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Health Behaviors and Health Literacy of IowaCare Enrollees with Diabetes: Third report in a series of evaluations of the IowaCare program

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Policy Report
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the IowaCare program**

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IowaCare program**

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Preface

This report presents the results of in-depth interviews conducted to assess the impact of IowaCare on the preventive health behavior, chronic care management, health information seeking, and health literacy of IowaCare enrollees. It is one in a series of evaluations of the IowaCare program, which is designed to provide health care to low-income adults in Iowa. This evaluation was conducted at the request of the Iowa Department of Human Services (IDHS) as part of their compliance to continue the IowaCare program, an 1115(a) demonstration project approved by the Centers for Medicare and Medicaid Services (CMS).

The evaluation includes in-depth qualitative interviews designed to follow-up on specific issues raised in the 2008 survey.¹

Researchers at the University of Iowa Public Policy Center (PPC) conducted this study with funding provided by the IDHS.

Information and conclusions presented in this report are the responsibility of the authors and do not represent the views of the IDHS, CMS, IowaCare or University of Iowa.

¹ Damiano, et al, First Evaluation of the IowaCare Program, The University of Iowa Public Policy Center, December, 2008.



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Chapter 1

Introduction

This report presents the results of in-depth interviews that were conducted to assess the impact of IowaCare on preventive health behavior, chronic care management, health information seeking, and health literacy of IowaCare enrollees. A better understanding of these intermediate outcomes provides improved evaluation of how IowaCare is changing the health outcomes of low-income Iowa residents.

In-depth interviews were selected for this data collection to delve deeper into issues raised by the IowaCare survey (2008). This qualitative data collection method was designed to provide context for the 2008 survey results and explore relevant issues more thoroughly. The previous IowaCare evaluation activities provided a broad swath of information regarding the program's performance during its first two years. The initial evaluation indicated unmet preventive care need in the IowaCare population that may result in poor health outcomes for enrollees. Previous analyses also revealed that IowaCare enrollees have many chronic conditions. It is thus important to understand how IowaCare works to facilitate the management of chronic conditions, to provide preventive care and to encourage preventive health behavior. Because of the number of IowaCare enrollees who have diabetes—and the personal, social and economic costs of this condition—this project examined how IowaCare enrollees manage their diabetes and what role IowaCare plays in this management.

Diabetes was selected as the disease focus because it requires management by both health care providers and individuals. For example, people with this complex disease require sufficient knowledge to perform regular testing and screening. Diabetes was one of the top 10 reasons for outpatient/physician visits for 2006 and 2007 in IowaCare. It was also in the top 10 co-morbidities for outpatient/physician visits in the same years. Further, 18% of respondents to the 2008 survey reported having been diagnosed with diabetes.

Health information seeking was also identified in the initial evaluation as an area that required further attention. Participants indicated that they were not aware of resources available to them. The in-depth interviews



were designed to uncover how the needs of chronic care management are related to prevention, how IowaCare facilitates appropriate management, and what barriers still exist to prevention and disease management, including care coordination issues. The interviews also examined the complexity of chronic condition management for IowaCare enrollees. Many IowaCare enrollees must manage significant chronic conditions. Health literacy is a skill that enables individuals to understand their health conditions, the prevention measures they need to take and how to negotiate the health care system. Questions about the challenges enrollees faced in understanding their medical needs and how those needs should be addressed revealed deficits in health literacy.

While the 2008 survey asked questions about enrollees' previous insurance status, the survey was not designed to determine how people came to be enrolled in IowaCare. Therefore the interviews also focused on understanding participants' health insurance histories and on discovering how they became enrolled in IowaCare. Furthermore, the 2008 survey indicated that IowaCare enrollees rated their health status as poor. As a result, the interviews were designed to give people the opportunity to explain more about their health status and complicated health issues. Because these in-depth interviews allowed enrollees to explain their circumstances and tell their story, information was gleaned about how IowaCare works for individual enrollees. Finally, this data collection also addressed issues related to preventive care and accessing care outside of the IowaCare network, which were raised in the 2008 survey.

Chapter 2

IowaCare background

The IowaCare program is a limited-benefit, public health insurance program for adults in Iowa. It was authorized by Iowa House File 841 under a Medicaid expansion program and began on July 1, 2005. The program was created, in part, to continue and expand adult health care coverage known as the Iowa Indigent Care Program (also known as the State Papers) under a statewide Medicaid benefit. The Indigent Care Program provided care vouchers to eligible Iowa residents to seek services at the University of Iowa Hospitals and Clinics (UIHC). IowaCare, as approved by CMS, replaced both the Indigent Care Program and the Broadlawns Medical Center's Community Care Program. It provides a limited set of benefits (inpatient and outpatient services, physician, and advanced registered nurse practitioner services, limited dental services, routine yearly physicals, smoking cessation, and limited prescription drug benefits) to adults ages 19 through 64 using a provider network of the University of Iowa Hospitals and Broadlawns Hospital. It also covered individuals served by the four State Mental Health Institutions through June 30, 2008. In addition, the program aims to capture a proportion of the medically needy uninsured population not otherwise eligible for Medicaid. The Terms and Conditions of this 1115(a) demonstration waiver required the elimination of Iowa's Intergovernmental Transfers (\$65 million), which were phased out under the direction of CMS.

Eligibility for IowaCare

The population eligible for IowaCare includes:

- Persons 19 through 64 years with a net income at or below 200% of the Federal Poverty Level (FPL), who are not otherwise eligible for Medicaid
- Pregnant women (regardless of age) if their gross income is below 300% of the FPL and whose allowable family medical expenses bring their income to below 200% of the FPL
- Newborn children born to qualifying pregnant women who reduced their income to below 200% of the FPL



Because of the elimination of the Indigent Care Program, provisions were made at the beginning of the IowaCare Program to allow former Indigent Care Program participants who were over 200% FPL and had a chronic health condition into IowaCare. In order to qualify for this exception, an applicant formerly under the Indigent Care Program but not meeting the income requirements must have received “state papers in SFY ’05 and have had a preexisting chronic condition requiring ongoing medical care for that condition.” Individuals who have access to other group health insurance are not eligible for IowaCare. However, an individual is not considered to have access if coverage under the group health plan is unaffordable, excludes certain pre-existing medical conditions, or does not cover needed services. Thus, an individual may be enrolled in both IowaCare and another group health plan if the individual has reached the limit of covered benefits under the other plan or if coverage under the other health plan applies exclusions for a pre-existing medical condition or does not cover needed services.

Enrollment and premiums

Following eligibility determination, coverage begins on the first day of the month of application. An individual may request retroactive eligibility of one month at the time of application if they received covered services from a network provider during that month. Eligibility determination is for a 12-month period. IowaCare enrollees pay a monthly premium, and are required to pay for at least four consecutive months of premiums. Premiums are based on a sliding fee scale and are calculated based on 2% of the poverty-level increment for incomes below 100% of the FPL, and at 5% of the poverty-level increments for incomes greater than 100% of the FPL.

Monthly premiums originally ranged from \$0 (for those under 10% FPL) to \$75. (Note: Effective July 1, 2007, IowaCare enrollees with income at or below 100% of the FPL were no longer charged a premium. As of April 1, 2008, the premium amount was \$0 for those with incomes at or below 100% of the FPL and ranged from \$43 to \$82 for those with incomes above 100% of the FPL.) An IowaCare enrollee may request a hardship declaration for premium payments on a month-by-month basis. Enrollees may file a hardship declaration by signing a statement included with each monthly billing statement. This statement must be claimed for each month an enrollee wishes to declare a hardship. Enrollment can be terminated for reasons such as: 1) the 12-month

certification period ends, 2) the enrollee becomes eligible for Medicaid, 3) an individual no longer meets income eligibility criteria, 4) an individual cancels coverage, or 5) an individual fails to pay their premium.

Provider network

The IowaCare provider network is based on county of residence of plan enrollees and includes:

- Broadlawns Medical Center (Broadlawns) in Des Moines, Iowa
- The University of Iowa Hospitals and Clinics (UIHC) in Iowa City, Iowa

IowaCare enrollees who are residents of Polk County have the option of receiving care from an IowaCare provider at UIHC or Broadlawns. Enrollees in all other counties must receive care from an IowaCare provider at UIHC.

There are two exceptions to the IowaCare provider network for a) pregnancy-related and newborn care, and b) preventive health visits. Pregnant women who live in Cedar, Clinton, Iowa, Johnson, Keokuk, Louisa, Muscatine, Scott, or Washington Counties must receive pregnancy-related services and newborn care at UIHC. Pregnant women in all other counties may receive pregnancy-related services and newborn care from any Iowa Medicaid provider. The second exception to the provider network is for preventive health visits, which may be provided by any Iowa Medicaid Provider in an enrollee's local.

Covered services

IowaCare provides coverage for most inpatient and outpatient services. Some limited coverage is also available for the services listed below.

Preventive visits

A preventive health visit assesses overall health and health behaviors to promote well-being. The primary focus is on the prevention and early detection of disease. Preventive health visits are covered under IowaCare, which allows an annual physical examination from any Iowa Medicaid Provider. Only one preventive health visit is allowed per year. If additional services are indicated as a result of the preventive health visit, such services must be performed by an IowaCare provider at UIHC



or Broadlawns. A three-dollar co-pay applies to all preventive health visits conducted by an Iowa Medicaid Provider not practicing at UIHC or Broadlawns.

Durable medical equipment

IowaCare provides a very limited Durable Medical Equipment benefit related to the IowaCare enrollee's inpatient-outpatient hospital service. UIHC provides some additional durable medical equipment to IowaCare enrollees on a case-by-case basis.

Dental

IowaCare covers only limited dental services. The Benefits Section on the IowaCare website is not particularly clear as to covered services. It states that IowaCare covers "Dental services described in the dental codes specified by the department." Dental services provided at UIHC, however, are limited primarily to tooth extractions, while some limited restorative care is provided at Broadlawns.

Transportation

Transportation is available to help IowaCare enrollees travel from their homes to UIHC and back. Transportation is by appointment only and enrollees must call to schedule transportation. Transportation is not funded under the IowaCare act, but is a service provided by UIHC. Lodging and meal costs that may result from overnight stays are not covered by IowaCare.

Prescriptions

IowaCare includes a limited prescription benefit. Only prescription medication received during inpatient care, plus a "take-home" supply of drugs is covered by IowaCare. Medication administered in the hospital outpatient clinic is also covered under the plan. IowaCare enrollees formerly enrolled in the Indigent Care Program who were treated and received prescriptions for a chronic condition in SFY 2005 are eligible to continue to receive prescriptions that are normally covered by Medicaid. As a supplement to the regular IowaCare coverage, UIHC provides some generic medications at no cost, but it is not an official IowaCare benefit. Broadlawns provides some limited medications through its community care program.

Chapter 3

Research methods

In-depth interviews were conducted to examine the impact IowaCare has had on the preventive health behavior, chronic care management, health information seeking, and health literacy of IowaCare enrollees. Diabetes was selected as the disease focus for these interviews because it requires management, both from health care providers and individuals. Moreover, people with diabetes require sufficient knowledge to perform regular testing and screening. The in-depth interviews were also designed to uncover how the needs of chronic care management are related to prevention, how IowaCare facilitates appropriate management, and what barriers still exist to enrollees, including care coordination issues.

The interviews focused on understanding what people's previous insurance experiences were and how they became enrolled in IowaCare. As the in-depth interviews allowed enrollees to explain their circumstances and tell their stories, information about how IowaCare works for individual enrollees was gleaned. This data collection also addressed issues related to preventive care and accessing care outside of the IowaCare network, which were raised in the 2008 survey.

The specific research questions explored in this evaluation are:

How are IowaCare enrollees' managing their diabetes?

What are barriers to good management?

What are facilitators to good management?

What can IowaCare do to help improve management?

Are IowaCare enrollees seeking preventive health care?

Are IowaCare enrollees participating in preventive health behavior?

What role do information seeking and health literacy play in the health of IowaCare enrollees?

Process and recruitment

The sample for this data collection was drawn from IowaCare enrollees who have diabetes (as identified in the claims data) and have been



enrolled in IowaCare for at least 1 year. Enrollees were drawn equally from Polk County (50%) and the rest of the state (50%) in order to gather information from those IowaCare enrollees who go to Broadlawns and those who go to UIHC.

A random, stratified-by-location (Polk County and rest of the state) sample of 122 IowaCare enrollees was sent letters inviting them to participate in an in-depth interview about IowaCare. Following the letter, enrollees were contacted via telephone and again invited to participate. Three attempts were made to contact the enrollee by phone. The attempts were made at various times of day (morning, afternoon, evening) during the workweek and weekend until 20 interviews were completed. Six letters were returned because of bad addresses and no other addresses could be located. For 45 enrollees no accurate telephone numbers could be located. Only five people refused to participate. Enrollees who were interested in participating were sent an informed consent form with a business reply envelope (n= 46). Twenty six of the enrollees returned their signed informed consent forms. A total of 20 interviews were successfully scheduled and completed.

Each participant received a \$25 Walmart gift card following the interview. This study recruitment process and protocol were approved by the University of Iowa, Institutional Review Board. All of the interviews were conducted over the telephone. The interviews were digitally recorded and notes were taken during the interviews.

The interviews required enrollees to compare and contrast their preventive health behavior, chronic care management, health information seeking, and health literacy before they entered the IowaCare program and after they had been enrolled for at least one year. Issues related to access to care outside and inside the IowaCare network were also compared and contrasted. See Appendix A for an outline of the in-depth interview protocol.

Analysis

In-depth interviews allow researchers to gather the wide range of opinions and attitudes present in a population without limiting the options a priori. This type of qualitative data collection is not designed to be quantifiable, as the goal is breadth (all possible answers), and depth



(detail about these answers), rather than frequency of response. In order to ensure that all possible answers (or most of the possible answers) are included in the data gathered, researchers are looking for saturation- themes and ideas to repeat themselves across interviews. Reaching saturation indicates to the researcher that all (or most) possible ideas have been uncovered. While each individual IowaCare enrollee story was unique, saturation on themes was reached.

Because of the straightforward nature of the interview protocol and the research questions, the recordings were not transcribed. The same researcher who conducted the interviews also analyzed them. The interviews were listened to multiple times and notes were reviewed in order to find themes that addressed research questions outlined previously. Other themes were uncovered that had not been identified in the protocol. Notes on themes and answers to the research questions were taken every time the researcher listened to the recordings. These notes were organized and compiled into themes to present the breadth and depth of issues uncovered in the interviews. Closed and open coding strategies were employed², with some of the themes identified a priori through the research questions coded, while themes identified through the interviews alone were also coded.

The results of the in-depth interviews are organized to mirror the organization of the results in the 2008 survey.

² Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.



Chapter 4 Results

Demographics

A total of 20 participants were interviewed for this project. Self-reported participants' ages ranged from 27 to 62 years old. One participant was reluctant to provide an age. Most of the participants were in their 50s. Half of the participants indicated they were male and the other half female. The educational experiences of the participants ranged from only completing 8th grade due to religious reasons to two participants who had attended graduate college. Four participants did not graduate from high school, although one of them had a GED. Eight of the participants had only graduated from high school. Two participants were currently in college, while another four had completed some college. Participants were asked to self-identify their race or ethnicity. The majority (n=17) identified as 'white' or 'Caucasian.' One participant identified as white, Native American. Two of the participants were African American. The demographic characteristics of this sample mirror the characteristics of those who participated in the 2008 survey. The figure below indicates the county of residence for interview participants.

Location of IowaCare Participants 2010



Health status of IowaCare participants

Most of the participants had been living with diabetes for many years. Many had been diagnosed more than five years ago, and most indicated that they probably had had diabetes many years before they were diagnosed. Besides diabetes, participants had many chronic and complex health concerns. High blood pressure and heart disease were common. Some stated their health was good or fine, but many indicated that they did not feel healthy. Chronic pain from injuries and back problems were mentioned. 'I am in a lot of pain,' said one participant. One woman summed up the experiences of many with her description of her health: "crappy—I am on disability. I have fibromyalgia, high blood pressure, high cholesterol, diabetes—can't forget that one...I used to work 18-hour days and it never bothered me...now I can't even work eight hours.' Most participants indicated that their health has gotten worse since they have been on IowaCare, but that this was due to the progression of their diabetes, not a reflection of the care they had been receiving. It was common for people to comment, 'I didn't know how bad it was getting' until they went on IowaCare or to state that they were, 'pretty bad... in denial.' Despite having numerous health problems many

The majority of study participants had very poor health

Study participants' enrollment experience was positive

participants recognized that they were now taking better care of themselves. One man said of his health status: 'Pretty crummy. I am on dialysis 'cause now my kidneys have failed. Half my right foot has been chopped off—but I am in better health than I was a year ago.' Compared to the results of the 2008 survey, a higher percentage of the group of enrollees interviewed perceived their health status to be poor or worse.

IowaCare enrollment

There were three broad paths by which people became enrolled in IowaCare. People (1) had a health crisis, (2) transferred from the State Papers program, or (3) were referred to IowaCare by a health care provider or social services.

Most of the participants had no insurance for many years previous to being on IowaCare. Only a few participants reported being on Medicaid at some point in the past. Most had experience with private health insurance through an employer at some time in their lives. Usually a job change or a layoff or a health concern that prevented them from working ended their access to health insurance. One participant explained: 'For the last eight years none, before that I had BlueCross/BlueShield...through an employer. I left employer due to health problems and I could not keep up the COBRA payments.' A few had been self-employed but found the health insurance too expensive to maintain. One woman summed up everyone's experience very succinctly by stating, 'I have been insurance-poor all my life.'

Health crisis

Many people described being without health insurance and having a health crisis that prompted them to enroll in IowaCare. One participant clearly stated he 'didn't have insurance and... needed medical attention.' One woman said, 'They found cancer, uterine cancer. Two weeks after I found I had cancer, I was in doing surgery....I never saw a bill. It was just great.' Another man just said, 'I lost my leg' and this surgery prompted him to enroll in IowaCare. Yet another participant reported, 'I hurt my knee and I didn't have a job and if it wasn't for IowaCare I would have been up a creek. IowaCare just really came through for me when nothing else would 'cause I don't have any children and I am too old, but not old enough.' Emergency situations were also common reasons for enrolling in IowaCare. One man stated, 'During first ice storm of the year, I fell and broke my leg quite severely. When they

A health crisis often prompted IowaCare enrollment



put me on the operating room to repair my leg, I had a heart attack...My wife went down to DHS and found out about the program and enrolled me. I was in the hospital.'

Transferred from the State Papers program

A few participants were originally part of the State Papers program and were seamlessly transferred to IowaCare.

Referred to IowaCare by a health care provider or social services

Some participants had been without health care coverage but had medical need. One man explained, 'I got laid off, participated in COBRA benefits plan. Paid my own insurance out of my own pocket for like 6 months...then I needed to find something and was told about IowaCare[s] by DHS.'

Health care providers also referred people to IowaCare. One woman told the interviewer, 'I had went to an eye doctor that was actually at Walmart...they seen some bleeding and that is how I got set up with IowaCare.' Another participant reported that he was going to a foot doctor when he lost his health insurance through his employer. The foot doctor told him about IowaCare and the nurse helped him apply.

Previous health insurance

IowaCare compared to other health insurance

When participants were asked to compare IowaCare and its benefits to their previous experiences with health insurance, most stated that they had had little need for care with their previous health care coverage, so it was hard to compare the insurance benefits. It was not unusual for people to report that they never used their previous coverage or had limited use of it. For example, one participant said she "only had to have a knee x-ray" on her previous insurance. Those who had used their previous health insurance believed that IowaCare was better than or equivalent to plans from BlueCross BlueShield and John Deere. One man explained why he thought IowaCare was superior:

'When I was on Blue Cross and Blue Shield I was being seen once a year for regular diabetic check ups....I believe you should be seen more often. The situation with IowaCare[s] is that I have to go to the doctor 4 times a year...sometimes I feel like it is

overkill...the complete honest opinion is that I believe this kind of close, well borders on insurance fraud type situation. Every time I get seen the state government pays a certain percentage for what I get done...I feel guilty when I go in there and there is nothing wrong.'

Another participant said, 'Any needs I have had had totally been covered by IowaCare –except ambulance and medications.' Other participants also noted that IowaCare did not have the same drug coverage as some insurance plans.

How participants coped without health care coverage

Because so many of the participants were without health care coverage for many years before enrolling in IowaCare, it is important to understand how they had their health care needs addressed during this time. Many participants stated that they simply did not seek medical care when they did not have insurance, while those who sought care either used free clinics or paid for the health care they needed. Some of those who did not seek care believed that they had no need for health care at that time. One woman reported, 'I am relatively healthy...most of my insurance needs are accidents,' while a male participant said, 'I had no health care issues.' Some people needed care but did not seek it out. For example, one participant told the interviewer, 'Nothing...Basically [I] never saw a doctor. That is why I was having so many eye problems. I wasn't able to keep up with it.' Those who needed health care and had to pay for it said, 'I just tried to do the best I could...I tried to get free samples of medication, uhhh I was buying antacid for my acid reflux disease...if you don't have IowaCare you can't get your prescriptions.' Some participants are still paying for the medical care they sought; one participant stated you, 'just ended up racking up bills.' These people made arrangements to make payments for the health care they needed, they went without medicine, and took advantage of pharmaceutical programs for reduced cost drugs. One man said he, 'wasn't too concerned about it...unfortunately I had to be admitted to the local Cass Community Hospital' before he got transferred to UIHC and put on IowaCare. Now he is struggling to pay off his bill at the local hospital. Some tried to, 'keep doctor's visits down to absolutely critical items...seeing the doctor as little as possible.' For free or reduced care, people, 'went to Broadlawns and they covered me' or they 'went to

community health care in the Quad Cities...they have rates based on your income.'

Administration of IowaCare

For the most part participants in the interviews praised IowaCare as a health insurance program and reported that the enrollment and re-certification processes are easy. There is a great deal of confusion around what is covered by this program, however. Most participants reported not knowing what was and was not covered.

IowaCare enrollment process and re-certification

Very few participants had difficulty enrolling in IowaCare. Most did not believe that their coverage had ever lapsed while they were enrolled. One woman reported that her coverage had lapsed because she had not paid. She believed her ex-husband took her money orders for IowaCare and used them for drugs. She said 'I only owed 10 bucks. I thought that was a little extreme [to end her coverage].' One man said he had let his coverage lapse, 'because there was a few years where I was in pretty bad shape and my brain just wasn't working.' Another man said that, 'After everything they had done at the University, I was off of IowaCare[s] 'cause I thought I was fine and didn't need it. I went off the program. Unfortunately I was stupid and didn't realize my condition was worse off...so they had to re-enroll me.' Many of those people who did report that their coverage had lapsed, discovered this when they were seeking services. One man stated, 'There have been times when we called to an appointment and we were told our coverage had lapsed and we needed to renew it.'

Confusion

Very few participants had a good, concrete sense of what was covered by IowaCare. Most seemed to rely on their health care provider to know what they needed and whether it was covered. Only a handful of enrollees said that they had received information about what services IowaCare covered. When asked about coverage, participants gave inconsistent answers about eye/vision care, dental care, and physical therapy. Some said that their eye examinations were covered by IowaCare, while others were under the impression that they would have to pay for this service out-of-pocket. It was for this reason that some of the IowaCare participants with diabetes were getting regular eye exams

Most study participants appreciated the increased access to care

There is confusion among study participants about what is covered by IowaCare

while others were not. The results of the 2008 survey pointed to this confusion when participants indicated that they did not know what their health care would cost.

Participants reported a general lack of knowledge about what was covered by IowaCare. One participant said, 'If they would inform me about what preventative care is available, I would use that.' There is confusion about the prescription benefit change. People reported different interpretations of it and at least one enrollee reported not knowing about it until he went to pick up his prescriptions. A few suggested that IowaCare could send people a newsletter or other information in the mail about what was covered or any policy changes. One person said that a packet explaining what was covered was needed, 'cause sometimes you don't know what you need.'

Quality

Most of the participants expressed deeply felt appreciation for the IowaCare program. In fact many of the participants mispronounced IowaCare as IowaCare[s]. This mispronunciation sums up how they feel about the program. Iowa is taking care of them. Some of the statements of appreciation include:

*Most participants
thought they
received good care*

- I would not be alive if it wasn't for IowaCare.
- I would be dead without it.
- I am very grateful. I know I would be dead.
- I have been really tickled with it.
- It has helped me a lot, financially, psychologically. I can't say enough about Iowa City hospital...they have been nothing but good to me. Nothing bad to say about them. IowaCare[s] really is as simple as I just fill out an application to get it renewed...basically everything is fine.
- I have been insurance-poor all my life and could never afford it and when I really needed it, it was there for me.
- IowaCare is fantastic. I have no complaints.

Even one of the participants who was very critical of IowaCare said, 'I have to give IowaCare an "A."' There were specific parts that some people felt were especially good about IowaCare. A few participants

Scheduling is a barrier to care—especially at UIHC

pointed out that IowaCare offers better coverage than any of their previous insurance. This finding was consistent with the 2008 survey. The application and reinstatement processes were also easy according to the participants, who mentioned that the reminders and lists of what participants are required to bring were helpful. In 2008, 80% of participants believed enrollment was easy. One participant also noted that IowaCare is truly interested in improving services. As evidence he cited the surveys he had received, this interview, and other clinic surveys.

Many people recognized that the clinics are very busy, that many of the workers and health care providers are overworked, and that the clinics are understaffed. Among some participants there was the perception that the IowaCare program had grown very large and had too many enrollees. This over enrollment was viewed as one of the reasons why it was difficult to get an appointment.

A few participants felt that IowaCare enrollees were not treated the same as other patients. 'I am thinking IowaCare patients don't quite get the attention as the rest of the patients...it is a long wait, long wait...sometimes it is a really long time...for an hour,' said one man.

Utilization

Personal doctors or primary care providers were very important to this group. Most reported very positive interactions and indicated that their doctor had a significant influence on their health. Urgent and emergent care are serious concerns for the participants in these interviews. There is a great deal of unmet need, and there are challenges related to urgent and emergent care. Those participants who sought regular preventive care declared the care they received to be excellent. They received frequent screenings, and their descriptions of their care mirrored indicators of quality diabetes care and management. The participants reported that preventive health care behaviors were hard to accomplish and that they could use more support in this area.

Personal doctor

Although the survey did not include a specific question on the importance of the health care provider, this topic came up in a majority of the interviews. Many participants liked their health care provider. Most talked about how their health care provider helped motivate them to take

Access to routine care was generally good



care of themselves. As one IowaCare participant put it, 'Dr XX has been so encouraging. He told me I could do this [keep my diabetes under control]...Three years ago I could've cared whether I was dead or alive. I felt there was nothing that could be done...I have the will to do it. He has encouraged me so much.'

One participant said his health care provider, 'demands that [he] do specific things' for his diabetes. The participant felt he needed that kind of enforcement. He was also under the impression that if he did not comply, his primary care provider would not prescribe him all the medicine he needed, or give him less testing strips, or might refuse to be his primary care provider.

A few participants had very negative experiences with health care providers through IowaCare. The following participant quote is an example:

'The doctors have been a challenge. I have seen so many different doctors and they all have their different opinions... So if you ask me—I don't think I have received the type of care that I should have....I think that is just because they got so many people going up there. You gotta wait 4-6 months to see the doctor...I haven't seen a decent doctor yet'

Another participant said,

'She doesn't listen to me...I had a big cyst on my finger...and my doctor down here [Quad Cities] said 'have your doctor look at it'...and she said oh—it's just a cyst and let it go... She doesn't listen. She just wants to get in and out to get to the next patient...I have feelings too'

This same woman recounted a story about her primary care doctor saying that he hated IowaCare patients because they are stupid. The doctor said he was dragged into doing IowaCare patients and he did not like them. The participant was very upset about this treatment and sought a different primary care provider.

One participant pointed out a disconnect between the health care providers and patients. Her doctor had said she should go on YouTube to find yoga poses, so that she could do yoga. It did not occur to the health care provider that someone living on very little money would not have a computer or internet access.

*Urgent and emergent
care is a challenge
for enrollees*

Most of the participants recognized that the health care providers were under pressure to see many patients. Some understood this pressure and blamed the system, while others were frustrated with the health care providers themselves.

Urgent and emergent medical care

Limited access to urgent care was a challenge for many participants. They have few options if they need to be seen immediately or in the next day or two. Most participants said it would not be possible to get an appointment to see anyone for an urgent issue. Participants reported going to the emergency room because their urgent care needs (but not emergency medical care issues) could not be met by the primary care providers primarily due to not being able to get an appointment within a day or two. 'It takes weeks to get in [for urgent care]...' according to a man with diabetes and severe, chronic back pain. One woman described how she ended up using the emergency room, although she did not think her medical issue required the emergency room, 'After my second bout with antibiotics [for a sinus infection]...I called to talk to a triage nurse...about 2 o'clock. The girl said we would take a message and get back to you. Well, two hours later no body called—so I called back.' The woman on the phone indicated that she didn't need to keep making multiple calls and the woman hung up on the participant. At 8:30 that night the participant called again and that nurse said that she needed to come into the emergency room. She did not get home from that ER visit until 2:30 AM.

One man described how he had recently lost his leg and was suffering from an intractable staph infection. He had been hospitalized many times already. He had been told by an emergency room doctor to get in and get seen by his doctor immediately—but the schedule would not allow him to be seen for almost 2 months. He was also frustrated with not being able to talk to a live person for scheduling. Leaving a message on a machine was not an adequate way to deal with his serious health care needs.

Routine medical care and preventive care

Unlike the 2008 survey, most of the participants to the in-depth interviews had been accessing routine, preventive care. The majority of participants received very regular and comprehensive care for their



diabetes. They usually saw their primary health care provider about once every 3 months. People who had more difficulty controlling their diabetes were seen more often (every 2 months or once a month) and those who had diabetes that was easily controlled saw the health care provider less (every 6 months). People did report not getting in as regularly as was recommended. Often issues such as weather, family emergencies, funerals, and forgetting they had an appointment were cited as reasons for infrequent appointments. Some missed appointments or did not get appointments scheduled because they could not negotiate the scheduling system. People with the most complex medical problems, such as recent amputations, kidney failures, cancer, and serious heart conditions were less likely to be seen for their diabetes by a primary health care provider. They reported seeing specialists or their health care team regularly and many of them said that these health care providers also paid attention to their diabetes.

Participants provided details about what was done during their regular visits to their primary care provider. The vast majority reported very comprehensive appointments that included Hemoglobin A1C testing, blood pressure checks, cholesterol tests, and examination of their feet. There was a great deal of variation in how participants received their test results. This variation appeared to be dependent on the preference of the particular health care provider and related to how well the participant's diabetes was controlled.

Most of the participants reported having various tests run during their medical visits. The manner in which the results of their tests were communicated differed greatly, however. Some participants received phone calls from a nurse about their test results following their appointment. Others reported receiving a letter, which explained the results and instructed the patient on how they should proceed going forward, for example, by changing their insulin regimen. A few of the individuals interviewed said that they would call their health care provider to find out about the results. Still others, mostly those who reported having little trouble keeping their diabetes under control, only found out their results when they went in for their next appointment. There were a few people who said that they never found out the results from their tests and assumed that the results must have been normal since they did not hear otherwise. Some of the difference in test result reporting appeared to be related to physician preference, the complexity



of patients' medical conditions, or how well controlled their diabetes was.

Most of the people interviewed believed they would not be getting the health care they are currently receiving without IowaCare. The majority indicated that they had been receiving virtually no health care before they went on IowaCare. Participants said things like, 'If it wasn't for IowaCare, they probably would have had to cut my leg off.' Participants stated that IowaCare increased their access to medicine/prescriptions, helped them get regular check-ups, and some reported that the health care provided motivated or inspired them to take care of themselves. One participant said, 'It [IowaCare] has made it a lot easier...I never have to worry about my medicine. I know I am going to get my medicine.'

Two participants commented on how IowaCare and the regular checkups 'force' people to keep their diabetes under control. One person compared IowaCare to BlueCross BlueShield in this respect and said IowaCare does a much better job.

Prevention health care and behaviors

The influenza and pneumonia vaccinations are two important preventive health services that diabetics should have. Some of the participants indicated that they had received these vaccinations, but many had not. It should first be noted that this was a challenging year for influenza vaccinations because so little vaccine was available during the influenza outbreak. Some of the participants reported wanting to have the vaccinations but not being able to find any vaccine. Some were able to find vaccines, but had to cover the cost themselves. Others said that their health care provider had recommended it, but they did not attempt to get it, while still others said their health care provider never mentioned the vaccinations.

Participants who smoked were aware that there are smoking cessation services available to them through IowaCare. Only one participant said 'IowaCare helped me get to the doctor' who helped her quit smoking. Other preventive health behaviors mentioned by participants were walking, exercise, eating right, and taking vitamins.

When participants were asked how IowaCare could help with preventive health behaviors, most people did not think IowaCare could do anything to help them. Some talked about personal responsibility and being motivated. Diet and physical activity were the two main areas people thought IowaCare could help them. People thought IowaCare could promote physical activity by encouraging people to be physically active, providing gym or YMCA memberships, starting exercise groups, and covering the cost of classes such as water aerobics. For diet, many were interested in recipes, information about nutrition, and some had dietary restrictions that were complicated and contradictory. People wanted information to help them make good decisions.

A few participants were concerned about using 'the system' too much. They wanted others who have health care needs to be able to participate in IowaCare, and therefore did not want to use too many of the resources for themselves. Some mentioned feeling guilty about getting multiple visits while other people had no access to care. As one participant put it when asked if he would like to know more about the preventive services IowaCare covers: 'I am aware that all such services have a cost to them that somebody has to pay. Philosophically I would rather be paying it myself if that were possible...I have a desire not to overuse or abuse the system by seeking to know every possible benefit I might be able to squeeze out and using them all. I am using it for what I absolutely have to have... not for luxury or something.'

Access to care while enrolled in Iowa Care

Participants voiced concerns about not having access to dental care, vision/eye care, and physical therapy. People sought care outside of the network for health issues in these areas, if they could afford it. Some reported seeking care outside the network because distance and travel costs made care outside of the network cheaper and more accessible. Most participants explained that there were limited slots for routine and preventive care appointments. The appointment scheduling system and distance were two serious challenges for almost all participants. Prescription costs were also a major barrier, and some participants were concerned with the lack of coverage for durable medical equipment.

*Scheduling and
transportation pose
barriers to care*

Unmet need

A few participants were struggling with some of the health care services not covered by IowaCare. Dental coverage was one such service. One participant suggested that the expense of dental care could be split in half, with IowaCare covering one half and the enrollee covering the other half. One woman had dry mouth, which contributed to major dental problems and eventually, the need for dentures. She thought IowaCare should cover dental services, 'when you have medical reasons' for needing dental care. One participant believed that Broadlawns covered dental care, while UIHC did not. The issue of IowaCare not covering oral health problems was an important finding in the 2008 survey. The results from these qualitative interviews also indicate that oral health is an important concern that has yet to be addressed by IowaCare. A few participants also wanted vision/eye care to be covered by IowaCare.

One participant complained about the role of gatekeeper that the primary care provider plays. The participant said that he had to be seen by his primary care provider to be referred to a specialist, even when he knew that he needed a specialist.

Care seeking outside of the IowaCare group

Very few people reported seeking health care outside of IowaCare. A few reported having to use the local emergency room or hospital, especially if they were transported via ambulance. Of those that did seek care outside of what was covered by IowaCare it was for two main reasons. First, the travel costs to Iowa City were more than the cost of seeking local care, or second, the participants were seeking care at a free clinic where they had been an established patient. As one woman said, 'I did go to a local doctor once when I had a cold and got medications from her.' When asked why she decided to go to a local doctor instead of using IowaCare she responded 'Umm because it was cheaper to go to her than to drive to Iowa City and go to the ER.' One participant still retains her physician in the Quad Cities because she can never get an appointment with IowaCare when she is sick. She said, 'I don't want two doctors, you know, it is ridiculous.' She goes to her non-IowaCare doctor about once every 3 months.

Ease of getting an appointment with primary care

One story really encompassed many of the experiences and feelings of the IowaCare interview participants. The man, who had already lost a leg to a staph infection, had noticed symptoms in his remaining leg that were similar to the leg that had been removed. He had been ‘fighting the staph infection’ and was concerned that the infection might have been in his remaining leg, so he called IowaCare and was told to go the emergency room. While at the emergency room he found out that he had a serious ear infection ‘which was draining like a faucet.’ He went on to explain, ‘They took a culture of the open wound on my good foot....I got five pages of explicit orders from the doctor that saw me that night while they were waiting on the results to come back from the culture.’ This event happened 3 weeks before the interview and he was still waiting on the results at the time of the interview. He was confused about what he should do. He said he ‘has been waiting on the edge of his seat,’ to find out what is wrong with his leg. His ear continues to drain pus continuously. He left the emergency room with orders to follow up with his doctor in 5-6 days. He called to make an appointment, but the first appointment IowaCare could give him was over 4 weeks after his ER visit. He was frustrated that he was not able to talk to a live person to schedule his appointment with IowaCare, and he was very concerned that something could be wrong with his remaining leg. He said it feels like ‘one hand doesn’t know what the other one is doing.’ Nevertheless, throughout the interview this man commented on how great IowaCare was, and how his real frustration is with the hospital, not IowaCare.

While many said it was difficult to navigate the system (getting an appointment, knowing what to do, who to call, what happens next, what is covered) those with many complex health problems, especially mental health issues, had more difficulty figuring out the system or having the patience to negotiate it (staying on the phone on hold, playing phone tag, remembering to call for appointments in the key window—not too soon, not too late). As one participant said, ‘My brain don’t work...diabetes just took over my life for the last 10 years...It has taken a few years to get back.’ This point is important in light of the 2008 survey findings that indicated mental health conditions were prevalent in



this group of enrollees, with over 25% needing mental health treatment or counseling.

Challenges to accessing health care

The two main challenges that individuals expressed repeatedly were difficulties with scheduling appointments and issues related to transportation and distance.

Scheduling

The scheduling systems at UIHC and Broadlawns are different. At Broadlawns participants reported that they could not schedule appointments more than one month in advance. This meant that participants needing an appointment once every 3 or 4 months were challenged to remember to call to schedule a month before the necessary appointment. They could not schedule their appointments when they were checking out from the previous one. One participant expressed the frustration others felt with the following statement:

‘The only problem I have at Broadlawns Family Health Center is they ONLY take appointments for one month at a time. Nothing over a month. They can’t schedule anything. You have to remember you know three months down the road. Oh ya my third month I need to call for an appointment.’

The woman went on to explain that this is only true for primary care. For specialties like endocrinology, patients may schedule in advance.

Scheduling at UIHC presents different challenges for IowaCare participants. Most participants who went to UIHC reported that scheduling through primary care was done first by leaving a voicemail message. The scheduler would return the message, and if the participant was not at home to receive the call, the scheduler would leave a message. The participant would again have to call and leave a voicemail message. This back and forth could continue for a while, as it is not possible for participants to directly call the scheduler. This ‘phone tag,’ as one participant called it, is complicated and frustrating. One participant described the most recent attempt to get an appointment:



'I have tried for the last 4 months to get an appointment. I had a cancel because of the weather. And then they never return my call up there to get an appointment. They told me they would call me back with one in about 4 months...so I haven't been in to see my eye doctor or diabetic doctor...because I keep getting the same thing that they will just call me back with an appointment.'

When patients are scheduling appointments at UIHC for clinics that are not primary care, being put on hold for extended periods of time is normal. One participant said she was on hold for 25 minutes the last time she called for an appointment. Some people indicated that this is expensive, since they do not use a toll-free number.

Unlike Broadlawns, UIHC will schedule appointments more than one month in advance, but the schedules are very full. One participant said, 'If you were to see the doctor on January 1st (and missed your appointment due to illness or funeral) it would be April before you could get in.' Another participant spoke more generally:

'If you call in for an appointment they will usually tell you that they are booked solid for...the last few times I went up there or called in they said they wouldn't have a spot available for at least four months or so and to call back then...I could call back and wait for cancellations or book an appointment for 4 months.'

Another participant stated that she had to wait a year from entering IowaCare before getting her first preventive appointment. As one participant pointed out, 'A regular doctor (the family doctor the rest of his family uses) can get you in within 2 weeks.'

Many participants try to schedule as many of their appointments on the same day as possible. This limits the number of trips they need to make. The time it takes to travel and the cost of gas were common reasons given for why they tried to schedule appointments all on one day. One participant who goes to Broadlawns said:

'[I] try to get some of my doctors' appointments on the same day, so I can get it all done, instead of going today get that done, tomorrow get that done....sometimes I can manage that. I got

there early for my eye appointment...I went to see if I could be squeezed in...I got all that done in two hours. I was doing good.'

A participant who must be seen at UIHC said, '4 hours to drive down there [Iowa City]...just a visit down there for a physical would be something we would avoid.'

Participants must coordinate the scheduling of these appointments on their own. It is a difficult task to call each clinic or department and find appointment times that allow them to work in all of their appointments. One participant explained in detail how the process worked for him and his wife in scheduling appointments. After confirming that that man had eligibility and authorization, they explained:

'...it is a little bit of a job...a week or two ago I made an appointment...I was coordinating 3 appointments, so I thought I would start on the hardest one- which is neurology finally got through to them but they weren't taking appointments in April yet. They gave me the voicemail of the guy who does appointments there to figure out if there was a pattern to the appointments. He called back in a day or two, but I wasn't there. I got ahold of neurology about a week later and they were taking appointments in April but authorization had expired. Got transferred to nurse line for IowaCare. Got voicemail...went back to make appointment at neurology...'

Participants admitted that remembering appointments is a challenge; some had missed appointments because they did not remember that they were scheduled. Many reported missing appointments because of the bad weather during the winter. Others also described unexpected events such as funerals preventing them from getting to their appointments. A few participants remember getting reminder letters about appointments, but remarked that those are not sent out any more.

Transportation/distance

In addition to scheduling, distance and transportation are serious challenges to IowaCare participants in accessing preventive health care. One participant said, 'It is a 2 and a half hour drive...I go there and there is no cost to me but obviously there is this commute...It kills a day to



see a doctor.’ Another reported, ‘I live in western Iowa. I am 4 hours away from Iowa City. And so there are times when it would be really nice to pop in real quick to see somebody...and I can’t.’

Participants rely on a variety of methods to get to their appointments. Although people who live in Polk County generally have less of a distance to travel, they still face difficulties. Some of them drive themselves, but the cost of gas prevents them from driving very often. Many receive rides from friends, spouses, relatives, and neighbors. For people who drive to their appointments, the cost of travel can be more than the cost of receiving health care at their local health care provider. A few mentioned that it cost less to go and have their blood pressure checked or a simple blood test done at a local health care provider than it would cost to drive to Iowa City.

A few participants had used the shuttle services for UIHC. While they were very appreciative of the service, they were not happy about having to leave their houses in the very early morning hours and return to them late at night. One man described how disappointing it was that some people called for a shuttle but when the shuttle got to their house they decided they did not need a ride or were not home. He thought it was very inconsiderate. He was very appreciative of the driver helping him get in and out of the van.

As outlined above, many participants like to have all their necessary appointments scheduled for the same day. This is tricky for participants who live far from Iowa City. Sometimes they may need to leave their homes at 3 am to drive to Iowa City for a full day of appointments. One participant remembered a time he drove to Iowa City and stayed overnight so he could have all of his appointments over a period of two days. This participant was previously on the State Papers program.

A number of participants mentioned severe winter weather as a barrier to travel. Some had to cancel appointments because it was not safe to drive across the state for a medical appointment.

One participant with severe back pain and another who had kidney failure said that the travel itself was physically hard for them. The man in pain said that sitting for long periods of time made his pain worse, which defeated the purpose of going to seek medical care. The man with



kidney failure said that the 4-hour trip to the appointment and the 4 hours back exhausted him. Fortunately, this man's dialysis treatment had recently been moved to a local hospital.

Participants who lived in Iowa City and Des Moines and used the local bus service had difficulties either getting to the bus stop or found that the bus rides were long (90 minutes).

One consistent suggestion was that IowaCare put clinics in more locations. 'In a perfect world, if I could make a suggestion. If they had a hospital in each quadrant, divided the state into fourths said one man. This participant later went on to say that he gives this idea a lot of thought as he is driving the 2.5 hours to his appointments in Iowa City. He would make the locations Iowa City for the southeast, Waterloo for the northeast, Fort Dodge for northwest and Des Moines for the southwest.

Unmet need for prescription drugs

All of the participants reported taking at least one prescription medication. Most were taking more than one medication. Some reported taking a large number of medications every day. One participant said that she had to take 41 pills a day.

The new fees for prescriptions are a problem for some participants. People voiced concern about how they were going to manage to pay for their medications. While some participants were having prescriptions filled locally at a Hy-Vee or Walmart pharmacy, many were having them filled at Broadlawns or UIHC. Not all participants were clear about how the new fee system worked. Most said that someone had to pay \$4 per prescription for a total of no more than \$20. According to one woman:

'I pay a little bit. When you are not working or working and not making a lot of money. . I really had to try to...and I don't have a checking or banking account. So I don't have any checks to send money up there [UIHC]...I only get \$188 a month from my disability.'



Later this woman said that she has to drive to Iowa City from the Quad Cities to pick up her pills because she owes money. She doesn't want to send money through the mail and money orders are expensive.

For the most part people tried to time their prescription refills with their appointments at Broadlawns and UIHC. This type of coordination is difficult. Participants who are not able to coordinate medication refills and appointments must make many trips. One woman reported making 3 trips a month to Broadlawns just to refill her medication. Some participants reported going without medication because coming in for the refills is difficult and not always possible. One participant said, 'sometimes I don't make it and I will go without for a few days...but sometimes I can get my brother to get it.' Many of the participants are on multiple medications that run out at different times during the month. This keeps them busy staying on top of the medication refills. Some of the participants even care for others with long medication lists, further adding to the burden of remembering to refill and pick up medications.

Some of the participants use the mail service available at UIHC's pharmacy. One man had his medications sent to him via FedEx for \$10 a month. He said the \$10 was cheaper than driving from south central Iowa to Iowa City. A drawback of the mailing option for prescriptions, however, is that the IowaCare participant has to pay with either a check or money order. Some of the participants do not have checking accounts and the cost of a money order is prohibitive. As one woman pointed out, 'I haven't been able to pay my last bill. I haven't be able to get my scripts for a couple of months here...' Later in the interview this woman was asked if she was without her insulin and she said yes. A follow-up question was how she manages without the insulin and she said 'My blood sugars run high.'

One woman who has her medication filled locally said, 'Most of the medications are generic...most I can get on the \$4 plan. And I can afford that so I haven't applied for any medication assistance.' While she is able to cover her medication, this woman also said later in the interview that she could not afford to test her blood sugar every day like she is supposed to. She cannot afford the test strips, which are \$125 for 110 strips.



Only one participant was frustrated by her impression that IowaCare would not cover 'name-brand' drugs. She said, 'I take 10 pills just for the fibromyalgia because IowaCare...can't prescribe Lyrica...because they don't do name-brand drugs. Lyrica is a much better drug than what I am taking...what I am taking now doesn't do jack. I am taking ten pills just to walk, to move.'

One man commented that the people at UIHC pharmacy are horribly overworked.

One participant also reported that he received free medication from his local health care provider.

Unmet need for durable medical equipment

One participant complained that IowaCare did not cover physical therapy, which he felt would have been beneficial to him. IowaCare does not cover all types of diabetic testing strips. This was a challenge for some people who already had a monitor they liked before they became enrolled in IowaCare. For some, IowaCare does not cover the test strips for their particular meters. Others reported that their test strips were covered by IowaCare, but that they were not allocated enough test strips to cover the number of times a day the health care provider wants them to test their blood. One participant also said, 'They will pay for medications but they won't pay for any devices...I need a sleeping device [c-pap unit] but IowaCare won't pay for it.'

Health literacy and information seeking

The participants claimed to be well informed about diabetes, since many of them were diagnosed many years ago. Most of them were not active information seekers, but had ideas about where they would go if they needed more information. For those with regular contact with a primary care provider, the provider was their source of information. Many of the participants had challenges with numeracy. The vast majority did not know that there was an IowaCare toll free number for them to get more information about IowaCare.

Information

Most of the participants had been living with diabetes for many years and had a good understanding of what is happening to their bodies and



what they can do to help control diabetes. As one participant put it, 'I have had it [diabetes] for 32 years...when you live with it that long you kind of pick up on these things.' When asked if they wanted to know more, they were split about 50-50. While some said they could never know enough, others believed that they did not need any more information about diabetes. A few even said that they knew more about it than their health care providers.

All of the participants were very well informed about their medications. They had been instructed on their medications by both their health care providers and their pharmacists. All of them reported receiving written information with every prescription they filled. Many of them had taken the time to read the information and some even had a filing system to keep all the written information in.

Very few participants said that they had issues remembering to take their medications. One man jokingly said he sometimes had trouble remembering but he thought it had, 'something to do with that disease they call a-g-e.' Most of the people interviewed had been dealing with diabetes and other complex diseases for a few years and were experts about their medications.

For the most part, these participants were not active information seekers. When they were seeking health information, they were most likely to be seeking information about diabetes and any new research or innovations regarding this disease.

Not all of the participants had access to the internet. Some had access via a friend, relative or the local library. Many mentioned the health information in their health care providers' examination room or waiting room as their source of health information. Some had friends or family who were in health-care-related professions and they asked them questions about health. Others had books at home. A few of the participants received a diabetes magazine.

Some of the participants suggested that IowaCare send out a newsletter or some other written communication with diabetes information, including the latest research, recipes and ways to lose weight. A few of those who suggested this were concerned that this would cost IowaCare a lot of extra money.

*Study participants
use health
information from a
variety of sources*

Health literacy

We asked some specific questions about numeracy related to health. Almost all of the participants said that understanding medical statistics was 'fairly easy.' Although most of the participants indicated that they did not have issues understanding medical statistics, there were a few participants who admitted that they had some challenges in understanding some parts of their medical care. In reference to the literature provided with prescriptions, one IowaCare participant said, 'Well, I'm no college graduate, but usually I can decipher it. I may have to read it 2 or 3 times (laughs).'

When participants were asked how easy or hard it was to understand medical statistics, the majority did not indicate that understanding medical statistics was either hard or easy. Many struggled with the phrase 'medical statistics,' but once it was explained that medical statistics are the numbers used by their health care providers, they mostly responded with 'it is kinda maybe a little tough,' or 'fairly easy.' Some indicated that they wished, 'they['d] just leave it in layman terms...you can't look it up...it ain't in no dictionary.' Only one person indicated that she did not understand medical statistics.

Participants were also asked how much they used numbers and statistics to help make decisions about their health. Ten participants agreed with the statement, '**In general, I depend on numbers and statistics to help me make decisions about my health,**' while 7 people disagreed. The other participants were unsure whether numbers and statistics played a role in their decision-making. Those who agreed that they used numbers and statistics to make decisions made statements like, 'Numbers don't lie,' and numbers and statistics 'kind of gives you an idea on what to keep your eye on.' Though it seems counterintuitive, some of those who reported that medical statistics were hard to understand also reported that they depended on numbers and statistics to make decisions about their health.

Participants were also asked to interpret numbers representing the risk of getting a disease. They were asked, '**Which of the following numbers represents the biggest risk of getting a disease? a) 1 in 100, b) 1 in 1,000, and c) 1 in 10.**' The majority (n=13) selected 1 in 10 as the statistic that represented the biggest risk. The other 7 inaccurately identified either 1 in 100 (n=4) or 1 in 1,000 (n=3) as the

biggest risk. Despite the fact that many participants answered the question correctly, all of the participants' required extra time to answer the question and some needed the question repeated and explained several times. This concept was obviously difficult to grasp and not part of their everyday knowledge.

Additionally, people were asked the following question: **'People can talk about the chance of something happening using either words, like "it rarely happens" or numbers, like "There's a 5 percent chance." When people tell you the chance of something happening, do you prefer they use words or numbers?'** Ten participants said that they would prefer numbers, 4 indicated that they would prefer words and 3 wanted both words and numbers. A few participants made comments like, 'What "rarely" is to one person might not be the same to me.' One person said it, "depends on the circumstance...cause I am the exception to the rule...like when they say normal people...I am not in the realm of the norm.'

Most people reported no difficulty understanding their health care providers. One said, 'My doctor is so awesome...he doesn't beat around the bush...he is just blunt with it...He knows what he is talking about.' Those that did have problems made statements like, 'Sometime they just like the throw the words out there.' Another woman with many health concerns and multiple chronic health issues said, 'Sometimes yah ...doctor [talks] gibberish ...if they could just keep it more simple.' One man was concerned that he did not understand side effects from complicated medications. He said, '...liver damage...how much more damage can it cause, how are we monitoring it, they explain but I have hard time understanding it.'

Surprisingly most of the participants reported that there was very little paperwork to fill out for IowaCare and almost nothing needed to be completed when they checked in for an appointment. Only one woman indicated that the forms at the health care provider were difficult, but she received help from the clinic staff.

IowaCare hotline

Only a few of the participants had ever heard of an IowaCare hotline or the Nurse hotline. The vast majority had never used or heard of the hotline and many wanted to know the number. These results are

completely in line with the 2008 survey results, which showed that few people knew about or used this service.

Additional suggestions for improvement

While some IowaCare participants had no suggestions for how to improve IowaCare, other participants had a number of ideas. Most of the ideas centered around providing more access to health care by increasing the locations, increasing the number of health care providers, and increasing what IowaCare covers.

People recommended that the number of health care providers at UIHC and Broadlawns be increased. Having more health care providers would make it easier to schedule appointments. One IowaCare participant suggested, 'more employees at primary care north...they are overloaded...they are vastly overworked.'

Participants also suggested that scheduling could be made easier by allowing the Broadlawns clinic to schedule more than 1 month in advance and by having someone available to answer the phone at UIHC.

Additionally, people wanted to have some urgent care options available to them other than waiting for an appointment or having to go to the emergency room. People wanted to know where they could go if they had a bad cold or issues with wound care.

Satellite clinics or clinics located in each quadrant of the state were suggested by many of the participants who live far from Iowa City. It was suggested that the clinics could, 'expand to all counties...one major hospital in every county.' One participant said it needs to be, 'easier to access doctors when I need them...so I don't make a full day of it. I literally take a day off of work or school...'

*More care locations
would significantly
improve the IowaCare
program according to
participants*

Chapter 5

Conclusions

Enrollment

In general, participants' experience with enrollment was positive. Most had had a health event or crisis that prompted them to become enrolled in IowaCare.

Health status

The vast majority of participants had very poor health. They were all working to control and manage their diabetes, but many had already suffered greatly from the consequences of their disease.

Administration

In general, people were very positive about IowaCare as a program and were appreciative of the opportunity to have access to care. There is confusion about what is covered by IowaCare and enrollees need more information.

Utilization

Access to routine care was generally good, but difficult for people with more complex medical and mental health issues. Urgent and emergent care is a serious challenge for enrollees in IowaCare.

Access

Scheduling issues related to a lack of appointments and challenging scheduling systems are major barriers to access. Those with the most experience and skills were able to overcome these challenges more easily than other enrollees. Distance and transportation are the other major challenges enrollees face to accessing care. Prescription costs represent yet another barrier to some enrollees.

Quality

Health care providers are key to the health of many enrollees. Most thought they received good care, although some negative experiences



were reported. The lack of urgent care and issues regarding scheduling and distance decrease the perceived quality of care. Further, some individuals require more help navigating the health care system, in particular scheduling, and their quality of care may suffer because they need more help.

Summary

In general, the participants are very thankful for the IowaCare program and many believe they would not be alive today without it. Some believe that the benefits they are receiving are better than those they received with private health insurance. This is a population of people who suffer from a chronic disease, and many have complex health issues. For the most part, they are receiving routine health care for their diabetes, which helps them manage and control it. The care they report receiving meets and in many cases exceeds the standard of care for diabetes management, but for those who have difficulties navigating the health care system, they do not receive the full benefit of the services they cannot access. Challenges or negatives of the program are related to the lack of appointments, the scheduling systems, distance, and transportation. Further, limited urgent and emergent care options pose problems for IowaCare enrollees.

APPENDIX A

In-depth interview protocol

Introduction

Thanks for agreeing to talk to me today. We would like to ask you questions about your experience with IowaCare. We are interested in how IowaCare works for you and if it has changed your health. Please feel free to be honest with me. I do not work for IowaCare. Nothing you say today can change the benefits or care you receive. There are no right or wrong answers. We are interested in YOUR experiences.

- 1) First off, can you tell me how long you have been enrolled in IowaCare?
When did you first get enrolled?
Why did you get enrolled?
Has there been any time since you were first enrolled that you haven't been covered by IowaCare?
- 2) Describe your previous health care coverage before IowaCare?
Probe—what programs were you on? How were they paid for?
How long were you on them? What did they cover? What did they not cover? How do they compare to IowaCare?
- 3) Were there times when you were without health care coverage in the last 5 years? Tell me about those times.
How many times? How long did they last? Why were you without coverage? What did you do for health care? What did you do for prevention/What did you do to maintain your health?
- 4) How would you describe your health today?
- 5) Do you have any conditions that you might consider 'chronic' or health issues that you have been dealing with for a long time? If yes, what are they?
- 6) What has been the biggest challenge to maintaining your health while on IowaCare?

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- 7) How would you describe your health before you were on IowaCare?

ANNUAL VISIT

- 1) Since you have been on IowaCare, have you been seen by a health care provider (doctor, nurse, physician assistant) for an annual exam or check-up (a medical visit when you go to have everything checked out- not just going to have one problem looked at)?
How often?
Do you have a primary care provider (someone who you see for these kind of checkups)?
- 2) Tell me about your experiences trying to get a check-up
Probe—was it hard? Easy? Who did you call? How long did you have to wait? How far did you have to travel?
- 3) Has IowaCare made it easier or harder to get these check-ups?
How?
- 4) What could IowaCare do to make it easier for people like yourself to get check-ups?

CHRONIC CONDITION MANAGEMENT

- 1) You have said that you have these chronic conditions XXXX, are they easier or harder to manage (have control over/understand) since you have been on IowaCare?
Explain why you think that is so.
Probe—change in access to medical care, change in health care provider
- 2) Do you take any medicines for your chronic health conditions?
 - a. Has someone explained why you take these medications?
 - b. Has someone explained what the medications do to you?
What about side effects?
 - c. Has anyone provided you with written information about your medications?
 - d. Did you read them? How easy were they to understand?

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- e. Are there any problems with taking your medications?
Remembering? Getting them filled?
- 3) In your opinion, do you have a good understanding of your chronic conditions and what you are supposed to do to control them?

PREVENTIVE HEALTH CARE (related to general diabetes)

- 1) Have you had a test to determine how well your diabetes is under control? This test might be called the HbA1c? It is a blood test.
 - a. Tell me a little about getting this test.
 - i. Did they poke you in the finger or draw blood from your arm?
 - ii. Did they tell you the results? When?
 - 1. Did they talk to you about what the results meant?
 - iii. About how long ago was that?
 - iv. Where did you get it done?
- 2) Have you had your eyes examined by an eye doctor recently?
 - a. Tell me a little about your eye exam
 - i. When was the last time?
 - ii. Where did you go?
 - b. Who told you that you needed an exam and who arranged it?
- 3) Have you had your cholesterol checked recently? This is a blood test.
 - a. Tell me a little about your test
 - i. Did they poke you in the finger or draw blood from your arm?
 - ii. Did they tell you the results? When?
 - 1. Did they talk to you about what the results meant?
 - b. When was the last time?
 - c. Where did you go?
 - d. Who told you that you needed this?
- 4) Have you been told that you have nephropathy?
 - a. When?

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- b. By whom?
 - c. Have you been told anything about what to do differently because you have nephropathy?
- 5) Have you had a kidney function/nephropathy screening test? This is usually a test looking at your urine (pee).
- a. Tell me a little about your test
 - i. When was the last time?
 - ii. Where did you go?
 - iii. Who told you that you needed this?
- 6) When was the last time a health care provider measured your blood pressure?
- 7) Has a health care provider examined your feet without your shoes and socks on?
- a. When was the last time this happened?
 - b. Did they feel for a pulse in your feet/ankles?
- 8) Do you know what preventive health care (things like flu shots ...) is covered by IowaCare?
- 9) Since you have been on IowaCare have you had any of the following:
- Flu shot? How often?
 - Pneumonia shot (age specific)?
- 10) How has IowaCare helped you get these things done?
- 11) What prevents you/makes it harder for you to get these things done?
- 12) How long did you have to wait to get any of these things done?
- 13) Do you wish to know more about the kinds of preventive health care you could receive or do you think you already know enough?
- 14) What could IowaCare do to make it easier for people like yourself to get these kinds of preventive health care /screenings?



PREVENTIVE BEHAVIOR

- 1) What kind of things do you do to help you maintain your health or prevent future health problems? (e.g., exercise, take vitamins, quit smoking, eat healthier, monitor blood sugar)
- 2) Has IowaCare helped you do any of these things?
How?
- 3) What prevents you/makes it harder for you to do these things for your health?
- 4) What could IowaCare do to make it easier for people like yourself to do the kind of things that prevent future health problems?
- 5) Do you think you know enough about the things you can do to maintain your general health or do you wish that you knew more about what you could do?

OUTSIDE OF IOWACARE

- 1) Have you been seen by health care providers outside of those covered by IowaCare since you have been on IowaCare, besides visits to the emergency room?
 - a. How many times?
 - b. What were the visits for?
 - c. Why did you go outside of the IowaCare providers?
 - d. Were any of these visits to a health care provider you had been seeing before you were on IowaCare?
 - i. Why did you return to this provider?

INFORMATION SEEKING

Some people look for information about a health topic because they are interested in knowing more about a health concern they have.

- 1) How frequently do you look for health information?
 - a. Where do you look?
 - b. What health topics have you looked for information on?
 - c. Have you ever looked for information on your chronic condition (diabetes)?
 - d. What did you find? Was it useful?
 - e. How easy is it to find the information you need?

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- f. How easy was it to understand?
- 2) Do you wish you knew more about your condition (diabetes)?
 - 3) Has being on IowaCare changed how you look for information, where you look, or what you look for? How important looking is to you?
 - 4) If you haven't looked for information – where would you look, if you wanted to find out more about your condition (diabetes)?
 - 5) What could IowaCare do to make it easier for people like yourself to find and understand health information?

HEALTH LITERACY

- 1) In general, how easy or hard do you find it to understand medical statistics?
- 2) How much do you agree or disagree with the following statement: In general, I depend on numbers and statistics to help me make decisions about my health.
- 3) Which of the following numbers represents the biggest risk of getting a disease?
 - 1 in 100
 - 1 in 1,000
 - 1 in 10
- 4) People can talk about the chance of something happening using either words, like 'it rarely happens' or numbers, like 'There's a five percent chance.' When people tell you the chance of something happening, do you prefer they use words or numbers?
- 5) Overall, do you have difficulties understanding your health care providers?
 - a. Explain or give me an example
 - b. What do you do when it is hard to understand?

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- 6) What about forms you have to fill out at the health care providers' office? Have any of these been difficult to understand?
 - a. Can you give me an example?
 - b. What do you do when it is hard to understand?

IowaCare RESOURCES

- 1) Have you used the hotline for assistance with care?
If yes, describe,
If no, did you know there was one?
Why did you not use it?, not need it?
- 2) What about Medicaid hotline?

END

We are almost done with the interview. I have just a few brief questions for you.

- 1) How old are you?
- 2) Are you male or female?
- 3) What was the last year of school you finished?
- 4) How would you describe your race or ethnicity?

Is there anything else you would like to tell me about IowaCare or how your health or life is different since you have been on IowaCare?