Caring for Patients with Diabetes
In Safety Net Hospitals and Health Systems:
What Patients Say About their Care

National Public Health and Hospital Institute

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1301 Pennsylvania Avenue, NW Suite 950 Washington DC 20004 Caring for Patients with Diabetes
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### Caring for Patients with Diabetes In Safety Net Hospitals and Health Systems: What Patients Say About Their Care

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#### **Executive Summary**

Safety net hospitals and health systems are among the largest providers of diabetes care in the nation. Each year, public hospitals and health systems see millions of patients with chronic diseases and provide critical health services in primary and specialty care outpatient clinics, emergency departments, and inpatient settings. Unlike community health centers, which concentrate on primary care, or public health departments, which focus on preventive services, public hospital systems can provide low-income and vulnerable patients with a broad and coordinated set of services that address the complexities associated with diabetes and other chronic diseases.

In 2002, with support from The Commonwealth Fund, the National Public Health and Hospital Institute (NPHHI) created a consortium of safety net hospital systems to work together to address common concerns regarding the care of patients with diabetes. As part of that project, NPHHI conducted a survey of patients with diabetes who received at least some of their care from four Consortium hospital systems: Cambridge Health Alliance; Community Health Network of San Francisco/San Francisco General Hospital; Cook County Bureau of Health Services; and LSU/Medical Center of Louisiana at New Orleans. Patients were surveyed on multiple domains of care, including overall satisfaction, access to important diabetes-related services, self-management, health status, and communication with their health care providers.

This effort, known as the *Consortium for Quality Improvement in Safety Net Hospitals and Health Systems*, was the first initiative of its kind to bring a group of safety net hospital systems together to examine quality of care provided for diabetes patients. The work of the Consortium underscores the critical role that safety net hospital systems play in delivering high-quality diabetes care to a patient population that is primarily low income, ethnically and racially diverse, and that has high rates of literacy problems. The study signals the need for comprehensive programs to support the care of vulnerable patients with chronic conditions and highlights areas for improved communication between providers and patients. Project outcomes can be summarized around several major findings:

- Although Consortium members care for large numbers of patients with diabetes who are
  racially and ethnically diverse, low income or uninsured, and often with limited English
  or literacy proficiency, the study found few significant differences among racial groups
  regarding assessment of health status and access to care.
- Despite programs at safety net hospitals to increase access to care for patients, uninsured
  patients continue to report poorer control of their diabetes and disparities in access to
  care. Compared with patients with any insurance coverage, fewer uninsured patients
  reported having a primary care provider and more reported skipping medications due to
  cost.
- Up to one-third of the patients at Consortium hospital systems reported having languages other than English as their primary language, and one-quarter reported having health literacy problems. Patients commonly reported problems understanding basic instructions involved in diabetes management. Safety net hospital systems are continually challenged to provide culturally and linguistically appropriate services for their diverse populations. Appropriate provider-patient communication becomes a particularly salient issue for patients with chronic illnesses like diabetes that require self-management and understanding of providers' instructions. More research is necessary to understand the cultural and linguistic needs of various patient populations and to design targeted programs that address these needs in the context of comprehensive care management.
- The NPHHI study revealed the importance of providing comprehensive care that draws on relevant health professionals in the management of chronic illness. Diabetes teams should be expanded to include health care professionals and social workers able to address the variety of factors that affect diabetes care for low-income and minority patients. Much more work is necessary to develop comprehensive, tailored diabetes management programs that take into account literacy, language, and co-morbidities.

- The study identified several key areas for improvement in care for patients with diabetes in safety net hospitals, specifically around patient-provider communication. In general, survey respondents reported few problems with the care they received and their communication with providers, but not consistently across race and ethnicity. A sizable group of patients (one-quarter or more) reported having difficulty understanding their providers' use of medical terminology, identified a need for improved communication, or noted the providers' failure to take into account the patient's religion or culture.
- Although patients generally identified few problems with the care they received, a
  remarkably high proportion of survey respondents indicated they were in fair or poor
  health and/or had pain that interfered with their ability to exercise. In part, this is a
  reflection of the experiences of patient populations in safety net hospital systems, who
  tend to suffer from co-morbidities such as heart disease and depression.

#### Introduction

Safety net hospitals and health systems are among the largest providers of diabetes care in the nation. Each year, public hospitals and health systems see millions of patients with chronic diseases and provide critical health services in primary and specialty care outpatient clinics, emergency departments, and inpatient settings. Unlike community health centers, which concentrate on primary care, or public health departments, which focus on preventive services, public hospital systems can provide low-income and vulnerable patients with a broad and coordinated set of services that address the complexities associated with diabetes and other chronic diseases.

In 2002, with support from The Commonwealth Fund, the National Public Health and Hospital Institute (NPHHI) created a consortium of safety net hospital systems to work together to address common concerns regarding the care of patients with diabetes. The goal of the *Consortium for Quality Improvement in Safety Net Hospitals and Health Systems* was to develop information about the care of patients with diabetes in safety net hospital systems and to share lessons about effective clinical practice across a broader group of safety net providers.

This report presents findings from surveys of patients who received care for diabetes from four of the NPHHI Consortium hospital systems. The Consortium selected diabetes as a starting point, with the expectation that additional cross-institutional projects would concentrate on other common concerns related to chronic disease management.

Diabetes is one of the nation's most critical public health concerns. An estimated 18 million people in the U.S. have type-2 diabetes, and the incidence of the disease is growing at an alarming rate.<sup>2</sup> According to the Centers for Disease Control and Prevention (CDC), 29 million

<sup>&</sup>lt;sup>1</sup> See: M. Regenstein, J. Huang, et al., *Caring for Patients with Diabetes in Safety Net Hospitals and Health Systems* (New York: The Commonwealth Fund, 2005).

<sup>&</sup>lt;sup>2</sup> National Institute of Diabetes and Digestive and Kidney Diseases, National Diabetes Information Clearinghouse. "National Diabetes Statistics," April 2004. NIH Publication No. 04-3892.

Americans will be diagnosed with diabetes in 2050, compared with about 11 million today.<sup>3</sup> Diabetes is the sixth leading cause of death in the United States, and its incidence disproportionately affects patients of racial and ethnic minority groups and the poor.<sup>4</sup> Minority group patients with diabetes are also at higher risk of developing microvascular complications of diabetes and having lower limb amputations than non-minorities.<sup>5</sup>

Diabetes care is expensive; people with diabetes have health care costs that are, on average, three times greater than costs for people without diabetes.<sup>6</sup> In addition, diabetes is the leading cause of end-state renal disease (ESRD) in the U.S., accounting for 44 percent of new cases.<sup>7</sup> Black patients continue to have the highest prevalence of ESRD, at more than three times the national rate.

Nowhere is the diabetes epidemic felt more directly than in safety net hospital systems—health care providers with a common mission to provide high-quality, accessible care for all patients in their communities. Safety net hospital systems often have large patient populations who are members of racial and ethnic minorities. In a study of patients at large metropolitan safety net hospital systems, the National Association of Public Hospitals and Health Systems (NAPH) found that nearly three-quarters of ambulatory care visits were provided to non-white patients.<sup>8</sup> These hospital systems also have many patients with limited English proficiency (LEP).

<sup>&</sup>lt;sup>3</sup> J.P. Boyle et al. "Projection of Diabetes Burden Through 2050: Impact of Changing Demography and Disease Prevalence in the U.S.," *Diabetes Care* 24 (November 2001): 1936-1940.

<sup>&</sup>lt;sup>4</sup> E. Arias et al. "Deaths: Final Data for 2001," *National Vital Statistics Reports* 52 (September 2003): 1-115. J.W. Lucas, J.S. Chiller, V. Benson. National Center for Health Statistics. "Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2001," *Vital and Health Statistics* 10 (January 2004): Tables 7 and 8.

<sup>&</sup>lt;sup>5</sup> A. Spiegel. "Diabesity<sup>TM</sup> What Are Our Priorities? What Are The Research Challenges?" National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health. http://www.shapeup.org/profcenter/diabesity/Spiegel3.htm (accessed July 20, 2004)

<sup>&</sup>lt;sup>6</sup> P. Hogan, T. Dall, P. Nikolov. American Diabetes Association. "Economic Costs of Diabetes in the U.S. in 2002," *Diabetes Care* 26 (March 2003): 917-932.

<sup>&</sup>lt;sup>7</sup> National Institute of Diabetes and Digestive and Kidney Diseases, National Diabetes Information Clearinghouse. "National Diabetes Statistics."

http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm#13 (accessed November 1, 2004).

<sup>&</sup>lt;sup>8</sup> M. Regenstein and J. Shearer. *NAPH Ambulatory Care Source Book: Findings from the 2001 NAPH Ambulatory Care Survey*. (Washington DC: The National Association of Public Hospitals and Health Systems, 2002).

Because minority populations have a higher incidence of diabetes, safety net hospitals are among the largest providers of diabetes care in the nation. The Cook County Bureau of Health Services, a public hospital system that includes two acute care hospital systems, primary and specialty outpatient clinics, and a network of over 30 community-based ambulatory care sites, provides care to about 30,000 patients with diabetes. The sheer volume of patients presents an immense challenge, made greater by the large proportion of patients who have limited English proficiency, limited resources, and low literacy.

Diabetes care is a complex task, and safety net hospital systems use a variety of tools and practices to help patients manage their chronic health conditions. These health systems must customize protocols and care management programs to meet the specialized clinical and non-clinical needs of their patients. With that goal in mind, NPHHI conducted its patient survey to assess the quality of care patients with diabetes currently receive.

Four of the Consortium hospital systems participated in the patient survey:

- Cambridge Health Alliance (CHA) in Cambridge, MA
- Community Health Network of San Francisco (CHNSF) in San Francisco, CA<sup>9</sup>
- Cook County Bureau of Health Services (CCBHS) in Chicago, IL
- LSU/Medical Center of Louisiana at New Orleans (LSU) in New Orleans, LA.

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<sup>&</sup>lt;sup>9</sup> San Francisco General Hospital (SFGH) is part of the Community Health Network of San Francisco.

Table 1: Patient and Visit Volumes at Consortium Hospital Systems, 2002 (rounded to nearest hundred)

	СНА	CHNSF	CCBHS	LSU
Discharges	15,700	16,500	33,800	25,000
ER visits	80,500	47,000	214,300	172,500
OP visits	527,800	656,400	750,200	354,600
Adult diabetes patients	4,800	7,700	30,000*	13,200

<sup>\*</sup>Estimated from Consortium Study Interviews, 2004.

Source: For discharges, emergency department and outpatient visits, see: *America's Safety Net Hospitals and Health Systems*, 2002: *Results of the 2002 Annual NAPH Member Survey*. Washington, DC: National Association of Public Hospitals and Health Systems, July 2004.

These systems are all public entities with extremely large patient populations and busy outpatient clinics and emergency departments (see Table 1). The Cook County Bureau of Health Services is the largest system, with over 33,000 discharges, 750,000 outpatient visits, and 214,000 emergency department visits in 2002. The outpatient visit volumes reflect care provided in outpatient departments as well as at "off-site" clinics – i.e., at clinics located away from hospital grounds.

#### **Data Collection Methods**

NPHHI conducted a survey of patients with diabetes who received at least some of their care from the Consortium hospital systems during the period January 1, 2000, through December 31, 2002. Patients were surveyed on multiple domains of care, including overall satisfaction, access to important diabetes-related services, self-management, health status, and communication with their health care providers. Participating hospital systems provided NPHHI with telephone numbers for a representative sample of patients with diabetes. Patients were surveyed via telephone during a four-week period in December 2003-January 2004. Informed consent was obtained from all respondents prior to initiating the survey. A total of 802 patients completed the survey; respondents were sampled to obtain an equal number of white, black, and Latino respondents are a relatively even distribution of respondents across the four hospital systems whose patients participated in the survey. The survey was conducted in English, Spanish, and Portuguese. The overall response rate was 47.4 percent and ranged from 41.3 to 62.8 percent across hospital systems.

The survey was developed using questions from the FACCT Diabetes Care Survey,<sup>14</sup> health literacy questions from Chew and colleagues' study on diabetes care within the Department of Veterans Affairs,<sup>15</sup> questions from Stewart and colleagues' survey on interpersonal process of

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<sup>&</sup>lt;sup>10</sup> Patients were included in the dataset if they were 18 years or older and had two or more outpatient visits during the period January 1, 2000 to December 31, 2002. Hospital systems also provided inpatient and emergency department visit data for these patients. Patients were determined to have diabetes if they had a primary or secondary diabetes-related ICD-9 diagnosis code, excluding gestational diabetes.

<sup>&</sup>lt;sup>11</sup> NPHHI subcontracted with Multicultural Connections to field the survey. Multicultural Connections is an opinion research firm that specializes in survey and market research involving linguistically diverse patient populations.

patient populations.

12 Patients belonging to other racial/ethnic subgroups, including Asian/Pacific Islanders and Native Americans, were not sampled for the telephone survey due to insufficient population sizes across the four survey sites.

<sup>&</sup>lt;sup>13</sup> The target of 801 patients, evenly distributed across race/ethnicity, was determined based on power calculations performed prior to finalizing sampling methodology, setting alpha at .05, and power at 80 percent to detect differences across racial group analyses.

<sup>&</sup>lt;sup>14</sup> FACCT—The Foundation for Accountability. *Diabetes Care Survey*. (Portland, OR: FACCT, December 1998).

<sup>&</sup>lt;sup>15</sup> D.L. Chew, K.A. Bradley, and E.J. Boyko. "Brief Questions to Identify Patients With Inadequate Health Literacy." [in press]

care,<sup>16</sup> and questions from Toobert and colleagues' instrument on self-care activities.<sup>17</sup> The survey also used questions that were validated in previous surveys of patients with diabetes that focused on physician communication, patient understanding in self-management, self-care activities, health literacy and quality of physician-patient communication, and difficulties with aspects of diabetes management.<sup>18</sup>

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<sup>&</sup>lt;sup>16</sup> A.L. Stewart, A. Napoles-Springer, and E.J. Perez-Stable. "Interpersonal Processes of Care in Diverse Populations," *Milbank Quarterly* 77 (September 1999): 305-339.

 <sup>&</sup>lt;sup>17</sup> D.J. Toobert, S.E. Hampson, and R.E. Glasgow. "The Summary of Diabetes Self-Care Activities Measure: Results From 7 Studies and a Revised Scale," *Diabetes Care* 23 (July 2000): 943-950.
 <sup>18</sup> Ibid. M. Heisler et al. "The Relative Importance of Physician Communication, Participatory Decision Making, and Patient Understanding in Diabetes Self-Management," *Journal of General Internal Medicine* 17 (April 2002): 243-252. Stewart et al., 1999. J.D. Piette, D. Schillinger, M.B. Potter, and M. Heisler. "Dimensions of Patient-Provider Communication and Diabetes Self-Care in an Ethnically Diverse Population," *Journal of General Internal Medicine* 18 (August 2003): 624-633. D. Schillinger et al. "Functional Health Literacy and the Quality of Physician-Patient Communication Among Diabetes Patients," *Patient Education and Counseling* 52 (March 2004): 315-323.

#### Findings: What Do the Patients Say?

#### **Patient Demographics**

NPHHI designed the patient survey and the sampling methodology to focus on experiences and perceptions of care among white, black, and Latino patients with diabetes who received care at selected safety net hospitals and health systems. The study was designed to determine whether there were significant differences in patients' perceptions of their health status, self-management, satisfaction, access to important diabetes-related services, and communication with their health care providers.

The NPHHI sample represents a group of patients that is largely low income, as evidenced by high numbers who were either uninsured or covered by Medicaid. About one-third (32.9 percent) of respondents were uninsured and another third were covered by Medicaid (35.6 percent). About one in five were covered by Medicare, and fewer than one in 10 were privately insured.

Coverage varied considerably by race/ethnicity. Latino and black respondents were more likely than white patients to report having no insurance (39.5 percent and 35.3 percent respectively, compared to 23.9 percent of white patients). Because patients from hospital systems in different parts of the country participated in the survey, these differences in coverage may reflect regional variations in Medicaid coverage. Insurance also varied significantly by country of birth. Nearly a third of respondents (30.5 percent) reported being born in a country other than the U.S. Foreignborn patients were more likely to be uninsured (40.9 percent) compared to U.S.-born respondents (29.3 percent). U.S.-born patients were also much more likely to have Medicare coverage (25.4 percent) compared to foreign-born patients (16.0 percent).

Two-fifths of the survey respondents (43.2 percent) reported not completing high school, and approximately one-third of the study population completed high school or its equivalent. Fewer than one-third of respondents (27.8 percent) had some college or higher.

#### Health Status, Diabetes Control, Experiences with Pain and Depression

The NPHHI survey included questions about patients' overall health status, their own assessments of how well they controlled their diabetes, and whether they experienced depression or pain as a result of their condition. In general, patients with diabetes at Consortium hospital systems report that they are in poor health; sizeable numbers also report that they routinely cope with pain and depression as a result of their health condition. Despite these findings, however, many Consortium patients believe that they are doing a good job controlling their diabetes.

As Table 2 indicates, nearly half (49.1 percent) of all respondents rated their health status as fair or poor. Only 31.2 percent rated their health status as good, and 19.7 percent said they were in excellent health. Privately insured respondents were most likely to rate their health status as excellent or very good while Medicaid patients were most likely to indicate that they were in fair or poor health. Assessments of health status were quite similar across race/ethnicity, especially when comparing the percentage of patients who viewed their health status as fair or poor (see Table 3). Latino patients were more likely to rate their health status as excellent or very good, compared to white and black patients (23.5 percent for Latinos, compared to 16.5 percent and 19.2 percent for whites and blacks respectively).

Respondents were more optimistic about the control of their diabetes, with more than half (57.9 percent) indicating that they had excellent or good control. Still, nearly one-third (30.5 percent) rated their control as fair, and another 11.6 percent said that their control was poor or very poor. Again, privately insured patients were significantly less likely to report poor or very poorly controlled diabetes (2.9 percent), while respondents who were uninsured or on Medicaid were most likely to report poorly controlled diabetes (14.6 percent and 13.1 percent respectively).

Assessments of diabetes control showed less variation across race/ethnicity. Black respondents were less likely than others to rate their control as excellent or good (54.0 percent for blacks, compared to 59.0 percent for whites and 60.8 percent for Latinos). The proportion of respondents who indicated that they had poor or very poor control of their diabetes (11.6 percent) showed little variation by race/ethnicity.

The majority of respondents (59.5 percent) indicated that they experienced depression, at least some of the time, as a result of their diabetes; one-quarter (25.7 percent) said that they felt depressed always or often in the prior three months. Medicaid patients were nearly twice as likely to indicate that they felt depressed always or often compared to uninsured patients (35.0 percent versus 18.9 percent). When asked about their experiences with pain, 36.5 percent of respondents indicated that pain interfered with their ability to exercise quite a bit or extremely in recent months. Likewise, Medicaid respondents were most likely to report having considerable pain (48.0 percent); uninsured and privately insured patients were the least likely to say that pain interfered with exercise (26.7 percent and 26.4 percent respectively).

Table 2: Health Status of Patients, by Insurance Coverage

Table 2. Hea	Table 2. Health Status of Fatients, by insurance coverage								
	%	<b>%</b>	<b>%</b>	% Private/	% All				
	Uninsured	Medicaid	Medicare	Commercial	<b>Patients</b>				
<b>Health Status</b>									
Excellent/Very good	21.6	16.2	16.4	26.5	19.7				
Good	31.6	27.7	33.9	35.3	31.2				
Fair/Poor	46.8	56.1	49.7	38.2	49.1				
<b>Diabetes Control*</b>									
Excellent/Well	57.5	59.6	55.4	55.9	57.9				
Fair	27.9	27.3	35.1	41.2	30.5				
Poor/Very Poor	14.6	13.1	9.5	2.9	11.6				
Pain Interferes with									
Exercise*									
Not at all/A little bit	57.1	37.9	46.5	54.4	48.1				
Moderately	16.2	14.1	15.3	19.1	15.4				
Quite a bit/Extremely	26.7	48.0	38.3	26.4	36.5				
Experience									
Depression*									
Âlways	6.0	12.4	6.5	7.5	8.5				
Often	12.9	22.6	15.4	22.4	17.2				
Sometimes	29.0	30.8	29.6	20.9	29.8				
Rarely	13.7	12.0	19.5	11.9	14.4				
Never	38.3	22.2	29.0	37.3	30.1				

<sup>\*</sup>These values refer to statistically significant differences between groups (at alpha=.05)

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

Black respondents were less likely to report experiencing depression than white and Latino respondents. They were also less likely than white patients to indicate that pain interfered to a great extent with their ability to exercise, although both white and black respondents indicated greater problems with pain than Latino patients.

Table 3: Health Status of Patients, by Race/Ethnicity

	%	%	%	% All
	White	Black	Latino	Patients
Health Status				
Excellent/Very good	16.5	19.2	23.5	19.7
Good	33.0	31.6	29.1	31.2
Fair/Poor	50.6	49.2	47.4	49.1
<b>Diabetes Control</b>				
Excellent/Well	59.0	54.0	60.8	57.9
Fair	29.1	35.5	26.8	30.5
Poor/Very Poor	11.9	10.6	12.5	11.6
Pain Interferes with Exercise*				
Not at all/A little bit	36.9	49.8	57.5	48.1
Moderately	19.0	11.7	15.4	15.4
Quite a bit/Extremely	44.1	38.5	27.1	36.5
Experience Depression*				
Always	10.4	6.0	9.0	8.5
Often	19.6	11.7	20.3	17.2
Sometimes	29.6	34.0	25.9	29.8
Rarely	17.3	12.8	13.2	14.4
Never	23.1	35.5	31.6	30.1

<sup>\*</sup>These values refer to statistically significant differences between groups (at alpha=.05) Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

These responses indicate that many safety net patients are facing challenges coping with their diabetes and believe their health status to be poor, even in the midst of effective diabetes control. This may indicate that these patients are facing multiple chronic conditions and that diabetes may be one of many factors affecting their overall well-being.

In addition, overall perceptions of health and diabetes control appear to be similar, regardless of the race/ethnicity of the respondent. However, experiences with depression and pain vary significantly by race/ethnicity. These differences signal the need for highly customized, patient-centered care that addresses the complex clinical conditions that patients with diabetes face. It also underscores the need for care that takes into account patients' own perceptions about health status and their ability to effectively manage their diabetes and other conditions that may present.

#### **Access to Care and Services**

The NPHHI survey included several questions about patients' ability to access important health and diabetes-related services. These services included the availability of a primary care provider as well as access to eye exams, flu vaccines, medications, and diabetes education (see Table 4). The survey also included questions about the respondents' perceptions of discrimination on the part of their providers or the health care organization that could affect overall access to or quality of care.

The majority of respondents reported having a primary care provider or primary nurse practitioner (87.4 percent). Over three-quarters (76.9 percent) reported having eye exams (in which their eyes were dilated) in the last year; the comparable percentage for people with diabetes in the general population is 63.3 percent. Only one-third of respondents (33.9 percent) reported having a flu vaccine within the past 12 months. Two-thirds (67.6 percent) reported that their health providers instructed them to take an aspirin each day. Only 28.9 percent reported attending group education classes; less than half (46.9 percent) said they received diabetes-related educational materials in the past two years.

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 <sup>&</sup>lt;sup>19</sup> J.B. Saaddine et al. "A Diabetes Report Card for the United States: Quality of Care in the 1990s,"
 Annals of Internal Medicine 136: (April 2002): 565-574.
 <sup>20</sup> Ibid.

Table 4: Access to Care Survey Questions, by Race/Ethnicity and Coverage

Table 4: Acces								
<b>Survey Question</b>	% All	%	%	%	%	%	%	%
	<b>Patients</b>	White	Black	Latino	Unin-	Medi-	Medi-	Private
					sured	caid	care	
Flu shot within 12	33.9	31.8	40.1	29.9	40.0	31.0	30.8	35.3
months*								
Dilated eye exam	76.9	77.8	77.4	75.7	73.3	79.0	82.0	77.9
within 12 months								
Have PCP^	87.4	91.2	87.0	84.1	80.3	92.5	87.0	89.1
Instructed to take	67.6	70.6	74.2	58.2	66.3	71.1	65.1	67.6
aspirin*								
<b>L</b>								
Received	46.9	47.1	44.9	48.5	44.0	49.6	39.5	58.2
materials^		.,,-						
materials								
Group class^	28.9	27.4	32.3	26.9	35.5	26.2	25.6	20.6
Group class	20.9	27.4	34.3	20.9	33.3	20.2	23.0	20.0
0	40.4	42.1	35.0	44.0	37.8	45.6	31.8	44.1
One-on-one class^	40.4	42.1	33.0	44.0	37.8	43.0	31.8	44.1
	21.1	10.0	21.2	22.0	26.4	17.0	240	1 4 7
Skipped meds	21.1	19.2	21.3	22.8	26.4	17.0	24.0	14.7
because of cost^								
Felt discriminated								
against*^								
Always/Often	4.9	4.5	4.2	6.0	3.6	5.5	6.4	
Sometimes	5.9	2.6	7.6	7.5	9.3	5.2	2.3	6.0
Rarely/Never	89.2	92.8	88.3	86.5	87.1	89.3	91.3	94.0

<sup>\*</sup>These values refer to statistically significant differences between race/ethnicity groups (at alpha=.05)

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

As Table 4 indicates, there were no significant differences by race/ethnicity related to having a primary care provider or having an eye exam over the past 12 months. However, there were statistically significant differences by race/ethnicity regarding whether patients were prescribed or instructed to take aspirin and whether they recently received a flu shot. Black patients were more likely to report getting a flu vaccine, and Latino patients were less likely to report being told to take an aspirin, compared to other survey respondents.

While there were few disparities in access to care by race/ethnicity, there were more disparities by insurance coverage, especially among uninsured respondents. Uninsured patients were less

<sup>^</sup>These values refer to statistically significant differences between insurance groups (at alpha=.05)

likely than other respondents to report having a PCP or primary nurse practitioner (80.3 percent for uninsured respondents compared to 92.5 percent for those covered by Medicaid). Interestingly, uninsured patients were more likely to report attending group classes but less likely to receive materials about diabetes. Conversely, privately insured patients were less likely to attend group classes and more likely to receive diabetes educational materials. Uninsured patients were also more likely than privately insured respondents to skip medications due to cost (26.4 percent and 14.7 percent respectively).

Over three-quarters (78.6 percent) of patients reported always or often feeling that following their recommended treatment plan helps their diabetes control and overall health status. Nearly as many (80.5 percent) rarely or never felt confused about medical care due to their providers not explaining their care well. Interestingly, over one-third (34.4 percent) reported that their providers called them without being called first, e.g., carried out anticipatory monitoring or surveillance.

By far, most respondents indicated that they rarely or never felt discrimination due to race/ethnicity, education, language, or income. Latino respondents were nearly twice as likely as white respondents to indicate that they had felt discrimination from their health care providers at least sometimes (13.5 percent compared to 7.1 percent). And more than one in 10 black respondents (11.8 percent) also indicated feeling discriminated against at least sometimes. When comparing across coverage categories, uninsured respondents were most likely to have felt some discrimination; 12.9 percent of uninsured patients responded as such, compared to 10.7 percent of Medicaid, 8.7 percent of Medicare, and 6.0 percent of privately insured respondents.

#### **Satisfaction and Communication**

The NPHHI survey included several questions about patient satisfaction with care, overall quality of care received, and patient-provider communication. The findings indicate that patients are generally satisfied with the care they receive and believe that they have relatively good communication with their providers (see Table 5). Respondents reported high levels of communication with their providers; 88.1 percent reported that they discussed pain, and 69.4 percent discussed depression with their providers. Over three-quarters of respondents (78.6 percent) reported that their providers made them feel that their treatment plan would make a difference in their health, a key aspect of empowerment in self-management of diabetes. Still, clear differences emerge across subpopulations in terms of their perceptions about the quality of communication with their providers.

While patients generally reported good communication with their providers, some patients nonetheless reported concerns about communication:

- One-third of patients (32.7 percent) indicated that their providers used medical words they did not understand always, often, or sometimes.
- Almost one-third of patients (29.6 percent) reported having problems reaching their health care providers via telephone.
- One-quarter (25.0 percent) of respondents indicated that their diabetes control would be much better with improved communication. While only 26 percent of white patients indicated that they believed their diabetes control would improve if communication with their health providers improved, nearly half (45.7 percent) of Latino respondents and 48 percent of black patients expressed this sentiment.
- Over two-thirds (70.1 percent) of patients reported that their providers rarely or never took their religion or culture into account.

- Over one-fifth (22.6 percent) of patients reported that their providers rarely or never asked whether they have problems following their recommended treatment plan.
- Over two-thirds (68.8 percent) reported their providers did not talk to them about problems they may have with filling prescriptions.
- Patients rating their health status as poor were most likely to report that their diabetes control would be much better with improved communication with their providers.
- Latino patients report more problems always or often reaching their providers on the phone (22.6 percent) compared to white (11.2 percent) and black (9.1 percent) patients. Latino patients are also more likely to report that their providers used words they did not understand, with 18.0 percent reporting their providers always or often used words they did not understand, compared to 8.7 percent of white patients and 7.1 percent of black patients.

The majority of respondents (79.1 percent) reported that they always follow their providers' recommendations regarding treatment or advice. Among patients reporting that they did not always follow their providers' treatment or advice, the top reported reasons were because it was difficult to do so (19.2 percent) and because they forgot (16.8 percent).

About two-fifths (41.1 percent) of survey respondents reported that they needed an interpreter at their most recent medical care visit (data not shown). Of the respondents who indicated that they needed an interpreter at their most recent visit, 66.7 percent reported that they got an interpreter when they needed one. In addition, 67.9 percent of respondents who needed an interpreter reported that they fully understood what their doctor, nurse practitioner, or health provider was saying with the help of an interpreter, and another 15.5 percent reported that they somewhat understood what their health providers were saying during their visit.

The NPHHI survey findings also illustrate important differences in patient perceptions of communication in relation to the primary language of the respondent. Patients reporting primary

languages other than English are significantly more likely to have problems reaching their providers on the telephone than patients whose primary language is English. They are also more likely to report that their providers use words they do not understand; they are less likely to say that following their providers' advice helps them with diabetes management; and they are less likely to report that their providers asked them about problems they may have following recommended treatment (see Table 5).

**Table 5: Communication Regarding Diabetes Management, by Race/Ethnicity and Language** 

and Language	0/ 411	0/	0/	0/	0/	0/ 0/1
Survey Question	% All	%	% Dii-	% T - 4'	% E1:-1-	% Other
	Patients	White	Black	Latino	English	Language
Talked about pain	88.1	91.2	86.9	85.5	89.0	84.2
Talked about depression*	69.4	75.9	63.2	68.3	70.3	65.8
Asked about problems filling prescriptions*	31.2	30.0	27.0	36.6	29.9	35.5
Problems reaching						
doctor on phone*^						
Always/Often	14.1	11.2	9.1	22.6	10.9	28.1
Sometimes	15.5	17.1	15.7	13.6	16.7	10.1
Rarely/Never	70.3	71.7	75.2	63.8	72.5	61.9
PCP called patient						
first*	34.4	42.6	31.6	29.1	35.6	30.4
Used words didn't						
understand*^						
Always/Often	11.3	8.7	7.1	18.0	8.6	21.6
Sometimes	21.4	22.0	24.9	17.3	23.1	14.4
Rarely/Never	67.3	69.3	67.9	64.7	68.3	64.1
Confused because	07.3	07.3	07.7	04.7	00.5	04.1
provider didn't						
explain things well						
Always/Often	6.5	6.1	6.0	7.5	6.4	7.2
Sometimes	13.0	11.8	15.5	7.5 11.6	13.9	9.6
	80.5	82.1	78.4	80.9	79.8	83.3
Rarely/Never	80.5	02.1	70.4	80.9	19.8	03.3
Felt following						
provider's advice helps^						
Always/Often	78.6	83.5	77.5	74.9	80.5	71.9
Sometimes	12.2	10.8	13.1	12.8	12.5	10.8
Rarely/Never	9.2	5.7	9.3	12.4	7.0	17.4
Provider asked about	7.2	3.7	7.5	12	7.0	17
problems following						
treatment*^						
Always/Often	62.9	66.7	62.3	60.1	63.8	59.6
Sometimes	14.5	11.8	17.2	14.6	14.9	13.1
Rarely/Never	22.6	21.5	20.6	25.4	21.2	27.4
Provider took	22.0		20.0	20.1	21.2	27.1
religion/culture into						
account						
Always/Often	22.5	20.9	28.1	19.2	24.4	16.0
Sometimes	7.3	5.7	10.1	6.3	7.6	6.2
Rarely/Never	70.1	73.5	61.8	74.6	68.0	77.8
Better communication	70.1	13.3	01.0	77.0	00.0	77.0
would improve						
diabetes control*						
Much more	25.0	13.9	30.7	30.3	22.5	34.5
A little more	15.2	12.4	18.0	30.3 15.4	15.9	13.1
The same	59.7	73.7	51.3	54.3	61.7	52.4
The same	39.1	13.1	31.3	J4.J	01./	JZ.4

<sup>\*</sup>These values refer to statistically significant differences between race/ethnicity groups (at alpha=.05)

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

<sup>^</sup>These values refer to statistically significant differences between language groups (at alpha=.05)

#### **Health Literacy**

A significant group of patients in the Consortium hospitals reported problems with health literacy. One-quarter (25.5 percent) of respondents indicated that they always or often needed help reading materials that they received from the hospital. Affirmative responses to this particular survey question, which has been validated in other surveys, serves as a marker for low health literacy.<sup>21</sup> About 7.5 percent of respondents reported always or often having problems understanding labels and instructions, and about one in 10 (9.9 percent) reported always or often having problems learning about diabetes because of difficulty understanding written information. Also, one-quarter (24.9 percent) of patients reported low levels of confidence in filling out hospital forms by themselves.

Latino patients were much more likely to report difficulties involving health literacy than other survey respondents (see Figure 1). They also were much more likely to indicate problems learning about diabetes because of written information and needing help reading materials. Latino respondents were also more likely to say they experienced problems understanding labels and instructions. Black respondents were less likely to report high levels of confidence in filling out medical forms by themselves than other respondents.

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<sup>&</sup>lt;sup>21</sup> Chew, et al. According to the study, "low literacy" refers to patients that answered that they "always" or "often" needed help reading hospital materials (see Figure 1 and Table 6).

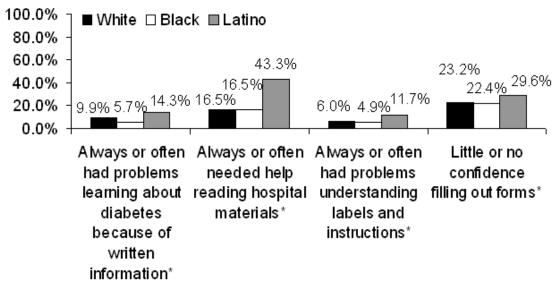


Figure 1: Health Literacy, by Race/Ethnicity

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005.

As can be seen in Table 6, patients with low literacy (as measured by the need for help in reading hospital materials) reported significantly more problems reaching their doctor on the phone. They also were more likely to report that their provider used words they did not understand. There were no significant differences in other measures of communication regarding diabetes management between patients with low literacy levels and other patients. Even with differences between patients with low literacy levels and other patients, across the board, significant numbers of patients reported difficulty understanding basic instructions related to management of diabetes. Concerns about health literacy should be integrated into the general practice of managing care of patients with diabetes in safety net hospitals.

<sup>\*</sup>These values indicate statistically significant differences between groups (at alpha=.05)

Table 6: Communication Regarding Diabetes Self-Management, by Literacy Level^

	% Low Literacy	% Other Literacy Levels	% All Patients	
Talked about pain	83.7	89.5	88.1	
Talked about depression	73.2	68.0	69.4	
Asked about problems filling prescriptions	36.6	29.3	31.2	
Problems reaching doctor on phone*				
Always/Often	20.3	12.1	14.1	
Sometimes	11.8	16.8	15.5	
Rarely/Never	67.9	71.1	70.3	
PCP called patient first	36.0	33.9	34.4	
Used words didn't understand*				
Always/Often	20.2	8.3	11.3	
Sometimes	18.7	22.3	21.4	
Rarely/Never	61.1	69.4	67.3	
Confused because provider didn't				
explain things well	0.4	7.0	6.5	
Always/Often Sometimes	8.4 14.4	7.9 12.5	6.5 13.0	
Rarely/Never	77.2	81.5	80.5	
Felt following provider's advice helps				
Always/Often	79.7	78.2	78.6	
Sometimes	11.4	12.5	12.2	
Rarely/Never	8.9	9.3	9.2	
Provider asked about problems				
following the recommended treatment	66.0	61.0	62.0	
Always/Often Sometimes	66.2 12.9	61.9 15.1	62.9 14.5	
Rarely/Never	20.9	23.1	22.6	
Provider took religion/culture into account				
Always/Often	20.0	23.4	22.5	
Sometimes	5.9	7.8	7.3	
Rarely/Never	74.0	68.8	70.1	
Better communication would improve diabetes control				
Much more	27.9	24.1	25.0	
A little more	15.9	15.0	15.2	
The same	56.2	60.9	59.7	

<sup>^</sup>Respondents with low literacy include those who indicated that they "always" or "often" needed help reading hospital materials.

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

<sup>\*</sup>These values refer to statistically significant differences between groups (at alpha=.05)

#### **Patient Self-Management**

Patients were asked to rate how much difficulty they had following their providers' recommendations and self-management protocols. Over two-thirds of patients (66.5 percent) reported that their provider explained "very well" the importance of following treatment aspects and self-care activities such as exercising, diet, checking blood sugar and checking feet conditions, and keeping one's heart healthy (see Table 7). Most patients also reported clear communication with their providers, with 83.9 percent reporting that their provider always or often explained clearly how to take medications. Patients reported the least difficulty with following recommendations for taking medications, checking feet for wounds or sores, and checking blood sugar; they reported more difficulty with following recommended exercise and diet plans.

Table 7: Provider Communication for Patient Self-Management, by Race/Ethnicity

	% White	% Black	% Latino	% Overall
Explained importance of exercise				
Very well/well	85.6	88.2	90.3	88.0
Not so well	6.5	5.3	4.1	5.3
Not at all	8.0	6.5	5.6	6.7
Explained importance of diet	0.0	0.5	3.0	0.7
	92.3	93.3	91.7	92.5
Very well/well				
Not so well	3.8	3.0	5.6	4.1
Not at all	3.8	3.8	2.6	3.4
<b>Explained importance of checking blood</b>				
sugar				
Very well/well	92.3	96.6	95.4	94.8
Not so well	4.6	1.9	2.6	3.0
Not at all	3.1	1.5	1.9	2.2
<b>Explained importance of checking feet</b>				
Very well/well	89.1	92.1	86.1	89.1
Not so well	5.4	3.8	5.6	4.9
Not at all	5.4	4.2	8.3	6.0
<b>Explained importance of keeping heart</b>				
healthy				
Very well/well	89.7	91.7	87.3	89.6
Not so well	4.6	3.8	5.6	4.7
Not at all	5.7	4.5	7.1	5.8
Clearly explained how to take medications*	:			
Always/Often	83.9	87.5	80.3	83.9
Sometimes	6.9	8.3	8.3	7.8
Rarely/Never	9.2	4.1	11.4	8.2

<sup>\*</sup>These values refer to statistically significant differences between groups (at alpha=.05)

Source: Consortium for Quality Improvement in Safety Net Hospitals and Health Systems, 2005

Respondents indicated an interest in alternative methods of communication with their providers, including non-traditional methods of learning about diabetes and their health. Forty-three percent of patients were interested in receiving group health care with other diabetes patients, and 32.3 percent said they would be interested in communicating with their provider about their health via computer or the Internet.<sup>22</sup> Over half (59.4 percent) also expressed interest in receiving regular phone calls from their provider to check in with them about their health. In particular, black and Latino patients were more likely to express an interest in group health care (49.4 percent and 46.6 percent respectively compared to 33.3 percent of white patients) as well as in receiving regular phone calls from their providers (65.2 percent and 69.3 percent respectively compared to 43.8 percent of white patients). Among respondents, black patients were most interested in communicating with providers via computer or the Internet (41.2 percent compared to 23.1 percent of Latino patients and 32.7 percent of white patients).

<sup>&</sup>lt;sup>22</sup> This number may underestimate interest in Internet communications; Consortium hospital systems anecdotally reported that patients frequently do not realize that Internet is free at many public libraries.

#### **Conclusion: Key Findings and Recommendations**

The Consortium project was the first initiative of its kind to bring a group of safety net hospital systems together to examine quality of care provided for diabetes patients. The work of the *Consortium for Quality Improvement in Safety Net Hospitals and Health Systems* underscores the critical role that safety net hospital systems play in delivering high-quality diabetes care to a patient population that is primarily low income, ethnically and racially diverse, and has high rates of literacy problems. The study signals the need for comprehensive programs to support the care of vulnerable patients with chronic conditions and highlights areas for improved communication between providers and patients. Project outcomes can be summarized around several major findings:

- Although Consortium members care for large numbers of patients with diabetes who are
  racially and ethnically diverse, low income or uninsured, and often with limited English
  or literacy proficiency, the study found few significant differences among racial groups
  regarding assessment of health status and access to care.
- Despite programs at safety net hospitals to increase access to care for patients, uninsured
  patients continue to report poorer control of their diabetes and disparities in access to
  care. Compared to patients with any insurance coverage, fewer uninsured patients
  reported having a primary care provider and more reported skipping medications due to
  cost.
- Up to one-third of the patients at Consortium hospital systems reported having languages other than English as their primary language, and one-quarter reported having health literacy problems. Patients commonly reported problems understanding basic instructions involved in diabetes management. Safety net hospital systems are continually challenged to provide culturally and linguistically appropriate services for their diverse populations. Appropriate provider-patient communication becomes a particularly salient issue for patients with chronic illnesses like diabetes that require self-management and understanding of providers' instructions. More research is necessary to

understand the cultural and linguistic needs of various patient populations and to design targeted programs that address these needs in the context of comprehensive care management.

- The NPHHI study revealed the importance of providing comprehensive care that draws on relevant health professionals in the management of chronic illness. Diabetes teams should be expanded to include health care professionals and social workers able to address the variety of factors that affect diabetes care for low-income and minority patients. Much more work is necessary to develop comprehensive, tailored diabetes management programs that take into account literacy, language, and co-morbidities.
- The study identified several key areas for improvement in care for patients with diabetes in safety net hospitals, specifically around patient-provider communication. In general, survey respondents reported few problems with the care they received and their communication with providers, but not consistently across race and ethnicity. A sizable group of patients (one-quarter or more) reported having difficulty understanding their providers' use of medical terminology, identified a need for improved communication, or noted the providers' failure to take into account the patient's religion or culture.
- Although patients generally identified few problems with the care they received, a remarkably high proportion of survey respondents indicated they were in fair or poor health and/or had pain that interfered with their ability to exercise. In part, this is a reflection of the experiences of patient populations in safety net hospital systems, who tend to suffer from co-morbidities such as heart disease and depression.

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