetes was the first condition covered by MNBTE, using performance rates published by MNCM. While the focus of the program is on health care provider performance, consumer engagement and an understanding of the D5 is critically important to success patient outcomes.
- *MN Shared Decision Making Collaborative (MSDMC)*: The MSDMC was formed in November 2008 to enhance effective shared medical decision-making between patients and their clinicians by studying and implementing methods to assure that medical decisions are well-informed by best available evidence and consistent with patient preferences. There was significant positive interaction between members of the CE Workgroup and MSDMC workgroups to achieve each group's goals.
- *Statewide Health Improvement Project (SHIP)*: Members of the CE Workgroup met with staff at the Minnesota Department of Health to explore the potential to integrate information about *MN HealthScores* and The D5 into the worksite strategies as part of SHIP, a grant program involving all 87 counties in Minnesota. Workgroup members specifically inquired about the potential to work with counties that have workplace wellness coalitions. Although the Health Department

staff expressed interest, staff turnover and the uncertainty of continued support of the state legislature have put these plans on hold. It is our hope to renew these conversations once the Minnesota Legislature has adjourned and the future of SHIP is clearer. In addition SHIP, the cardiovascular program at the Minnesota Department of Health has partnered with local chambers of commerce to promote workplace wellness. We may explore ways of partnering with this local initiative.

- *State Diabetes Steering Committee:* The state's Diabetes Steering Committee has been, in many ways, on a parallel path to the CE Workgroup over the course of our work, as they have focused on updating the state diabetes plan. As a result, our CE Workgroup has shared information, and through our overlapping members, intend to use the CE Workgroup results and learnings as an opportunity to shape and guide the state's ongoing work in the future.
- *Health Commissioner's Consumer Engagement Task Force:* Consumer engagement was part of Minnesota's health reform legislation passed in 2008. The state health commissioner convened a Consumer Engagement Task Force, and Jennifer Lundblad served as the liaison from the AF4Q CE Workgroup. She shared the diabetes focus group results, and the cultural community learning circle findings, and was able to advise and support the Commissioner's work on behalf of AF4Q.
- *American Association of Diabetes Educators, (AADE) Minnesota Network:* AADE offers a website designed for its members to connect locally or with more than 13,000 AADE members across the U.S. CE Workgroup member Jan Pearson developed a PowerPoint presentation introducing The D5 Communication Tools and shared it with the Network to increase awareness of the D5 as a resource for members to use in education programs, clinical practice sites and various community venues.
- *The Minnesota Diabetes Collaborative (<http://mn-dc.org/>)* has been an important partner and promoter of the D5, especially providing in-kind support for dissemination of D5 communications tools and messages at the annual ADA Diabetes Expo events.
- *Minnesota Council of Health Plans:* The AF4Q CE Workgroup undertook steps to keep the Council staff apprised of the workgroup's D5 and other consumer engagement efforts throughout the duration of the CE project. Often this involved notices that the Council staff could forward to health plan representatives to keep them "in the loop" and to disseminate patient education materials, as appropriate.

The range of organizations that the CE Workgroup has connected with in a deliberate way demonstrates both the opportunities and challenges of patient and consumer engagement, reflecting the wide range of what it means to be a "consumer" or "patient." It also demonstrates the need for regular and ongoing communication and coordination between and among consumer engagement efforts, to be able to leverage learning and opportunities. Consumer engagement is dynamic and ever evolving, and our AF4Q CE Workgroup efforts have been an important contribution to the base of knowledge and experience that we hope is widely utilized going forward.

V. Synthesizing Key Learnings

To synthesize the AF4Q CE Workgroup key learnings, we posed a series of questions to members of the workgroup. Their aggregated responses are reflected here.

How useful were the statements of vision, aim, and strategic planning framework in guiding our efforts?

- Initial charge---to analyze best practices for engaging consumers to access and utilize provider performance data as a way to engage further with their provider and more fully participate in their care—was challenging, difficult task because relatively new field of disseminating health-quality information to consumers in a concise, easy-to-read format and little documentation or evidence available to inform us.
- Processes/documents (e.g., literature review, focus groups) were critical to focusing our efforts on the specific disease of diabetes, a good place to start for all stakeholders since this condition has significant, adverse, long-term impact on individual health as well as health systems costs. We established a framework and foundation for moving forward and a touchstone for looking back.

How well did these processes lead us to creating shared goals?

- We addressed shared goals from two perspectives: First, within the workgroup itself where the processes and thinking together were helpful in getting to a good sense of shared goals. Second, we thought our spread and impact could be greater by connecting and leveraging our group work to goals and projects within our own organization or community, and while difficult to measure, we view our work as a success based on qualitative and anecdotal feedback.

What did we accomplish together? What worked well?

- Workgroup members who came from diverse perspectives brought out the best in each other in a team approach and collaborative spirit, guided by a strong, effective chair to keep us challenged, focused, and results-oriented. The team made learning together and hard work easier.
- Our accomplishments together are centered in these three highlights:
 - 1) the selection of diabetes arena to focus consumer engagement needs and opportunities led to launching The D5 website and a series of related tools to improve the interactions and partnership between patients and their clinical providers;
 - 2) understanding the needs and preferences of cultural communities in Minnesota both in diabetes and the collection of R/E/L data by collaborating with the Cultural Wellness Center, although it feels like we just opened the door, scratched the surface;
 - 3) connections made and linkages developed between our work and other consumer-oriented efforts in Minnesota that helped us to live up to the “Aligning Forces” underpinnings and name and to learn how to partner with other organizations better, ranging from the Diabetes Expo to diabetes education groups to disease advocacy groups to state initiative and programs.

What could we have done differently?

- We could have approached the challenge of communicating with the broad community differently to have a larger impact rather than relying on methods with which we were familiar in reaching out to various communities.

- We could have used the Consumer Engagement “Sweet Spots” model more effectively as a visual to convey our goals and desired results, and more regularly updated it to reflect the dynamic and changing work of consumer engagement.

What have we learned?

- While consumer engagement is very hard, challenging work with no one recipe or cookbook, it is rewarding. It begins with developing relationships and is fostered by respect, access to accurate information and ongoing trust. It requires diligence and patience, repeating the same messages many times.
- Because no clear path or direction supported by evidence (there is growing base of research), we recognized and allowed room for creativity, innovation, experimentation, and failure. There are a lot of talented people who can bring their varied gifts and perspectives to the table for thinking and acting together.
- By starting small and keeping goals and approach focused, the CE Workgroup made progress, having success to demonstrate impact in both processes and products and creating models and learnings for the future.
- We learned more about the needs and gaps in the metropolitan area by listening to each other and reaching out to peers, colleagues, and others.
- We looked at diabetes from the perspective of the person and family not only from a medical perspective, and to take this knowledge and communicate its richness to health professional and clinical providers.
- We tried to communicate with the general public about how quality data/information could contribute to them making healthier choices whether choosing a health care provider or priorities for managing their own diabetes.

What were our best products, results and outcomes?

- The D5 and its communication tools such as the User’s Guide and Spanish language translation of the Health Tracker
- Data on the use of The D5.
- The results of the learning circles of the culturally diverse communities.
- The survey of existing patient/consumer advisory groups.
- Recognition that consumer engagement is an area in which more research and work is needed.

VI. Formulating an Action Agenda

Consumer engagement is dynamic and ever evolving, and our AF4Q CE Workgroup efforts have been an important contribution to the base of knowledge and experience that we hope is widely utilized going forward. We want to make a set of specific recommendations for organizations and groups going forward that will be working in the consumer engagement arena, both within the AF4Q project and throughout the community.

1. It is critical to engage the consumer and patient first and foremost based on their own interests and needs (i.e., based on their health or their disease or condition), and only then will data, web sites, and tools be relevant and meaningful.
2. The use of a visual model (for example, our CE Workgroup Venn Diagram) is a helpful tool to bring focus and identify linkages – it helped us to stay grounded, and to sequence our efforts appropriately, amidst the vast array of possible consumer engagement activities.
3. It is important to draw upon consumer engagement research when available. The body of research and knowledge is growing rapidly, and we recommend regularly re-visiting the research studies to inform evidence-based consumer engagement work going forward, updating our literature review and how it can be applied to consumer engagement efforts.
4. Experimentation and innovation are necessary as we continue to learn more about consumer engagement. We recommend the continued use of pilot projects to learn and prepare for larger scale efforts.
5. We recommend that greater attention be given to consistent communication and common messages. These concepts are important in consumer engagement efforts as supportive tools to drive and reinforce changes in consumer and provider behavior and actions.
6. The learnings in this report are directly relevant and applicable to other disease conditions and topics. We recommend that the next iteration of the AF4Q project take these learnings and actions into account.
7. A wide range of perspectives and expertise is important in developing and implementing consumer engagement activities. We recommend taking the time to establish a vision, measurable goals, project charters, and strong processes and infrastructure to support effective engagement, implementation, and achievement of goals.

It has been an exciting journey for the Minnesota AF4Q Consumer Engagement workgroup over the past five years. We have made great progress toward our vision and aim, and have produced a wealth of tools and reports that have served Minnesota consumer well. While this report represents the final formal work product of our group, we look forward to continuing to share our story and experience, recognizing that consumer engagement is one piece of a larger picture. We are confident that our experiences, learnings, and action recommendations leave a legacy for future consumer engagement efforts in Minnesota and beyond.

Appendix A

AF4Q Consumer Engagement Workgroup
Selected Literature Review
November 2006

Appendix B

The Minnesota Consumer Engagement Focus Group Study
Final Report
June 22, 2007

Appendix C

Healthcare Information Forum
September 27, 2010
Ways to Communicate Information about Diabetes

Appendix D

Healthcare Information Forum
September 27, 2010
Collecting R/E/L Information

All reports available upon request.

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