

Patient Panel Summary Panel Survey Wave 2

This document summarizes the results of the Healthy York: Aligning Forces for Quality (AF4Q) consumer panel, wave 2. The consumer panel includes patients with diabetes (n=154), coronary artery disease (n=189) and heart failure (n=68). The Center for Opinion Research at Franklin and Marshall College recruited panel members using random procedures. Family First Health, Memorial Primary Care, and WellSpan Medical Group provided lists of all patients who had an office visit for one of the three designated conditions during 2006. Eligible panelists were between the ages of 18 and 65, lived within York County, and provided confirmation they had the noted condition. The panelists included in the second interviewing wave, conducted during August 2008, includes interviews with 389 respondents who also completed the first-wave interview.

The panel is a tool for 1) evaluating the effectiveness of the AF4Q initiative, and 2) identifying ways to improve patient comprehension of quality issues. Specifically, the second wave panel survey instrument was designed to address four questions:

1. What are the unique problems, fears, needs, and goals of patients with chronic conditions?
2. How successful have patients been in setting goals to stabilize their conditions?
3. How do patients with chronic conditions prepare for their doctor visits?
4. How well do patients with chronic conditions communicate with their physicians?

Living with a Chronic Condition

Most panelists define the phrase “chronic health condition” as a permanent or life-long condition (25%), as a serious condition (19%), as a persistent and constant affliction (12%), or as a condition that requires medical attention and regular monitoring (12%). About one in ten (8%) define the term as life threatening, deadly or fatal. The uses of these definitions are similar within each category of condition. Most (78%) panelists say they do not prefer a different term to describe their condition. Half of those who do prefer a different term to describe their condition are unsure about what the term should be.

Table 1 presents panelists’ most common responses to four questions about their problems, fears, needs, and goals. Panelists’ responses differ considerably for these questions depending on their condition. Diabetes patients have the greatest difficulty with diet, are most concerned about amputation (18%) and blindness (16%), and feel they need the greatest assistance with diet (30%). CAD patients say their biggest problems relate to a poorer quality of life (20%), their biggest fears are a worsening of their condition (27%), and many say they need help with diet and weight loss (25%). HF patients identify many problems: breathing issues (22%), a reduced quality of life (18%), and physical limitations (16%). HF patients are more likely to fear death (22%) and are less likely to report anything specific that would help them deal with their condition. In fact, HF patients are more likely than others to say they fear nothing about their condition and there is nothing that would help them deal with it.

Table 1 Panelists' Top Problems, Fears, Needs and Goals by Condition	Diabetes	Coronary Artery Disease	Heart Failure
What are the biggest problems your condition has caused you?			
Diet	29%	9%	6%
Energy level low, tired, weak	2%	7%	10%
Heart issues	1%	18%	10%
Breathing issues	0%	7%	22%
Physical activity/mobility limitations	6%	10%	16%
Quality of life lessened	3%	20%	18%
Nothing, don't know	20%	17%	16%
What do you fear most about your condition?			
Amputation, losing limbs	18%	1%	0%
Death, dying	5%	17%	22%
Eye problems, losing eyesight	16%	0%	2%
Life span, shortening life	1%	10%	10%
Reoccurrence, worsening of condition	12%	27%	4%
Nothing, don't know	13%	28%	30%
What do you think would help you the most to deal with your condition?			
Diet, weight loss – stick to it	30%	25%	6%
Education about condition, management education	10%	4%	4%
Exercise	3%	10%	10%
Medication, better medication	3%	10%	7%
Nothing, don't know	21%	22%	32%
What is your primary health goal?			
Diet, weight loss – stick to it	47%	39%	20%
Exercise	6%	16%	18%
Managing condition, keeping under control	36%	23%	25%

Goal Setting

More than three in four (77%) diabetics have a specific health goal related to their condition, which is a greater proportion than either CAD (68%) or HF (59%) patients, as Table 2 shows. Only about one in five panelists have a written health goal and only about one-third say their doctor helped them set that goal. Respondents whose physician helped them set their goal are no more likely to have written it down. Patients with a health goal have higher patient activation scores: 43% of PAM stage 1 patients have a health goal compared to 67% at stage 2, 75% at stage 3, and 73% at stage 4. Diabetes (47%) and CAD (39%) patients' primary goals are losing weight and dieting (see Table 1). High proportions of each group do not identify a specific goal, but instead say their goal is simply to keep their condition under control.

Table 2 Goal Setting Behaviors by Condition	Diabetes	Coronary Artery Disease	Heart Failure
Do you have any health goals related to your condition?			
Yes	77%	68%	59%
Is that goal written down?			
Yes	19%	15%	21%
Did your doctor help you set that goal?			
Yes	39%	37%	31%

Preparing for Doctor's Visits

Most (90%) patients in the panel visit their doctors on a regular basis rather than going only when they don't feel well. Many (42%) patients do not prepare at all for their doctor visits, and about one in three (37%) say their only preparation is to gather their test results. One in seven (15%) panelists prepares questions or notes to take along to their visit. Most (90%) patients say their doctors give them advice about how to improve their health, but many (40%) find it difficult to follow that advice primarily because they find it difficult to change their habits (52%). A few (12%) panelists do not follow their doctor's advice because they simply do not want to.

Doctor-Patient Communication

The first wave of interviewing found that patients were comfortable with the inter-personal aspects of their health care. Most believe their physician or health care professional treats them with dignity and respect, talks in a way they can understand, and spends enough time with them. Although the patients in the first panel seem generally satisfied with the inter-personal aspects of their care, gaps were evident in physician-patient communications. The second wave survey finds that these gaps in communication persist. Most patients say their doctors invite questions and most are satisfied they can ask as many questions as they want (see Table 3). Still, few patients have ever been asked to explain their understanding of their conditions to their doctors and fewer still were given written information about their condition at their last visit. About three in five patients say their doctors use medical words they don't understand and only about a third are "extremely confident" when leaving their doctor's office that they understand what they've been told.

Table 3 Panelists' Assessments of Doctor Patient Communications by Condition	Diabetes	Coronary Artery Disease	Heart Failure
How easy is it for you to remember the information that you receive from the doctor?			
Extremely easy	46%	47%	44%
Quite a bit	30%	28%	29%
How confident do you feel when leaving the doctor's office that you understand what the doctor has told you?			
Extremely confident	30%	36%	43%
Quite a bit	36%	39%	35%
How often does your doctor use medical words that you don't understand?			
Never	38%	35%	41%
Does your doctor invite you to ask questions about anything you do not understand about your condition?			
Yes	94%	93%	85%
Does your doctor normally answer all of your questions or are you limited in the number of questions you can ask?			
Normally answers all questions	93%	95%	91%
Does your doctor ever ask you to explain what you understand about your condition in your own words?			
Yes	40%	34%	37%
During your last visit, did your doctor give you any written information to answer questions about your condition and treatment?			
Yes	24%	17%	18%

Note about the Patient Activation Measure

The survey included the Patient Activation Measure (PAM) instrument to assess consumer knowledge, skills and confidence for self-management.ⁱ The PAM instrument places consumers into one of four stages based on their confidence in their ability to self-manage their conditions. Stage 1 consumers do not understand that they need to play a role in their own health care, Stage 2 consumers lack basic knowledge about their condition, treatment options, and/or self-care, Stage 3 consumers have the basic facts related to their conditions and treatments, and Stage 4 consumers have made many behavioral changes, but may have difficulty maintaining those behaviors over time or during times of stress.ⁱⁱ Using the PAM stages as a guide, about two in ten diabetics and CAD patients, and about one in three HF patients, do not believe the patient's role in health care is important or lack the confidence and knowledge to take action.

ⁱ The Patient Activation Measure is copyrighted by Insignia Health. Center for Opinion Research staff used scoring guidelines provided by Insignia health to create the final PAM categorical scores.

ⁱⁱ This description of the PAM stages is taken from the Insignia Health license materials.