



New Hampshire Medicaid Care Management

MEMBER SEMI-STRUCTURED INTERVIEWS,
SUMMARY REPORT
SPRING 2021

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EXECUTIVE SUMMARY

The New Hampshire Department of Health and Human Services (DHHS) conducted an independent qualitative study of Medicaid Care Management Program beneficiaries who had been diagnosed with either Type 1 or Type 2 diabetes. Between March 15, 2021, and April 5, 2021, Horn Research¹ interviewed 30 members, including four members who had both diabetes and a developmental disability. The study used four points of inquiry: Description of Participants, Access to Information and Services, Diabetes Self-Management Education and Support Programs, and Diabetes Care and Self-Management Skills.

Most participants reported well or adequately controlled glucose levels and recent Hemoglobin A1c (HbA1c) testing. Overall, participants said they had not faced challenges in getting answers to their questions about diabetes or medications and favor one-on-one interactions. Participants who received case management support from their MCO were enthusiastic about the service and had better HbA1c results than those who had not. A handful of participants reported challenges in accessing medications due to delays at their pharmacy, issues with prior authorization, and/or issues with transportation. The most significant problem described by participants was not receiving sufficient numbers of test strips and lancets to adequately cover their glucose testing needs.

A minority of participants said they had taken a class to learn how to manage their diabetes, but the bulk of these participants felt the class was helpful and gave them new information. Reasons for not attending a class included not needing the information; a lack of interest; a lack of awareness of, or availability of, classes; mental or emotional inability to attend; a lack of transportation; fear of COVID-19; or a lack of time. Participants universally reported receiving blood pressure testing and nearly all said they had annual cholesterol and triglyceride testing. An annual retinal eye exam was reported by most, but not all participants. Nearly all participants were suffering from at least one other physical health condition besides their diabetes and most reported having what they needed to manage those conditions. Just over half of participants said they had experienced mental health issues in the past 30 days. A third of whom said they were not doing anything to address those difficulties. A third of participants said their diabetes was relevant to their mental health issues, both in terms of the disease causing stress and mental health issues affecting their diabetes.

Participants were most likely to say that the difficulties they faced in managing their disabilities were internal challenges, rather than external. Participants said managing their diet, following their diabetes regimen, and exercising were the most difficult challenges. Participants most frequently said having the willpower to make good food choices and the high cost of healthy foods made maintaining a healthy diet difficult. They also said a lack of motivation, cold weather, COVID-19, physical health limitations, and time limitations made it difficult to exercise.

¹ Horn Research is a contractor of Health Services Advisory Group, which is NH's External Quality Review Organization.

Recommendations from the report include:

Case management for people recently diagnosed with diabetes

Participants who reported access to a case manager through their MCO were more likely to report well-controlled blood glucose levels than those who did not have a case manager. This information suggests it is a helpful tool in diabetes self-management, particularly soon after diagnosis.

Diabetes self-management education and support

A majority of participants did not attend diabetes self-management education classes because they did not perceive the need, did not know classes were available, or were not offered the opportunity to attend. Diabetes self-management classes which are tailored to involve families/caregivers, available at flexible times, offer 1-on-1 support, and provide new information over the lifespan as needs change, should be made available. Support for mental health should also be included in these efforts to address the stressors associated with diabetes and the impact of mental health issues on diabetes self-management.

Provide prevention services to those at high risk

Participants wish they had knowledge to prevent the development of diabetes and many are interested in supports to lose weight and becoming more physically active. Providing prevention services to those at high risk for developing diabetes or with poor glucose control, including programming tailored to those with mobility limitations, may serve to reduce overall disease impact.

Research into encouraging healthy behaviors

Motivation and willpower were identified as key challenges in diabetes self-management. Interventions to encourage, or incentivize, healthy behaviors and outcomes, such as attendance at diabetes self-management classes, weight loss, and lowered A1c levels, should be explored to address those motivation challenges.

Ensure people have sufficient test strips and lancets

A streamlined process which allows members access to test strips and lancets in order to refine their diet in accordance with their providers' testing recommendations may improve blood glucose level monitoring and outcomes. This process could include revising limits on test strips, reducing approval wait times, and ensuring beneficiaries understand their transportation benefit includes transportation to the pharmacy.

Support to access healthy foods

Participants frequently mentioned not being able to afford healthy food as a barrier to healthy eating. Interventions which provide, or link people to, fresh produce and other healthy foods could have a positive effect on diabetes self-management for Medicaid beneficiaries. MCOs could provide programs directly, or partner with other providers to do so.

INTRODUCTION

In support of an external quality review of New Hampshire's Medicaid Care Management Program, Horn Research gathered qualitative data from people who were Medicaid Care Management Program beneficiaries at the time of sampling, and had been diagnosed with either Type 1 or Type 2 diabetes. Members with gestational diabetes were not included in the sample. The sample population included members from across New Hampshire. The qualitative interviews were conducted over the telephone between March 15, 2021, and April 5, 2021.

Four Key Points of Inquiry were developed based on material provided by DHHS to frame the information to be gathered from participants. The Key Points of Inquiry were as follows:

1. Description of Participants

- Demographic details
- Resources and support
- Understanding of, and experience with, blood glucose testing

2. Access to Information and Services

- Sources of information about diabetes and diabetes medications
- Challenges accessing information about diabetes and diabetes medications
- Participants' experience receiving information from their MCO
- Challenges accessing and taking diabetes medications and supplies

3. Diabetes Self-Management Education and Support Programs

- Participants' understanding of HbA1c and experience with the test
- Participants' experience with diabetes self-management education
- Participants' experience receiving critical diabetes management testing including blood pressure checks, cholesterol and triglyceride testing, and retinal eye exams
- Participants' experience receiving support and care for other physical health conditions
- Participants' experience receiving support and care for mental health issues

4. Diabetes Care and Self-Management Skills

- Challenges participants experience in caring for their diabetes
- Challenges participants experience when trying to eat healthy
- Challenges participants experience when trying to be physically active

METHODOLOGY

Horn Research engaged a standard qualitative data gathering process as detailed below.

Sample Size and Composition

DHHS provided a population list of all Medicaid beneficiaries aged 18 and over diagnosed with either Type 1 or Type 2 diabetes. A random sample of 234 members was selected from the full population. Thirty-five people with a developmental disability were included in the total population list. In an effort to ensure participation by at least one of these members, all 35 people with a developmental disability were included in the sample population. Four people with a developmental disability participated in an interview. Two were joined by either their parent or support staff to assist them throughout the interview. Two others were offered the option, but declined. Both of these two participants reported having Asperger's syndrome.

Participant Recruitment

The sampled members were sent a letter (Appendix 1) on March 12, 2021, explaining the project and asking for participation. Participants were offered a \$35 gift card to participate. The interviews were completed between March 15, 2021, and April 5, 2021.

The general rule applied to determining sample size for qualitative interviews is the point at which you reach "saturation." Saturation refers to when no new themes emerge from interviews. A total of 30 interviews were completed. The completed number of interviews for this study adequately met the data saturation expectation.

Data Collection Process

Horn Research conducted the semi-structured interviews by telephone. The telephone interviews were led by an experienced facilitator with participant responses captured in real-time through verbatim note-taking. Interviews were directed by an Interview Guide (Appendix 2) developed to address the Key Points of Inquiry. The interviews lasted approximately 25–30 minutes. All participants received a summary of the purpose of the project at the beginning of the interview, and the facilitator read a statement verifying the confidentiality of the information collected. All participants were mailed a \$35 gift card in appreciation of their participation in the project. The identities of the interviewees were confidential to the interviewer and not revealed to the New Hampshire Medicaid Program.

Data Analysis and Validity

After completing the telephone interviews, Horn Research analyzed the information by identifying, coding, and categorizing primary patterns in the data. The consistent patterns found in the analysis of the data and the representative sample supports the validity of the information gathered but should not be assumed to be *statistically* representative of the whole population. The information provided in this report should be used to identify salient issues relevant to the population, provide contextual information for the larger assessment process, and identify avenues for further research. Quotes from interview participants were lightly edited for content and clarity.

DESCRIPTION OF PARTICIPANTS

Participants were asked a series of questions about themselves, the resources they have available to them, and their experience with blood glucose testing.

Demographic Details

Nearly three-quarters of participants were enrolled with New Hampshire Healthy Families (NHHF), only 20% with Well Sense Health Plan (Well Sense), and 6.7% with AmeriHealth Caritas New Hampshire (AmeriHealth) resulting in an over-representation of NHHF participants (*Table 1*). Participants aged 65 and over were slightly over-represented and participants aged 55-59 were slightly under-represented as compared to the population sample (*Table 2*). Men were slightly over-represented in the study (*Table 3*).

Table 1. Number of Participants and Percent of Population by MCO

County	Interviewed Participants		Study Population
	Number	Percent	Percent
Well Sense	8	26.7%	34.3%
NHHF	20	66.7%	62.0%
AmeriHealth Caritas	2	6.7%	3.7%

Table 2. Number of Participants and Percent of Population by Age Group

Age Group	Interviewed Participants		Study Population
	Number	Percent	Percent
20–29	1	3.3%	3.7%
30–39	4	13.3%	13.2%
40–49	4	13.3%	16.0%
50–59	8	26.7%	36.5%
60–69	13	43.3%	27.9%
70–79	0	0.0%	2.0%
80+	0	0.0%	0.6%

Table 3. Number of Participants and Percent of Population by Gender Identity

Gender Identity	Interviewed Participants		Study Population
	Number	Percent	Percent
Female	17	56.7%	66.5%
Male	13	43.3%	33.5%
Non-Binary	0	0.0%	Unknown

The bulk of participants were aged 40 or over when first diagnosed with diabetes. Only one participant was less than 18 years of age (*Table 4*). Just over a third of participants had been diagnosed with diabetes more than 10 years ago and five participants were newly diagnosed (*Table 5*).

Table 4. Number and Percent of Participants by Diagnosis Age

Age when diagnosed with diabetes	Number	Percent
Under 18	1	3.3%
20–29	3	10.0%
30–39	6	20.0%
40–49	9	30.0%
50–59	9	30.0%
Don't remember	2	6.7%

Table 5. Number and Percent of Participants by Time since Diabetes Diagnosis

Length of time since diabetes diagnosis	Number	Percent
Less than 2 years	5	16.7%
3–5 years	3	10.0%
6–10 years	9	30.0%
More than 10 years	11	36.7%
Don't know	2	6.7%

Over three-quarters of participants said they are currently not employed (*Table 6*). Two participants reported full-time employment, and three said they were employed part-time. One participant said he owned a small vending machine business which was currently not operating due to COVID. One other participant said he received a small stipend for providing home-health care to his disabled son.

Table 6. Number and Percent of Participants by Employment Status

Employment status	Number	Percent
Not employed	23	76.7%
Full-time	2	6.7%
Part-time	3	10.0%
Other	2	6.7%

Resources and Support

Twenty participants said they have reliable access to transportation. One other said their vehicle is normally reliable, but was currently in the shop. Four participants said they rely exclusively on the Medicaid transportation provided through their MCO. One participant uses public transportation, and one other relies on family members and friends. Two participants said they use a mix of options including family, friends, public transportation, and Medicaid transportation.

Twenty-three participants said they had access to the internet. Two of these mentioned that they did not use it. Seven participants said they did not have access.

Nine participants said they live alone. Two participants said they live in a group living environment and one was currently living in a homeless shelter. Eighteen participants said they live with family members.

Of the participants who live with family members, 14 said their family members did not assist them in managing their diabetes. Four said their family members assist somewhat by helping with reminders and assistance making healthy food choices. One participant with a developmental disability said her parents help her a great deal with her diabetes management, including administering her insulin shots. The two participants living in group homes said the staff at the home helps them extensively with managing their diabetes. A participant living in a homeless shelter was not receiving any diabetes management assistance from staff members. One participant said he was not currently managing his own diabetes, and neither was his family member.

Blood Glucose Testing

Participants were asked to describe their understanding of HbA1c. Over half of respondents provided an explanation that matched the correct definition (*Table 7*). An additional seven participants gave a description that was correct, but vague. One participant said, “I think it has to do with how much sugar is in your blood. I know the lower the better.” Seven participants said they could not provide a definition.

Table 7. Number and Percent of Participants by Understanding of Hemoglobin A1c

Understanding of HbA1c	Number	Percent
Correct	16	53.3%
Mostly correct	7	23.3%
Don't know	7	23.3%

Male participants were much more likely to have a poorer understanding of HbA1c (*Table 8*). Nearly 40% of the men participating in an interview said they did not know what HbA1c was while only 12% of women reported not knowing what HbA1c was.

Table 8. Number and Percent of Participants by Understanding of Hemoglobin A1c and Gender Identity

Understanding of HbA1c	Male		Female	
	Number	Percent	Number	Percent
Correct	6	46.2%	10	58.8%
Mostly correct	2	15.4%	5	29.4%
Don't know	5	38.5%	2	11.8%
Total	13		17	

Length of time since diagnosis and age did not appear to have an impact on participants' understanding of HbA1c.

Twenty-eight of the 30 participants said they had received an HbA1c test within the past year (*Table 9*). Nearly two-thirds of participants reported a test within the past 3 months, and another quarter said they had received one 4–6 months prior to the interview. One participant said her last test was approximately 18 months prior. She noted that her doctor said she was doing very well with her glucose control and did not need another test for another year. She said the COVID-19 pandemic prevented her from getting the test at the one year mark. One participant did not recall ever receiving an HbA1c test.

Table 9. Number and Percent of Participants by Length of Time since Last Hemoglobin A1c Test

Most recent HbA1c test	Number	Percent
Within past 3 months	19	63.3%
4–6 months ago	7	23.3%
9–12 months ago	2	6.7%
More than a year	1	3.3%
Don't know	1	3.3%

Over half of participants reported HbA1c test results that were indicative of well controlled glucose (Table 10), and another quarter had adequate glucose control. Three participants had HbA1c test results that were indicative of either elevated glucose or poor glucose control. Four participants said they did not recall the level, two of whom reported that their doctor said their level was fine. One participant said her doctor told her the result was high, but she had not been given a number. As noted above, one participant said he did not recall ever having an HbA1c test.

Table 10. Most Recent HbA1c Results

Most recent HbA1c results	Number	Percent
Well controlled glucose (<7%)	16	53.3%
Adequate glucose control (7.1–7.9%)	7	23.3%
Elevated glucose (8.0–8.9%)	1	3.3%
Poor glucose control (>9%)	2	6.7%
Don't know	3	10.0%
Don't remember test	1	3.3%

Men were more likely to report not knowing what their HbA1c results were. Three of the four who said they did not know their test results were men.

Participants with their own personal transportation were much more likely to report well-controlled glucose levels than participants who relied on Medicaid transportation, family and friends, and public transportation (Table 11).

Table 11. Number and Percent of Participants by Hemoglobin A1c Result and Transportation

Most recent HbA1c results	Well Controlled		Less than Well Controlled	
	Number	Percent	Number	Percent
Own transportation	14	73.7%	5	26.3%
Reliant on others	2	28.6%	5	71.4%

There was no connection between timing of participants' most recent HbA1c and access to transportation.

ACCESS TO INFORMATION AND SERVICES

For the most part, participants said they rely on their primary care physician (PCP) or other medical provider to answer their questions about diabetes. Most participants said they had not experienced any difficulties getting answers to their questions. Participants reported liking a variety of formats for receiving information. The most frequently mentioned formats were one-on-one interactions and self-directed research. A minority of participants said they like going to classes. When asked to describe the information about diabetes they had received from their MCO, participants were most enthusiastic about the case manager support they received from their MCO. Participants noted that some of the recipes they received were helpful, but the printed materials often did not offer new information beyond what they had received from their providers or had gathered from their own experience. As with diabetes in general, participants said they ask their medical providers and pharmacists questions about medications. On the whole, participants did not have any difficulty getting these questions answered. A handful of participants reported challenges in accessing medications due to delays at their pharmacy, delays at the MCO in obtaining prior authorization, and/or issues with transportation. A small group of participants noted some difficulty in remembering to take their medication, experiencing some side effects, and having difficulty self-administering insulin shots. The most significant problem with diabetes supplies described by participants was not receiving approval from their MCO for a sufficient numbers of test strips and lancets to adequately cover their glucose testing needs.

Information about Diabetes

When asked who they turn to when they have questions about their diabetes, 19 participants said they rely on their PCP. Six participants said they ask a family member or friend. Five participants said they generally ask their endocrinologist. Four participants said they speak with a case worker or other support staff, and three participants said they look information up themselves.

Preference for Mode of Information

When asked how they preferred to receive information about diabetes, most participants (N=17) said they favor one-on-one interactions. One participant who said she had a case manager from her MCO remarked, *"I prefer having a person to talk to, especially if I get off track. She actually left a message a couple of weeks ago and said she's not doing the job any more. She sent me some information in the mail that I will have for a while. I do like having someone I can contact. In the past, I never used anything like that with my insurance company, but this helped me."* Another participant said, *"I prefer first hand from the doctor or the nurse. I don't like to do the internet unless I have to. I did like classes, but I feel like I have the information I need."* Another participant said, *"I prefer to get it from my doctor, but most of the time, I research it on the internet."*

Eleven participants said they like to research information on their own. One participant said, *"I like to look it up online just because I'm not a big phone person. And then, if I have any further questions, I just go to my doctor."* Another participant said, *"Before COVID, we were meeting once a month at a support group. I prefer to read. I do love to read online, I read a lot about nutrition, and diabetes."* Some participants noted that they had concerns about doing their own research. One participant said, *"(I prefer) either a class or one-on-one. I don't mind researching, but I don't know if it's correct or not. When you type stuff in, it can take you to a nutball's page. I would, of course, have common sense, but I'm not sure if where I'm searching is okay. I am cautious about researching online."*

Six participants said they liked the class format. One participant shared, *"I like classes and groups. At NHHF a few years ago, they had a cooking class. I liked that a lot. A bunch of us met and they provided*

us transportation to the food bank, and we practiced cooking. That was through NHHF. We did it for eight weeks.”

Three participants said they preferred written material. One participant shared, *“I like reading it because I can see the print, and I can get a grasp of it easier.”*

Challenges Getting Answers

The bulk of participants (N=25) said they had not experienced any difficulties when trying to get their answers about diabetes answered. One participant said, *“There haven’t been any challenges. He’s a really good physician. It’s important to have a good relationship with your diabetes doctor.”*

One participant who had been recently diagnosed had significant difficulty getting answers to her questions. She said, *“I didn’t have a very good start with all of this. I went to the ER (emergency room), because I had an SVT (supraventricular tachycardia). They told me that my blood sugar was a little high. They didn’t tell me how high, but told me to call my doctor. The doctor said it was over 400. I guess my whole thing with all of this was my doctor put in for the monitor and the strips to test every morning before I ate, but then she went on vacation and didn’t put in referrals for the cardiologist or dietician, and this was the first week of COVID. I didn’t get any help at the beginning. I had to do it all by myself. I could pick up my medication and strips, but didn’t have any help about explaining what levels meant. I had to do research on my own and I didn’t have anyone to ask. And put on top of that, COVID unfolding. It was pretty tough.”*

Another participant said the information he had received when he asked questions was very poor. He said, *“They did send me to a specialist, but their specialists told me I should reuse the needles several times. I’ve found out since then you don’t want to do that... (and) the doctor told me that my A1c was 5.8, but he didn’t tell me it was a little low. He just said we could cut down on the Metformin. I said I’d rather just have some potatoes sometimes.”*

One participant noted challenges with access to timely answers. She said, *“Sometimes I have to wait for them to call me back, and sometimes it’s on the weekend, and I can’t get an answer at all.”*

Another participant said he has difficulty negotiating the technology to correspond with his physician. He said, *“I’m not that familiar with that patient portal. That seems to be rather difficult to get into and it wasn’t as easy as I had thought to use. It’s not clear. You just can’t get where you want to be with that. It’s difficult. You want to talk to your doctor on a certain level and you can’t because this portal doesn’t provide you with a certain way to communicate with them. It’s just really very confusing to do. I can’t just go and tap on that and expect to send a message or get a response.”*

One participant said his main difficulty was with transportation to get to the doctor to get answers to his question. He said, *“I use the service through the insurance. I don’t have a vehicle. The problem is that I can’t get a pickup time through the scheduling company. I had to cancel an appointment. Also, I don’t have a cell phone or computer access and they can’t contact me when I’m outside. And with this doctor, he’s booked solid. There are really no challenges with my questions. It’s just getting there to the doctor when you have to go every three months, with transportation.”*

Information Provided by MCO

When asked what information about diabetes they had received from their MCO, participants most frequently (N=15) said they had received printed nutrition information such as recipes and meal planning guides. One participant said, *"They send me some nutritional stuff, what to eat, and stuff like that. How important your blood sugars are, carbohydrates, education about the food. It was printed and had pictures."*

They send me a calendar every year with tips and they send me recipes that I wouldn't have even thought of. They send it once or twice a year.

Nine participants said they had access to a case manager through their MCO who checked on them periodically and provided support and information about their diabetes. Eight of these participants were enrolled with NHHF and one was enrolled with AmeriHealth. One participant said, *"I just went through a support thing with them, I don't know if it was specifically diabetes. I took a cooking class that was sponsored by NHHF a couple years ago, and that was really nice. That was for diabetes specifically. That was really good. I have had some other support from them, too. I think the girl that was calling me once a month, that was diabetes related. She was sending me recipes and things after we talked. This was all during COVID. I've had a lot of support during COVID. A lot of phone or video supports."* Another participant mentioned the app her MCO used to have. She said, *"They had an app for a while that whenever I did test, it went to them. I could message a woman any time of day and she'd get back to me on questions. She could see my results. It was called On Duo. And then they stopped it."* Another participant described, *"I have a coach. She calls and sends me stuff about diabetes. NHHF helped me more than my doctor did. She sent me all sorts of stuff, recipes, helps me with my weight loss."* While the data is not statistically significant, more participants who reported access to a case manager through their MCO reported well-controlled blood glucose levels than those who did not have a case manager.

Two participants mentioned they received a calendar to track their blood sugar levels. One participant said she had received information on weight loss; and another had received information where to find special foods and the location of clinics where she could receive assistance.

Six people said they had not received anything from their MCO and three additional participants said they did not recall whether they had or not. Participants from all three MCOs indicated they had not received any information.

Quality of Information

Of the 21 participants who said they had received information from their MCO, about half (N=10) said the information was helpful. In particular, participants who had access to a case manager through their MCO were pleased with the information and support they had received. One participant who had access to a case manager through an app on her phone said, *"It was helpful. My doctor didn't want to see me because I was doing well. She said I didn't need to really test much. With the app, I was doing it semi-regularly. It kept me engaged and motivated. I have only tested once since (they stopped the app)."* Another participant with a case manager said, *"Absolutely very useful. I don't know what I would have done. There was no way I was going to go into a doctor's office back then. She's been a tremendous help."*

Some participants were pleased with the printed material they received. One participant said, *"It's very helpful. I can understand and I can always go back to it. If someone were telling me something on the phone, I'd probably remember for a day. It's easy to forget things. I save the paper and if I have to refresh myself, I'll go back to it."*

Seven participants said the information they had received from their MCO was somewhat helpful. These participants commented that it was generally information they already knew and was repetitive.

Four participants said the information was not at all helpful, remarking that the material had not provided them with new knowledge.

Diabetes Medication Information

Of the 26 participants who said they take medication for their diabetes, 18 said they ask their PCP when they have questions about their prescriptions and three said they ask their endocrinologist.

Ten participants said they ask their pharmacist questions about medications. One participant said, *"I speak to the pharmacist. I'm on a boatload of medications, and I want to make sure the diabetic medication doesn't interfere."* Another participant said, *"I work at a pharmacy. So, my first questions would go to the pharmacist I work with, and then my doctors, just because it's convenient. And they know more about the drugs than the doctors."*

I find the printed information helpful, and I also found the care manager helpful. I lost 60 pounds and I can't lose anything beyond it. She told me what to eat, what to do. She taught me some things I didn't know. I wish I still had access to (the care manager).

My doctor can be harder to get a hold of. If it's medicine related, I go to the pharmacist first.

Two participants said they ask a family member their questions about medications, and one participant said she asks her psychiatrist. Another said he asks the medical technicians at the brain injury clinic he uses. One participant said he asks the support staff at the group home he lives in.

Challenges Getting Answers

All but four of the participants who take medication said they had not experienced any difficulties getting answers to their questions about their prescriptions. One parent of a participant with a developmental disability said they had experienced difficulties getting information about her daughter's reaction to her medication, testing process, and test strip coverage. She said, *"My daughter was having a lot weight loss and loss of appetite, and then she fell, and they don't know why. (The nurse practitioner) thinks maybe it was low blood sugar and said, 'why don't we give her medication vacation'. But then there was a confusion on whether she should have a different medication and how much to take and when. It was hard to explain to my daughter. We had to have an appointment to get on paper what she should be taking and how much. At some point, the nurse practitioner said a lower dose was needed, but not to stop all together. There was also a big confusion because I showed up at the clinic and said she was a patient, but the lab tech didn't know who the diabetes nurse was. We finally got the message to the nurse practitioner, got the test, and got her back on the medication. Also, my daughter is not good about taking daily tests, and we didn't have any strips. She hadn't gotten the A1c. The strips that were prescribed weren't covered, so I had to talk to the pharmacy technician to get the right ones."*

There was a lot of confusion about the number that were covered. We were in limbo until they figured that coverage out."

Another participant reiterated his challenges related to his provider's patient portal for communication.

One participant had not had specific challenges getting answers, but rather expressed fears about having her prescriptions changed due to changed formularies. She said, *"Sometimes, through the insurance company, they don't want to pay for my medication and they transfer me to a new medication, and I'm afraid I'm going to be allergic to it. That scares me. Once you know you can take something and not have an allergic reaction, you feel great."*

One participant said she had difficulty with her pharmacy not filling her medications at one point. She said the pharmacy did not have her medications in stock and she frequently ran out before they were able to fill her prescription. She resolved the issue by switching pharmacies.

Diabetes Medications and Supplies

Participants were asked to describe any challenges they experienced getting their medications, taking their medications as prescribed, and accessing diabetes supplies. Twenty-six participants said they take medication for their diabetes.

Getting Medications

Of the 26 participants who take medications, 18 said they had not experienced any challenges in getting their prescriptions. Three participants noted they had experienced delays with prior authorization. One participant said she had difficulties getting the right number and type of testing strips prescribed and authorized. Two participants explained that there were challenges with their pharmacy and doctor's office coordinating with regard to prior authorization. A participant said, *"One of the biggest issues is when they need a new prescription, they send an electronic request to the clinic, but it's been over two years now since that clinic could receive electronic request. As I understand, it's not something that can be easily fixed. With the pharmacy itself, there were issues before that, they'd blame the doctor, the doctor would blame them. I usually try to order my prescription a week early to make sure they can figure it out."* All three participants who experienced challenges with prior authorization were covered by NHHF.

Three participants said they had experienced difficulties with the time it takes to get their prescriptions filled. One participant remarked on a need for either automatic refills or reminders. He said, *"There's been a few times in the past when I ran out, and I noticed it last minute. It was hard to get a refill so quick."* Another participant said, *"If I have a new prescription, it can take longer than it should."* The third participant said one pharmacy she was using could not get her insulin in a timely manner. She said, *"When I was using Walgreens, they couldn't get the insulin in. They kept saying it was ordered, but it would take a month to get it in."*

Two participants said transportation had been a problem for them in getting access to their medications. One person resolved the issue by switching to delivery. The other changed to a pharmacy within walking distance, but said it was still difficult to get her medications. She was unaware that transportation support may be available for trips to the pharmacy.

Two participants said they sometimes had difficulty paying for medications. One participant said, *"I know it's only a dollar, but it's still hard."*

Taking Medications

Of the participants taking medication, 19 said they had not experienced any challenges in taking their medications. Four participants said their main difficulty was forgetting to take them. One participant mentioned that having pill packs helped her address that problem. She said, *"I have a problem with my memory. I had some little strokes, so sometimes that gets in the way. It's pretty easy, they put it in little compartments, so I know when I miss something. I can feel it, and I take them then."*

Two participants mentioned having some difficulty with side effects from medications unrelated to their diabetes.

One participant said she had difficulty giving herself insulin shots. She said, *"It's just me giving myself the shots. Sometimes it's difficult to do. I'm a big woman, I don't like needles anyway, and the only way I'm comfortable giving myself a shot is in the belly. I know I need to switch around. And I'm too afraid to do it. I haven't gotten any help with that."*

Getting Supplies

Ten participants said they had experienced challenges in getting diabetes supplies. Five of these participants, all with NHHF, said their MCO did not cover a sufficient number of test strips and lancets per month. One participant said, *"NHHF limits your test strips to 100 to every 90 days. I'm trying to experiment with different foods, and there are some days I'd like to test two or three times. They had a deal with a different meter, and would send strips. It was a pain in the butt. I had to use a phone app. I got frustrated with it, they cancelled me and then they stopped the program. It's more aggravation to deal with."* Another participant said, *"The prescription is for one test a day, one strip, one lancet. Sometimes I'll need to test more than once because I feel off. I wasn't eating enough carbs. The nurse from NHHF told me I needed some carbs. If I need more than one a day, then I do have to buy out of pocket. The insurance company will not cover it unless I am taking insulin. It's not a huge burden, but it's an annoyance. I can pay for it, but for somebody else, it might be a big deal. If I need to test it, I need to test it. I'm old enough to remember when everything was covered. It's hard for me, I remember how it used to be and now how it is."* A third participant noted her doctor had told her to test more often, but she couldn't due to the limit imposed by NHHF. She said, *"When I last saw my doctor, he told me check my sugars more often, but my insurance says I can only have one stick a day. In the morning, (my sugar is) always high. My doctor wants me to test it before and after I eat, but that would be more than one stick a day."*

Another participant said he was experiencing difficulty with prior authorization for his test strips. He said, *"I'm going through an issue right now. I ordered some test strips maybe three weeks ago, and they said I wasn't approved."*

One other participant said the MCO kept switching the type of lancets that were approved which resulted in needing to re-use lancets until the issue was resolved. Another participant said the fact that lancets require a prescription is yet another hurdle in caring for his diabetes. He said, *"The doctor has to write a script to get lancets. He shouldn't be bothered to get that through NHHF or Medicaid. It's one more little barrier. I have to call his office to get a refill for lancets. It seems like it should just go through with the meter. It should be the same thing with test strips."*

Although transportation may be provided to members for trips to the pharmacy, one participant reiterated her difficulty with transportation to get their supplies from the pharmacy. One other participant said she had difficulty getting the supplies for her insulin pump. She said they couldn't find a

company that took her primary insurance and ended up having to use the pump supplies longer than recommended.

DIABETES SELF-MANAGEMENT EDUCATION AND SUPPORT

Participants were asked to share their experience with diabetes self-management education classes, receiving ongoing testing/exams related to their diabetes, such as blood pressure checks, cholesterol screening, and annual retinal eye exams, and the support and care they are receiving for other physical and mental health conditions. A third of participants said they had taken a class to learn how to manage their diabetes. The bulk of these participants felt the class was helpful and gave them new information. Reasons for not attending a class reported by participants included not needing the information, a lack of interest, a lack of awareness and availability of classes, mental or emotional inability to attend, a lack of transportation, fear of COVID-19, and a lack of time. Participants universally reported receiving blood pressure testing and nearly all said they had an annual cholesterol and triglyceride testing. Annual eye testing with dilation was reported by most, but not all, participants. Barriers to eye testing reported by participants included the COVID-19 pandemic, a lack of motivation, and lack of insurance coverage for their preferred provider. Nearly all participants said they were suffering from at least one other physical health condition besides their diabetes. A handful of participants said they did not have what they needed to manage those conditions including not having an at-home blood pressure machine, compression stockings, transportation to appointments, and approval for needed testing. Just over half of participants said they had experienced mental health issues, most of whom reported on-going mental health diagnoses. A third of those with mental health issues said they were not doing anything to address those difficulties due to not believing there was anything to be done, assuming the issues would resolve on their own, or not liking the options available to them. A third of participants said their diabetes was relevant to their mental health issues, both in terms of causing stress and the mental health issues affecting their diabetes.

Diabetes Self-Management Education

Ten participants indicated they had taken a class on how to manage their diabetes. Three participants said the class they had taken was comprehensive and covered all aspects related to their diabetes, including nutrition, exercise, and testing. One participant shared, *"They cover everything. The HbA1c, how to do the test strips, they have speakers come in and talk to us about diet and exercise. They bring food for us to eat and drink while we're there."* Another participant said, *"We've had all kinds of talks. We did a tour of Hannaford's to learn about the foods that are good. Our regular meetings have a speaker or something. It's either exercise or diet. One man described how he's gotten his A1c down and how he eats. It goes about an hour and the speaker is always really good. I think they have a good program. It just got stopped because of COVID. Also, the diabetes educator calls me every month."*

Four other participants said that the class had provided information on nutrition and eating. One participant explained she learned about, *"carbohydrates, starches, portion control, what your plate is supposed to look like, colors."* Another participant said he learned, *"basically lay off the Gatorade, lay off the starches, how to portion your food, what to eat and not eat."*

One participant mentioned that in addition to nutrition information, he had received information about exercise.

Two participants said the information they had received was basic and not particularly helpful. One participant said, *"It was rudimentary stuff a long time ago. It wasn't interesting."*

Location and Length of Class

Four participants said the class they took was at a clinic or health center. Three reported their class was at the hospital, one of which was a one-on-one consultation. Two participants said they attended classes at their doctor's office, one of which was a one-on-one consultation. And one took a class at her local community center.

Two participants said they had only attended one class. Four said they had attended two or three classes and four had attended four or more classes.

Quality of Class

When asked what they liked best about the classes they attended, six people mentioned they appreciated all the new knowledge they gained from the class. One participant said, *"I thought it was informative. It was a lot of stuff I didn't know. Their version of the plate was a lot different than mine. I'm a pretty big person, and they showed their plate and mine, it was quite shocking. It was a big wake-up call."* Another participant said, *"I liked the ideas and options of what to eat, what will give me more energy, and won't bring me down."* One participant said she appreciated both that she received a lot of information and that there was a lot of camaraderie among classmates.

Two participants said they liked the opportunity to get their questions answered. One participant said, *"It helped with some things. Some things I already knew. It was more if I had a question about food or something, she could answer those."*

Two participants said they had not liked anything about the class they had taken. One participant said, *"It was just basic knowledge. It only last only a half hour."*

For the most part, participants said there was nothing they would change about the class they took. One participant shared, *"There is nothing I would change. They're actually really good. I wish I had been going to them all these years. I just started going back. In the summer, we actually met at the pond and had a picnic. It's very nice. It's a small group, you get to know everybody. I kind of miss everybody. I really like it. I think it's a wonderful program. I'm surprised it's available. It's so well run and it's through the clinic."*

One participant said the amount of useful information was limited. He said, *"It was fine. Once you've gone a couple of sessions, unless you're having issues, it's all the same thing. I knew what caused it. It was my obesity and my diet. You can only harp on the subject so long."*

One participant said the introductory class she took was not useful, but would have been willing to go to other classes. She said, *"I don't remember much, it was so long ago. They expected me to continue with the actual class, but my insurance wouldn't cover it. I would have gone if they would have covered it."* Another participant who had only attended an introductory class said, *"It was not useful. I'm too busy to take it anyway."*

Another participant mentioned the food at the meetings is sometimes contradictory to the lessons being taught. She said, *"Sometimes they bring bagels, and that is a lot of starch. They need to bring healthier foods. One lady brings quiche, and fruit and vegetables."*

Reasons for Not Attending

When asked why they had not attended a class on diabetes self-management, seven participants said they did not need to take a class. These participants mentioned that they had already gained the knowledge through various other avenues, including attending classes with family members, going to a nutritionist previously, or discussing their diabetes with their providers. One participant shared, *"I took it with my husband when he was seeing a dietician specialist, and I got a lot of information from that. I've already heard a lot of this stuff because of my dad and my husband having diabetes and my husband going to the nutritionist. I learned a lot there, why take the space for someone else who might need it?"* Another participant said, *"I had gastric bypass. During the course of a year getting ready for that, I spoke to many nutritionists and what not. I have a good understanding. My endocrinologist talks to me in depth."* One participant said that since she was diagnosed with diabetes as a child, a class was not needed. She said, *"I was a little kid, only seven, when I was diagnosed. I haven't felt a need to as an adult. I did take a class to learn about my insulin pump. That was a one-on-one. And one for my tester. It was a diabetes educator at Dartmouth/Hitchcock, and it was helpful."*

Three participants said they were not interested in taking a class, and one participant said he didn't like to take classes, preferring instead to research on his own.

Two participants said they did not know that classes were offered and available, and two participants said classes were not offered to them. One participant mentioned that her anxiety prevented her from attending a class. A support worker assisting a participant with a developmental disability indicated he was not a good candidate for a class due to his disability.

A newly diagnosed participant said she had not gone to a class due to the COVID-19 pandemic. She said, *"If there was something online, that would be awesome. That would be great to do a Zoom meeting kind of thing."* One participant said transportation was a limitation for her to attend a class. She said, *"I had trouble getting there because I don't have transportation. I'm not sure if I'd have wanted to go even if I had transportation. I'd have to think about it."*

One participant said she did not have time to attend a class. She said, *"I have a family, and I have two children that are disabled. I basically take care of my family, and I don't take care of myself. And that's on me, that's on nobody else."* One participant simply said he did not know why he had not taken a class.

Recommended Diabetes Care

When asked whether they had their blood pressure checked at their last well visit, all 30 participants indicated they had. Two participants volunteered that they also check their blood pressure at home regularly.

All but two participants said they have their annual triglyceride and cholesterol checked. One participant said their endocrinologist said it was not necessary and the other participant said they did not know.

Five participants said they had not received an annual eye exam at an eye doctor. Two others said they had this past year, but normally did not do so. Two participants said they had not gone because of COVID. Two participants said not going was simply a matter of motivation to go. One said, *"I just don't get it done. The doctor asks if I want an appointment, I tell him to set it up, something comes up and I don't go."* Another said he just keeps forgetting. One of the two participants who normally do not get the testing said he avoids it because it is not covered by insurance. He said, *"I just went, but I usually don't do it annually because it doesn't get paid for. There are only a few people who accept Medicaid."*

The doctor I had been going to over 20 years didn't accept it. I scraped some money together and got it. There's only one person who takes Medicaid in Manchester so he gets booked up. I just went to my regular eye doctor who knows my family history and my history. I don't want to go to someone who doesn't know all that. She knows my mother has had macular degeneration. I'm more cautious with my eyes."

Care for Other Physical Health Conditions

Participants most commonly mentioned high blood pressure, high cholesterol, arthritis and joint pain, and heart issues as physical health conditions they currently deal with (Table 12).

Table 12. Number of Participants by Physical Health Condition

Physical Health Condition	Number
High blood pressure	13
High cholesterol	7
Arthritis/joint pain	7
Heart issues	5
Weight issues	4
Back pain	4
Thyroid issues	3
None	3
Sleep apnea	2
COPD	2
Nerve damage	2
Asthma	1
Kidney issues	1
Strokes	1

Of the 27 participants who noted at least one other physical condition besides their diabetes, 17 said they had everything they needed to manage those conditions, five participants said they did not, two said they were waiting for care, and three could not answer the question.

Two participants said they did not have a home blood pressure machine which would enable them to manage their blood pressure better. One participant said, *"The insurance company does not pay for a blood pressure cuff to check at home, and with COVID, the machines at stores aren't available. I had one that goes around your wrist that I picked up free, and I had another one that went around your forearm, but I brought them in to the doctor's office and found they weren't reading correctly. The insurance doesn't cover a good one. I can't check at home, like (my doctor) asked me to. If I have a feeling, she said to come in a check it out, but I can only do that during business hours which isn't when things usually happen."*

One participant said she had not received the correct compression stockings for her edema. She said, *"I got a prescription for compression stockings from my primary because I have lower edema, but I think they didn't give me the right ones. I was supposed to get the ones with bandages. My podiatrist said my insurance probably wouldn't cover that type. I'm scheduled to go to a vascular surgeon for my legs. If they determine if I have vascular problems, they would possibly cover it. But with just diabetes and joint*

issues, it wouldn't be covered. But I know the edema is part of the diabetes. That would be helpful if I could get that covered."

One participant said transportation was a significant barrier to getting other physical health issues taken care of. He said, *"I hate to harp on this, it's the transportation issue in getting to the urologist, my primary care, and all the doctors. It's fine to get a bus, but then you're waiting to get in to doctor's office. They don't want me showing up early at the doctor's office."*

One other participant said that the surgeon had said there was nothing to be done about her back pain. One participant said she's waiting for approval for an MRI to diagnose her nerve pain and another participant is trying to determine whether she could get a wheelchair to help with her arthritis.

One other participant, who said her other medical needs are taken care of, mentioned a need for dental care. She said, *"I take a lot of medications and the pharmacy has made my medicine management a thousand times better than any other pharmacy. I can go online and see everything. It's just wonderful. I don't have to call and check on refills. They're sending me texts. They're a lot better for someone who has a lot of health conditions and medications and supplies. Everything is covered. The only thing that is missing is my dental. I was receiving dental at Easter Seals and they closed the dental here in Manchester, so all of us Medicaid patients don't have any adult dental. I don't know what they're doing about it, but I'm going to have to go out on my own to get it and it's hard to afford. I'm trying to figure out what I'm going to do. I've been waiting since December. I'm needing some serious dental work. I have severe sensitivity to cold in my whole mouth. I have pockets in almost all my teeth and cracked to the root. I can't drink or eat anything cold. It's gotten really bad just in this past year. They want to get my teeth out and give me dentures, I'm suffering now. We need to have dental here for the adults. We need a program put back in here really bad."*

Three participants were not able to answer whether they had what they needed. One of these participants said, *"With my emphysema, they just tell me to quit smoking."*

Care for Mental Health Issues

Eighteen participants said they had experienced some kind of mental or emotional issues within the past 30 days. Of those, eleven indicated their issues were long-term, on-going mental health issues, such as bipolar disorder, depression, and generalized anxiety disorder. One participant said, *"I do take medication for anxiety as needed. I always have stress. I had anxiety when my son getting his COVID vaccines, and I think I get the normal blues. I take a very low dose of Prozac, have been for years. I am his 24/7 caregiver, and I have all the things that go along with all that. I've hit menopause and how do you know if you're just menopausal or what. I had a very hard time when initially diagnosed with diabetes, and the stress from that was making my blood sugars go up. I do notice that if I'm really stressed, my blood sugar does go up. I don't eat anything I'm not supposed to. My sister still drinks iced coffee with sugar. I don't feel right if my blood sugar is off. I think in the beginning it was very stressful. My A1c was 9.6 when first diagnosed, and 5.6 now. I still get worried, but I think I've gotten it pretty well under control."* Another participant said, *"I take medicine for it – bipolar. I do have depression and anxiety. I'm on a lot of heavy meds, and it works."*

Seven participants said they had been experiencing stress and anxiety due to situation-specific circumstances. One participant said, *"It's not critical. There's time when I get a little down and I want to stay in my bunny slippers every day. I try to stay active and not worry about financial issues and health issues and live as normal a life as I can."* Another participant shared, *"Since COVID, I get these little bouts of anxiety, a pressure in my chest. A little bit of deep breathing helps. I think I am having anxiety."* Another participant attributed her stress to her living situation. She said, *"I'm homeless, and it's stressful."*

Six of the eighteen participants reporting mental health issues said they believed their diabetes played a role, both in terms of causing stress and the mental health issues affecting their diabetes. One participant said she has, *"PTSD, anxiety, depression. It makes my sugar go up when I'm stressed."*

Efforts to Address Mental Health Issues

Twelve of the 18 participants with mental health issues said they are doing something to address them. Six participants said they take medication, and six participants said they are receiving counseling. Two participants said they try to stay active and exercise, and one participant said she relies on friends to help.

Of the six who said they are not addressing their mental health issues, two said there was nothing to be done about it. One said, *"The only thing I can do to help me about feeling down is to become more financially secure."* The other participant said, *"I know what it is. There's no point. Everybody is having problems, I know I'm not different. I've never had any mental health problems before. I know it has to be something to do with the isolation."*

Another participant mentioned the COVID-19 pandemic as the main cause of not receiving care for her mental health issues. She said, *"I have been to counseling for depression quite a few years back, and it helped a little. But with the pandemic, for the past year I've been isolating because I'm high risk. I'm not comfortable going anywhere."*

One participant said the weather changing would be the key to her feeling better emotionally. She said, *"I think it's because I'm locked up in the winter-time. In the summer, I take off and go fishing. I try to get myself away and do my thing. I grew up on the water. I love going. My father was a fisherman. I get out in the woods, and people leave me alone."*

One participant said she did not like the format for counseling that was offered to her. She said, *"I used to see a counselor, but they want me to go to group therapy and I don't want to do that."* One other participant said she was given a referral to a counselor, but had not followed up yet.

I get anxiety every once in a while. I try to set goals for myself every day and if I don't meet those, I feel like I failed. Sometimes circumstances are out of your control, something happens. I take Celexa for depression, but overall, it's pretty good. I try to stay positive, but there are days that I'm down some. I have a cat who keeps me positive. I live alone, and he's a good buddy. I think it's separate from my diabetes, but sometimes there is stress associated with the diabetes. I try to remain positive, and I always think there's somebody worse off than me. That usually does the trick.

DIABETES CARE AND SELF-MANAGEMENT SKILLS

Participants were asked a series of questions about potential challenges they faced in managing their diabetes, in trying to maintain a healthy diet, and in being physically active. Participants said managing their diet, following their diabetes regimen, and exercising were the most difficult challenges. Participants most frequently said having the willpower to make good food choices and the high cost of healthy foods made maintaining a healthy diet difficult. They also said a lack of motivation, cold weather, COVID-19, physical health limitations, and time limitations made it difficult to exercise. When asked, if given a magic wand, what change they would make to help with their diabetes, participants most frequent responses were to eliminate their diabetes altogether or to change their relationship with food in some way. Participants also mentioned they would either eliminate, or adjust, their medications, know about diabetes sooner, lose weight, not have to use needles, have access to better diabetes technology sooner. One homeless participant said she would want reliable housing.

Challenges with Diabetes Management

When asked what challenges they faced in trying to manage their diabetes, twelve participants said the difficulty of making good food choices was their primary issue. One participant shared, *"I think my biggest thing is the food part of it. I am a picky eater. Sometimes it's hard to think of different things that I like that I can eat."* A man with a developmental disability said the food he cannot eat was the hardest part. The staff member supporting him during the interview said, *"We monitor the amount of sweets he has. The man has a sweet tooth, and a junk food tooth, as well."*

Seven participants noted challenges associated with the cost and accessibility of healthy foods. One participant said, *"Money is a little bit of a factor. All of the healthy stuff, vegetables, are expensive as compared to pasta and potatoes and all of that. I think that I'm getting there. I have my A1c below 7, that's not too bad. It's a process. I'm getting there."* Another participant said, *"I'm only on so much income and planning meals is really hard. I've got teenagers that like the sweet stuff that I can't have. Potatoes, pasta, all that good stuff."*

We used to have the pill cases and bottles in the house and it was harder for me to take my medications. And 9 out of 10 times, I'd probably forget to take it. But now with the pharmacy packs, it's easy for me to take my medication because it's all packed together.

Seven participants said that various aspects of the regimen associated with their diabetes was difficult, particularly remembering to test their glucose levels and taking their medications regularly. One participant said, *"Just remembering everything. Once in a while, I forget to do a blood sugar test. It's not all the time, it's once in a while. And trying to keep up with all my appointments, I try to do all of those."* Another participant shared, *"Just remembering to take my meds"* was a problem. Participants also said it was difficult to have to prick their fingers and give themselves insulin shots. One participant said, *"I*

would say the hardest part of it is the finger sticks every day. Constantly poking myself with a needle and giving myself insulin. I'm in the routine, but I think that's the worst part."

Three participants mentioned exercise and weight as primary challenges with their diabetes. One participant shared, *"It's hard for me to exercise. I just bought a rollator, because I have a walking disability. Back when I was better able to walk, I could keep my numbers down. Now that I have it, it's easier to get out and walk. My weight loss is challenging especially with the pandemic. I was in physical*

therapy for my joint issues, so I do have some exercises that I do at home. That helps to keep some level of activity."

Two participants mentioned that transportation was a challenge with respect to their diabetes. One participant said, *"Transportation and trying to get to a grocery store (is difficult). I end up walking to the store, but it's hard to bring many things home at once. My neighbors, with COVID, don't want to take me for trips to the store."*

One participant said that being responsible for the cooking was a challenge for her. She said, *"The fact that I don't like to cook and I'm the only one who does it" is hard. Another participant mentioned the emotional toll of the diabetes saying, "Feeling like not a normal person (is hard). I really can't go and have a huge sundae."*

Three participants said that there wasn't anything that was difficult about managing their diabetes. One participant said, *"I really don't (care) about my diabetes. It's the last thing on my mind every single day. I do my meds. I just called in to NHHF about this letter I got from the pharmacy department that says your health is important, if you're having trouble taking meds, call your doctor, ask the pharmacist, if you have questions about managing your diabetes, call this number. I called, and they said just do your meds. That's pretty much in a nutshell. What's to worry about - nothing."*

Challenges in Maintaining a Healthy Diet

Fourteen participants said having the willpower to resist unhealthy foods and managing their cravings

was the most difficult part of maintaining a healthy diet. One participant said, *"I really do love my fruits and vegetables. It's just the desserts. I have learned to limit myself."* Another participant noted,

"Sometimes I manage to avoid my cravings and sometimes I don't." A person with a developmental

disability said, *"I tried going on diets before, and I do eat fruits and vegetables, but not as much as I should. With my vending machine business, I always have access to the product in my house. It's hard to resist the junk food."*

I love soda, and that's a challenge to not drink as much soda.

Nine participants said that cost was a significant barrier to being able to have a healthy diet. One

The salads, and that stuff, is kind of expensive. To compensate for some of it, I go to the food pantry, but their fruit and vegetables aren't that great. Then the expensive fruit and vegetables, I don't eat it fast enough. You can only eat so much of it.

participant shared, *"It's just more expensive to buy healthy foods. Money, overall, is just tight. I'm on disability. The savings I did have, I spent taking care of my mother. I was paying a lot to keep her medical stuff going on."* Another participant said, *"I get food stamps, and it's a balancing act. That's the hardest job of all, because I have to prepare 30 breakfasts, lunches, and dinners. Usually, I do a list and I have to do it four or five times just to balance out the food with the cost. That's the biggest thing. I like to get produce, but everything is so expensive now. That's a big issue."*

One participant reiterated her dislike of cooking as one of the barriers to having a healthy diet while another participant said that it was a challenge balancing the desires of other family members with the

requirements of her diet. One participant noted that being homeless made it extremely difficult to maintain a healthy diet. Another participant said that accessing healthy food during the COVID-19 pandemic has been challenging. One participant said that he lacked sufficient nutrition knowledge to have a healthy diet. He said he struggled with, *"knowing what is healthy and what is not, knowing what is a good level of carbs, proteins, sugars to eat. I can read the back of the box, and it's all Greek to me."*

Four participants said they did not find anything difficult about trying to maintain a healthy diet.

Challenges with Being Physically Active

Seventeen participants said that other health issues were a barrier in being physically active. Participants noted back pain, arthritis, joint issues, heart issues, and breathing issues all as reasons why they could not be physically active. One participant shared, *"I'm not very active because I have severe osteoarthritis in my left hip which causes a great deal of pain. I also have lower back stuff and left knee problems. It's hard to go up and down the stairs. I don't get out there to be active. It's challenging to walk on unlevel ground. I will occasionally walk down the mailbox. But just walking back up trying to go up the hill, that's a little more challenging."* Another participant said, *"I do suffer from COPD, and I have emphysema. I've had surgeries because I did try to shoot myself. Instead of just having a messed up arm, I got a messed up leg to go with it."* One participant said her mental health also posed a barrier. She said, *"Depression makes it hard to be active."*

Seven participants said that a lack of motivation made physical activity challenging for them. One participant said, *"I'm not one to exercise. Unless I have something to do, I'm not going to go out."* Six participants said that the cold weather exacerbated the lack of motivation. One participant said, *"Sometimes I don't have motivation. I want to go out and walk, but because of the cold right now, I don't want to go outside."* Another participant said, *"I love to walk and I maintain my exercise throughout the year except in the winter. I cannot walk in the winter time. It really incapacitates me. Unless it's an emergency, I can't. I'm not a winter person. I completely shut down."*

Four participants said the COVID-19 pandemic had reduced their options for being physically active. One participant with a developmental disability said, *"My old day staff had a Planet Fitness membership, and I started going with her as her guest. She got me into getting my own card and I was using my membership with her three times a week, but now that she's no longer there, I stopped going. I started going on my own and with my new staff, but with the COVID situation, we can't go anywhere out in public other than walks. If we get to the next phase, we can go out in public."*

Three participants said family responsibilities limited their ability to be physically active. One participant said, *"Right now, with my mother, it's hard to get out as much as I'd like to. I'm the only person there. She doesn't need 24-hour care, but she needs someone there quite a bit. I don't have any other support for her, I'm trying to get my brother more involved, and we are looking to get some home health care people come in."*

One participant said she had difficulty managing her blood sugar with exercise. She said, *"I hate that I have to eat to deal with my blood sugar right after I exercise. I'm just filling in those calories I just burned."*

Two participants said they did not have any challenges trying to be physically active. One participant said, *"I try to take a walk at least once a day, sometimes more. I had both knees replaced, so I can walk now."*

Magic Wand

Participants were asked what change they would make to help with their diabetes, if they were given a magic wand. Seven participants, unsurprisingly, said they would make their diabetes disappear altogether. One participant summed it up as, *"I guess I would just make it disappear all together."*

Eight participants said they would change their relationship with food in some way. One participant said she wanted, *"to be able to eat whatever I want."* Another participant said she wanted, *"a private chef that would cook stuff. That's the hardest part for me. I just don't want to cook any more."* Another participant said she would wish for, *"having the world's food systems change to what it was before 1972. They're trying to kill us with the food. Everything is processed. It's hard to eat anything clean. Unless you eat keto, and that's what I'm trying to do."* One participant said he would want greater willpower with his eating habits.

Five participants said they would eliminate, or modify, their medication. One participant said she would like to, *"just to be able to get off the medications and control it with diet and exercise."* Another participant said she wanted to, *"not take Metformin ever. I can't stand that medication; my body doesn't like it. It makes me so nauseous. I have to take an anti-nausea pill to get through the night. I can take only two a day, and I can't take extended release. I know it's a wonderful drug and I want to try to stay on it as much as possible. It just makes me sick. It does that to people - I know that's common."*

Four participants said they would have the knowledge of how to prevent diabetes sooner. One participant said, *"I guess maybe knowing at a younger age that I could have done more. I know it's in my family history strongly. Maybe a magic wand of starting younger at knowing how much I could have been affected by it."*

Three people said they would want to lose weight if they had a magic wand. One participant said she wanted, *"to be able to lose more weight to get off the insulin again. I've gone off and on it."* Another participant shared, *"I think weight loss would help a lot. I know people that are overweight have a tendency to be diabetic. I think my numbers would go down a lot. I'm working on my weight loss. At one time, I went to Weight Watchers and I lost 40 or 50 pounds. That was a few years ago. And I gained back 10 or 15 pounds since then. I was close to 300 pounds at one time. Weight loss would definitely help."*

One participant with a developmental disability said she would wish to not have to deal with needles for the blood testing. One other participant said she would have accessed advanced diabetes technology sooner. She said she would want to, *"have a pump sooner - or a continuous glucose monitor. When my husband died, I wasn't taking care of myself. I was more concerned with caring for my kids, and I was dipping low in the night. Not having it at all would be great, but I've had it since I was seven. I wouldn't know what to do with myself if I didn't have it."*

The homeless participant said housing was a key for her. She said she would want, *"the medication to actually fix the problem, instead of just maintain. My weight is mostly part of it. I wish there was a pill for that. It gets harder as you get older. I've struggled with my weight most of life. I'm on a constant diet, I can't willingly eat what I want to eat without gaining 150 pounds. I'm not one of those people who can do that. I look at something, and I gain five pounds. It's been hard and I've been trying to maintain eating healthier foods and I get so stressed out sometimes and I say screw it and binge. It gets so frustrating with my circumstances. I have days, and sometimes a week, where I say I don't care any more. I'm going to die, and I'm so tired, I'm done fighting. I'm tired of it all, but then I come out of it and come back to reality and understand it was a moment and I have to resume my life and try to make the best of it that I*

possibly can. I have children and grandchildren. I don't want to die. I'm trying to maintain. I'm not belittling anyone worse off, but I'm extremely frustrated from the housing situation. It really hinders my health. I know I can be doing a lot more, but I can't because I'm not given that option. I'm on tons of waiting lists, but preference is given to people who are more mentally ill and addicted. A person that needs a little help is at the bottom of the list, and it's not fair."

OTHER COMMENTS & CONCERNS

Participants were offered the opportunity to provide any additional comments or share any concerns related to their health coverage.

Four participants shared their satisfaction with their insurance coverage and providers. One participant said, *"I think the insurance has helped me a lot. I feel protected, other than those test strips. Hopefully they will agree to give me more than one a day."* A parent of a participant with a developmental disability said, *"I just know that the doctors are very helpful. She is the best one we've had. She sees her every three months. She knows more than her PCP, she gets more blood tests quicker, so she changes medications appropriately. I always feel like she's a phone call away. I do have a frustrating process to get through, but once I get through, it's good."*

One participant said he needs more proactive connection and communication from his MCO. He said, *"NHHF has been pretty good as far as looking after my health needs. I keep trying to stress to them that I need a little more interaction than the average person because I'm kind of disassociated from the whole concept of proper medical living. Overall, I'd give them a good grade, and they reach out semi-regularly. I just need a little more hands-on involvement. I've stated that to more than one person."*

Although transportation can be provided for members who need to go to the pharmacy in certain circumstances, one member was not aware of this service. A participant noted she would like transportation made available to get her prescriptions. She said, *"The only thing would be is if there was better transportation to get my prescription. I can get a taxi, but I don't know how much that will cost."*

Another participant said she wished there was greater access to camps for children with diabetes. She said, *"I wanted to join these camps, but my parents couldn't afford it so I was never able to go. That would be one thing, if there are camps for kids with diabetes to go to. I felt excluded. There was never anyone in my grade that had it. That would have been beneficial to see other kids to know I wasn't the only one who was going through it."*

I just wish the State would either offer classes, or encourage these doctor's offices to offer classes, about how to manage diabetes.

Another participant mentioned the impact family demands can have on people's ability to care for their diabetes. She said, *"I don't know how much attention is paid to people who have special needs children. That factors into a lot for people. I don't really have backup. It's really just me."*

One participant said she wishes there was a wider range of family practice doctors who took Medicaid, and one other participant expressed his concern about the competency of people working at pharmacies.

RECOMMENDATIONS

Based on the experiences and feedback reported by interview participants, six recommendations have been developed to address the challenges faced by people with diabetes.

Case management for people recently diagnosed with diabetes

While the data is not statistically significant, participants who reported access to a case manager through their MCO were more likely to report well-controlled blood glucose levels than those who did not have a case manager. This information, in addition to feedback from participants concerning the value of their case manager, suggests it is a helpful tool in diabetes self-management, particularly soon after diagnosis.

Diabetes Self-management Education and Support

A majority of participants did not attend diabetes self-management education classes because they did not perceive the need, did not know classes were available, or were not offered the opportunity to attend. Diabetes self-management classes which are tailored to involve families/caregivers, available at flexible times, offer 1-on-1 support, and provide new information over the lifespan as needs change should be made available. Support for mental health should also be included in these efforts to address the stressors associated with diabetes and the impact of mental health issues on diabetes self-management.

Provide prevention services to those at high risk

Participants wish they had knowledge to prevent the development of diabetes and many are interested in supports to lose weight and becoming more physically active. Providing prevention services to those at high risk for developing diabetes or with poor glucose control, including programming tailored to those with mobility limitations, may serve to reduce overall disease impact.

Research into encouraging healthy behaviors

Motivation and willpower were identified as key challenges in diabetes self-management. Interventions to encourage, or incentivize, healthy behaviors and outcomes, such as attendance at diabetes self-management classes, weight loss, and lowered A1c levels, should be explored to address those motivation challenges.

Ensure people have sufficient test strips and lancets

A streamlined process which allows members access to test strips and lancets in order to refine their diet in accordance with their providers' testing recommendations may improve blood glucose level monitoring and outcomes. This process could include revising limits on test strips, reducing approval wait times, and ensuring beneficiaries understand their transportation benefit includes transportation to the pharmacy.

Support to access healthy foods

Participants frequently said the cost of healthy foods was a barrier to having a healthy diet. Interventions which provide, or link people to, fresh produce and other healthy foods could have a positive effect on diabetes self-management for Medicaid beneficiaries. MCOs could provide programs directly, or partner with other providers to do so. The partnership between the Catholic Medical Center in Manchester and the New Hampshire Food Bank may provide insight into this type of endeavor.

APPENDIX 1. RECRUITMENT LETTER

March 12, 2021

Dear [NAME],

The New Hampshire Department of Health and Human Services is asking for your help with a project about New Hampshire Medicaid Care Management. The Department hired Horn Research to gather opinions from people like you to better understand your experience with your health plan and health care.

We would like to invite you to participate in a **telephone interview** where you can share your experiences learning about and managing your diabetes. *[For people with developmental disability waiver]* Please feel free to have a family member or support person join you in the interview to provide assistance.

We are only asking a small number of people to take part so **your participation is very important**. You will receive a **\$35 VISA gift card** as a thank you for your time if you participate in a telephone interview.

We will be conducting the telephone interviews between **March 17, 2021 – April 16, 2021**. The interview will take about 20-30 minutes and we can schedule it at your convenience. We have a limited number of interview slots and they will be filled on a first come, first serve basis. All information you share will be kept completely private and will not affect your benefits or health care in any way. No one from Medicaid will see your individual answers and your name and personal information will never be made public.

If you would like to schedule an interview, please call Horn Research toll-free at **(888) 316-1851** or email at Lisa@HornResearch.com.

Thank you for sharing your experience and thoughts about New Hampshire Medicaid Care Management.

Sincerely,



Susan Drown, MBA, LICSW
Director, Bureau of Quality Assurance and Improvement

APPENDIX 2. INTERVIEW GUIDE

Introduction

The goal of this interview is to try to understand your experience with your diabetes management and the support you receive.

Your feedback is very important and will help the State of New Hampshire evaluate the Medicaid Care Management program. We want to know about your experiences. Your participation will not affect the benefits and services you receive through the Medicaid Care Management Program and all the information you provide will be kept completely confidential. At no point will your name or any other identifying information be released.

I. Demographics / Context

1. **Current Age (Years)**
2. **Gender (Man, Woman, Non-Binary, Transgender, Prefer not to answer)**
3. **How old were you when you were first told you have diabetes? (BRFSS question, age in Years)**
4. **Are you currently employed? If yes, is it FT, PT, temporary, etc.?**
5. **Do you have reliable access to transportation?**
6. **Do you live alone, with a partner/spouse/roommate, with dependent children/relatives, in a residential community / assisted living, etc.? If with another person(s), how involved are they in helping you manage your diabetes?**
7. **Do you have access to a phone, tablet or computer with internet access?**
8. **In your own words, how would you describe what Hemoglobin A1c (HbA1c) is?**
Probe: HbA1c is a blood test that helps monitor your diabetes condition by measuring your average blood sugar (glucose) levels was over the past 2-3 months. The American Diabetes Association recommends routine HbA1c testing to assist in the management of diabetes.
9. **Do you know when your most recent HbA1c was? When was it taken and what was the level? (# and date)**

If you have not had an HbA1c in the past year, why not?

Probe: My doctor didn't not recommend this blood test, I did not want to go to the lab during COVID, Transportation issues, etc.

II. Access to information & services

10. **When you have a question about your diabetes, who do you contact for information?**
Probe: doctor, nurse, pharmacist, diabetes educator, community health worker, health plan, other
11. **What challenges have you had in getting your questions about diabetes answered?**
12. **When you learn about diabetes, how do you like to get information?**
Probe: website/online, magazine, group education class, one-on-one, group class, telehealth
13. **What kind of information about diabetes have you received from your MCO/Health Plan? Have you found it to be useful/helpful? In what ways? If so, please describe. (Care manager, printed information, etc.)**
14. **Do you take diabetes medications? (IF NO SKIP TO QUESTION 18)**
Probe: For example, insulin, metformin (glucophage)
15. **If yes, how do you get answers to questions about your medications? Who do you ask? What has been difficult about getting answers to your questions about medications**
Probe: Who? (pharmacist, nurse, doctor, diabetes educator, care manager, health plan)
16. **Are there things that get in the way of getting your medications as prescribed?**
Probe: affordability, transportation
17. **Are there things that get in the way of you taking your medications as prescribed?**
Probe: difficult/complicated regimen, side effects
18. **Do you have any difficulty getting diabetes supplies? If so what supplies and what are the difficulties?**
Probe: test strips, meters, etc.

III. Diabetes Self-Management Education and Support Programs

19. **Have you ever taken a class on how to manage your diabetes? (IF NO SKIP TO QUESTION 24)**
Probe: this could be in group format, or one-on-one with a diabetes educator, community health worker, care manager/health plan, or other healthcare professional
20. **If yes, what topics did you learn about?**
Probe: checking blood sugar, nutrition, physical activity, stress management, etc.
21. **Where were the classes?**
Probe: hospital, clinic, in-home, other community location
22. **About how many sessions have you attended?**
23. **What do/did you like about the diabetes education? What didn't you like (or could be improved)?**
24. **If you have not taken a class on how to manage your diabetes yourself, why not?**
Probe: My doctor didn't refer me, I am not aware of any education programs, I don't want to go, transportation, inconvenient times, would rather get information from another source, etc.
25. **Did you have your blood pressure checked during your last well care visit? If not, why?**
Probe: Was not aware that all adults with diabetes should be routinely monitored for high BP (hypertension) because they are at greater risk for cardio-vascular disease.
26. **Do you receive an annual cholesterol and triglyceride (a type of blood fat) blood test (LDL-C)? If not, why?**
*Probe: Was not aware that all adults with **diabetes** should have a cholesterol and triglyceride test every year because they are at greater risk for cardio-vascular disease, My doctor didn't refer me, transportation issues, etc.*
27. **Do you receive an annual eye exam with an eye doctor? If not, why?**
*Probe: Was not aware that all adults with **diabetes** should have a dilated **eye exam** for diabetic retinal disease every year (The American Diabetes Association recommends that diabetics have retinopathy screening at least once every year), My doctor didn't refer me, transportation issues, etc.*
28. **What other physical health conditions do you have such as high blood pressure, high cholesterol, eye problems, kidney problems, etc. and do you have what you need to manage those conditions?**
29. **Now thinking about your mental health, have you experienced any issues with your mental health, including stress, depression, and problems with emotions, during the past 30 days?**
Probe: Please tell me more about that.

30. If yes, did any of the mental health issues have a connection to your diabetes?

Are you doing anything for these issues? If not, why?

Probe: seeing a behavioral health provider, peer support group, online/social media groups; or informal friends, family, etc.

IV. Diabetes care and self-management skills

31. What is hard about taking care of your diabetes?

Probe: financial, transportation, housing, time, appointment availability, access to healthy foods, access to safe place to be physically active, etc.

32. What, if any, challenges do you face when trying to eat healthy?

33. What, if any, challenges do you face when trying to be physically active?

34. Thinking back on everything we've talked about today, and your experience living with diabetes, if you had a magic wand that you could use to make one change to help with your diabetes... what would it be?

APPENDIX 3. MCO-SPECIFIC RECOMMENDATIONS FOR QAPI REPORT

ACNH

Table 13 lists opportunities for improvement from the Member Qualitative Interview Report to include in the quality assessment and performance improvement report for ACNH.

Table 13. EQRO Findings and Recommendations for Improvement from the Member Qualitative Interview Report to Include in the QAPI Report for ACNH

ACNH EQRO Findings/Recommendations for Improvement to be Included in the QAPI		
Member Qualitative Interview Report		
1	ACNH-2021Sp-QAPI-SSI-01	ACNH should refer members to care management as soon as possible after a member is diagnosed with diabetes.
2	ACNH-2021Sp-QAPI-SSI-02	ACNH should make available diabetes self-management education classes tailored to involve family/caregivers, offer 1-on-1 support, and provide new information over the lifespan as needs change.
3	ACNH-2021Sp-QAPI-SSI-03	ACNH should provide prevention services to those at high risk for developing diabetes or with poor glucose control, including programming tailored to those with mobility limitations.
4	ACNH-2021Sp-QAPI-SSI-04	ACNH should explore interventions to encourage, or incentivize, healthy behaviors that assist in controlling their diabetes (i.e., attending diabetes self-management classes, achieving weight loss, lowering HbA1c levels, etc.).
5	ACNH-2021Sp-QAPI-SSI-05	ACNH should ensure that members with diabetes have access to an adequate supply of lancets and test strips to assist members in controlling blood glucose levels.
6	ACNH-2021Sp-QAPI-SSI-06	ACNH should create educational information for members about accessing fresh produce and other healthy foods from government-assisted programs that could have a positive affect on diabetes self-management. The partnership between the Catholic Medical Center in Manchester and the New Hampshire Food Bank may provide insight into this type of endeavor.

Table 14 confirms that there are no findings/recommendations for improvement from the Member Qualitative Interview Report to be included in the EQR Technical Report.

Table 14. EQRO Findings/Recommendations for Improvement from the Member Qualitative Interview Report to be Included in the EQR Technical Report

ACNH EQRO Findings/Recommendations for Improvement to be Included in the EQR Technical Report	
Member Qualitative Interview Report	
There are no findings/recommendations from the Member Qualitative Interview Report that need to be included in the EQR Technical Report.	

NHHF

Table 15 lists opportunities for improvement to include in the quality assessment and performance improvement report for NHHF.

Table 15. EQRO Findings and Recommendations from the Member Qualitative Interview Report for Improvement to Include in the QAPI Report for NHHF

NHHF EQRO Findings/Recommendations for Improvement to be Included in the QAPI		
Member Qualitative Interview Report		
1	NHHF-2021Sp-QAPI-SSI-01	NHHF should refer members to care management as soon as possible after a member is diagnosed with diabetes.
2	NHHF-2021Sp-QAPI-SSI-02	NHHF should make available diabetes self-management education classes tailored to involve family/caregivers, offer 1-on-1 support, and provide new information over the lifespan as needs change.
3	NHHF-2021Sp-QAPI-SSI-03	NHHF should provide prevention services to those at high risk for developing diabetes or with poor glucose control, including programming tailored to those with mobility limitations.
4	NHHF-2021Sp-QAPI-SSI-04	NHHF should explore interventions to encourage, or incentivize, healthy behaviors that assist in controlling their diabetes (i.e., attending diabetes self-management classes, achieving weight loss, lowering HbA1c levels, etc.).
5	NHHF-2021Sp-QAPI-SSI-05	NHHF should ensure that members with diabetes have access to an adequate supply of lancets and test strips to assist members in controlling blood glucose levels.
6	NHHF-2021Sp-QAPI-SSI-06	NHHF should create educational information for members about accessing fresh produce and other healthy foods from government-assisted programs that could have a positive affect on diabetes self-management. The partnership between the Catholic Medical Center in Manchester and the New Hampshire Food Bank may provide insight into this type of endeavor.

Table 16 confirms that there are no findings/recommendations for improvement from the Member Qualitative Interview Report to be included in the EQR Technical Report.

Table 16. EQRO Findings/Recommendations for Improvement from the Member Qualitative Interview Report to be Included in the EQR Technical Report

NHHF EQRO Findings/Recommendations for Improvement to be Included in the EQR Technical Report	
Member Qualitative Interview Report	
There are no findings/recommendations from the Member Qualitative Interview Report that need to be included in the EQR Technical Report.	

Well Sense

Table 17 lists opportunities for improvement to include in the quality assessment and performance improvement report for Well Sense.

Table 17. EQRO Findings and Recommendations for Improvement from the Member Qualitative Interview Report to Include in the QAPI Report for Well Sense

Well Sense EQRO Findings/Recommendations for Improvement to be Included in the QAPI		
Member Qualitative Interview Report		
1	WS-2021Sp-QAPI-SSI-01	Well Sense should refer members to care management as soon as possible after a member is diagnosed with diabetes.
2	WS-2021Sp-QAPI-SSI-02	Well Sense should make available diabetes self-management education classes tailored to involve family/caregivers, offer 1-on-1 support, and provide new information over the lifespan as needs change.
3	WS-2021Sp-QAPI-SSI-03	Well Sense should provide prevention services to those at high risk for developing diabetes or with poor glucose control, including programming tailored to those with mobility limitations.
4	WS-2021Sp-QAPI-SSI-04	Well Sense should explore interventions to encourage, or incentivize, healthy behaviors that assist in controlling their diabetes (i.e., attending diabetes self-management classes, achieving weight loss, lowering HbA1c levels, etc.).
5	WS-2021Sp-QAPI-SSI-05	Well Sense should ensure that members with diabetes have access to an adequate supply of lancets and test strips to assist members in controlling blood glucose levels.
6	WS-2021Sp-QAPI-SSI-06	Well Sense should create educational information for members about accessing fresh produce and other healthy foods from government-assisted programs that could have a positive affect on diabetes self-management. The partnership between the Catholic Medical Center in Manchester and the New Hampshire Food Bank may provide insight into this type of endeavor.

Table 18 confirms that there are no findings/recommendations for improvement from the Member Qualitative Interview Report to be included in the EQR Technical Report.

Table 18. EQRO Findings/Recommendations for Improvement from the Member Qualitative Interview Report to be Included in the EQR Technical Report

Well Sense EQRO Findings/Recommendations for Improvement to be Included in the EQR Technical Report	
Member Qualitative Interview Report	
There are no findings/recommendations from the Member Qualitative Interview Report that need to be included in the EQR Technical Report.	