WHAT DOES DIABETES LOOK LIKE IN OUR REGION?

A Summary of the Regional Diabetes Needs Assessment Study | 2017

The Diabetes Institute at Ohio University is a collaborative group of research scientists, clinicians, educators, health administrators and students with a common interest in diabetes.

It is the mission of the Diabetes Institute to *improve the quality of life for those affected by diabetes and related diseases through innovative basic and translational research, progressive clinical care, education and community outreach.*

To help achieve this mission and more fully understand the impact of diabetes in the region, the Diabetes Institute needed to conduct a diabetes needs assessment. In early 2016, the Institute was awarded an Ohio University Innovation Strategy planning grant to fund, in part, the diabetes needs assessment for an eight county region in Southeastern Ohio (Athens, Hocking, Meigs, Morgan, Perry, Vinton and Washington counties) and West Virginia (Wood County). The institute worked in partnership with the Ohio University Voinovich School of Leadership and Public Affairs to complete the assessment. The results provide an important glimpse into the lives of residents in the region living with diabetes and will guide the strategic direction of the Diabetes Institute as well as diabetes prevention, education, and healthcare initiatives in the region.

The mixed method study utilized a telephone survey (n=1884), focus groups (n = 36) and interviews (n=9) with people experiencing diabetes, and interviews (n=43) with healthcare providers who treat patients with diabetes.

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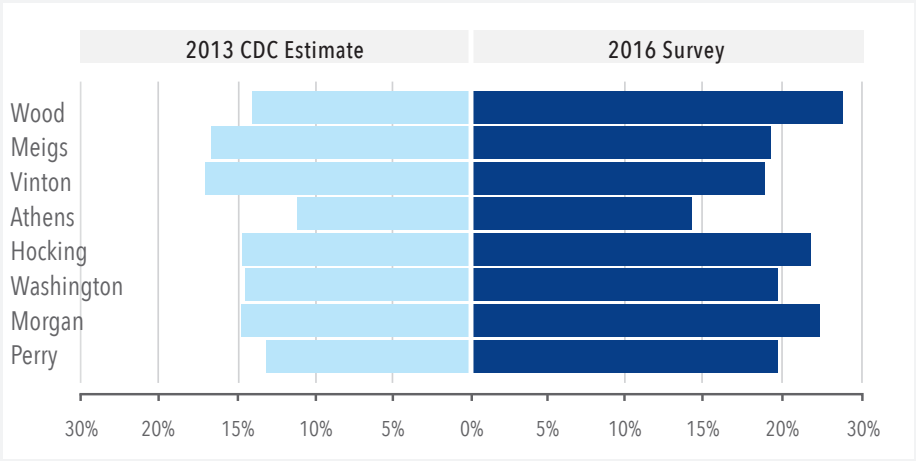
www.ohio.edu/medicine/di/needs-assessment.cfm

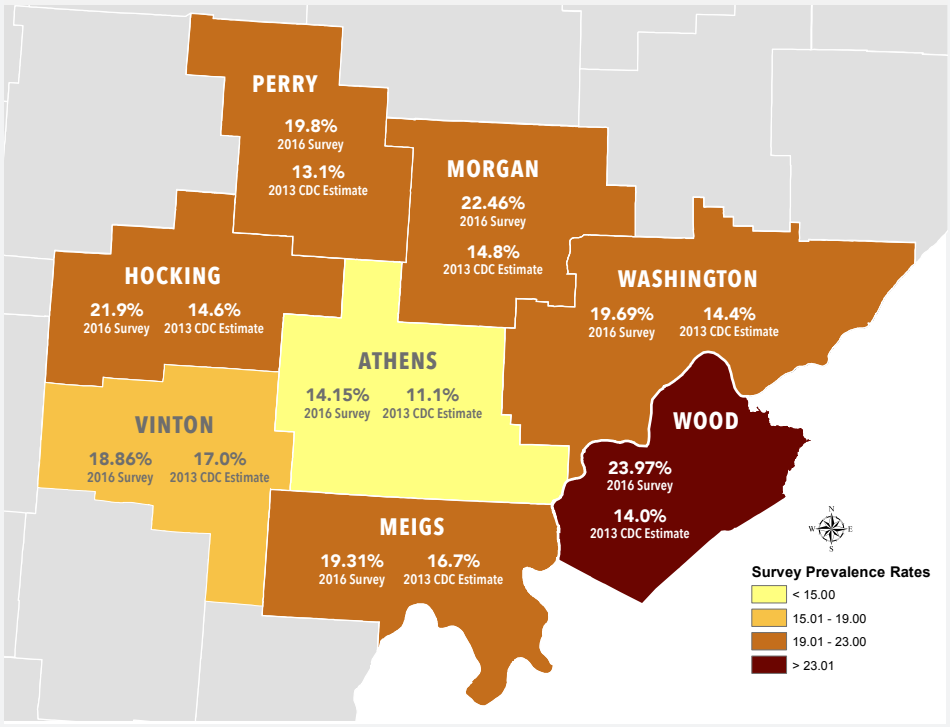
DIABETES PREVALENCE

Although the national estimates from the Centers for Disease Control identifies Appalachia as an area with a high prevalence of diabetes, **this study shows that the rates are higher than the estimates.**

Using a weighted phone survey of 1884 adults, randomly selected (% white, % female), this study found that the rates in a number of counties were substantially higher than the estimates from the Centers for Disease Control, highlighting the seriousness and intensity of the problem of diabetes in this region.



Map of Diabetes Prevalence Rates



Approximately, 1 out of every 5 people surveyed indicated that they had been diagnosed with diabetes and nearly a third of those were currently taking insulin. Sixty-three percent of the people diagnosed with diabetes had previously been diagnosed with prediabetes.

Have you ever been told by a doctor or other health professional that you have pre-diabetes or borderline diabetes?

19.7%
YES

1.9%
YES
BUT DURING PREGNANCY

78.3%
NO

Have you ever been told by a doctor or other health professional that you had type 1 or type 2 diabetes?

19.9%
YES

79.6%
NO

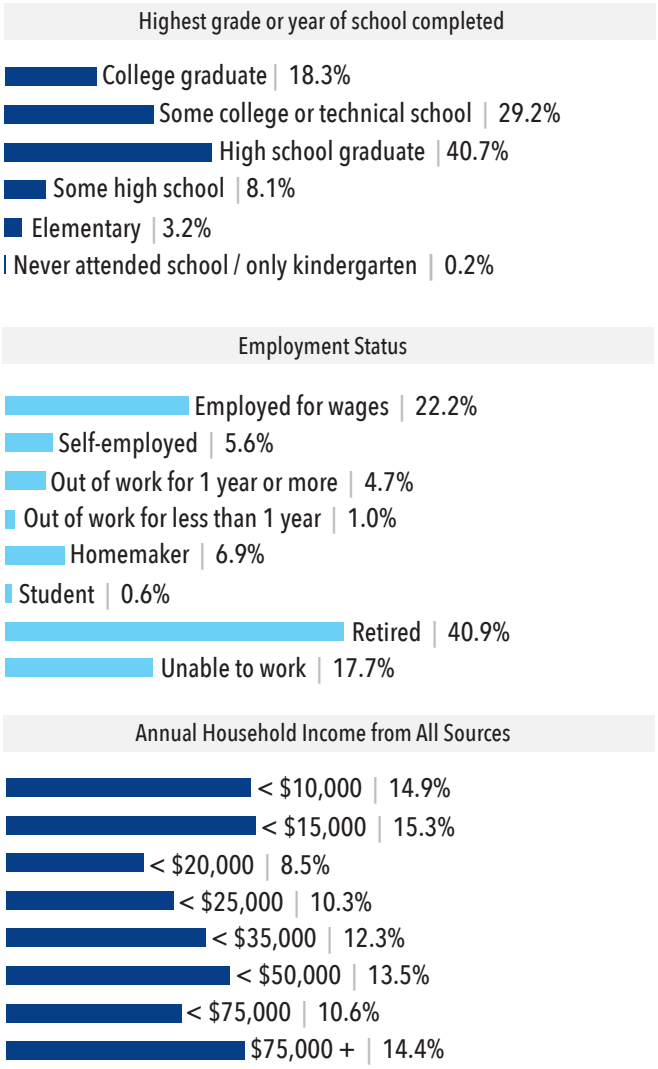
0.5%
YES
BUT DURING PREGNANCY

Are you now taking insulin?

28.7%
YES

70.5%
NO

Over half (52.4%) of those surveyed, who had a diagnosis of diabetes, had a high school education or less. 40.9% of those with diabetes were retired and 27.8% were employed or self-employed. The prevalence of diabetes increased with age as 65% with diabetes were 55 years or older.



Being diagnosed with diabetes is a critical first step toward proper treatment. People who participated in focus groups or interviews described very different experiences when they were first diagnosed. Some said that they received a great deal of information from their healthcare provider and others report being referred to a diabetic specialist, but a number of people talked about the lack of information and confusion following their diagnosis and the treatment prescribed.

> *"The endocrinologist told both of us. They brought in paperwork and explained this was why we were having these symptoms of being tired and different things like that. But we were given a lot of information. Both ways, she discussed stuff with us. She also gave us a lot of visual pamphlet type things."* [Patient]

> *"I was diagnosed a couple months ago. I was told from a kidney doctor about my A1C tests…He just told me to get with my family doctor. The family doctor put me on the pill and to follow a diet…and that they would repeat my A1C in three months. That's really all they told me."* [Patient]

> *"I wasn't even showed how to inject my insulin. I had to go home after I went to the pharmacy and picked it up. And call my sister, and said 'please come over to the house, cause I have no idea how to do this."* [Patient]

> *"I think that's one of the hardest things about it though, is it's sneaky. You don't feel sick, and so it's really easy to say you don't have it."* [Patient]

Providers offer a different perspective. At diagnosis, providers struggled to communicate the severity of diabetes to patients. Providers felt that the pervasiveness of diabetes in the region contributed to indifferent and apathetic views toward diabetes. Providers also noted that patients may not feel bad when they are first diagnosed, which complicates the message they are trying to send to their patients that diabetes is a serious illness requiring constant time and attention.

> *"I don't think they take it seriously enough because they don't feel bad. If you had problems breathing or something, you would feel bad, but with the first stages of diabetes they don't necessarily feel bad, so they're kind of in denial, you know what I mean?* [Health Educator]

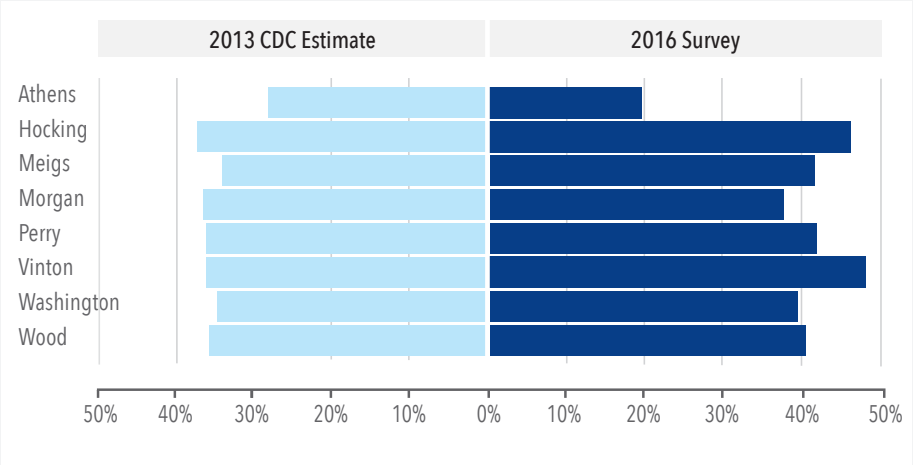
> *"I don't feel some of them actually grasp how it can affect their whole body. I think they think it's a diagnosis; they don't really understand that…it can affect their whole body.* [Nurse]

OBESITY IS A KEY RISK FACTOR FOR DIABETES.

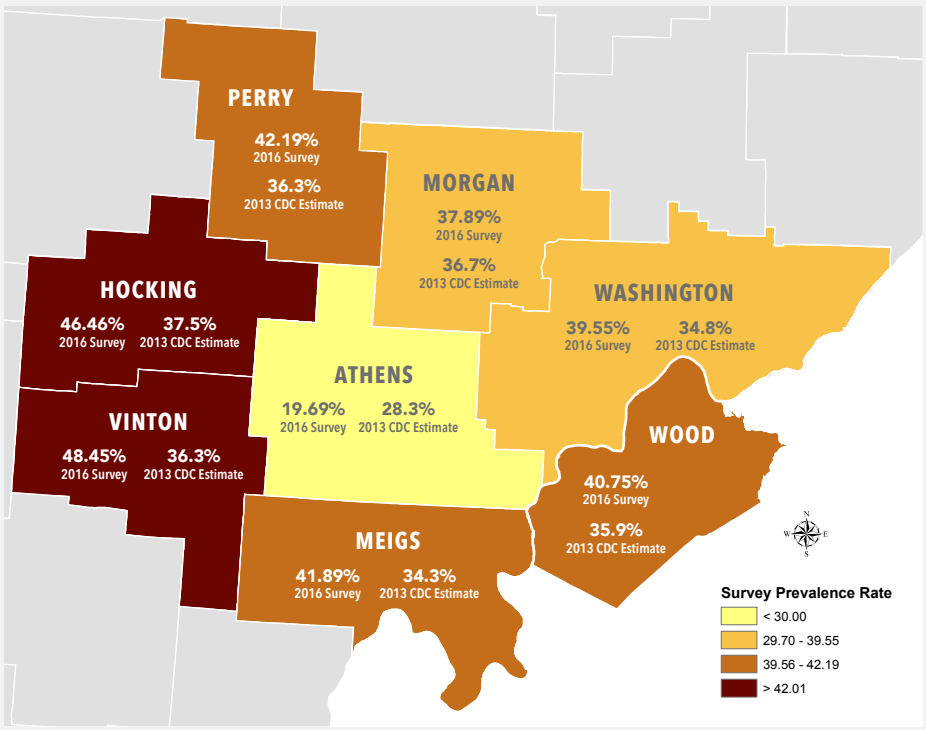
When examining the responses of all the survey participants, including those with and without a diagnosis of diabetes, two thirds of the people without diabetes had a Body Mass Index in the overweight or obese range, compared to 90.0% of the people with a diabetes diagnosis. Only 10.0% of the people with diabetes were within the healthy weight category. While weight is not the only factor that determines an individual's risk for diabetes, it is a factor that can be addressed.

> *"Probably the biggest challenge that I face is food. I like to eat. I like to cook. And it shows, because I'm not in any kind of a physical shape to say that I'm at all on track with that."*

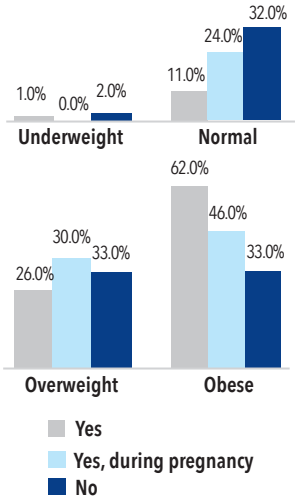
Similar to diabetes rates, this study shows higher rates of obesity in the region than those reflected in the Centers for Disease Control estimates, with the exception of Athens County.



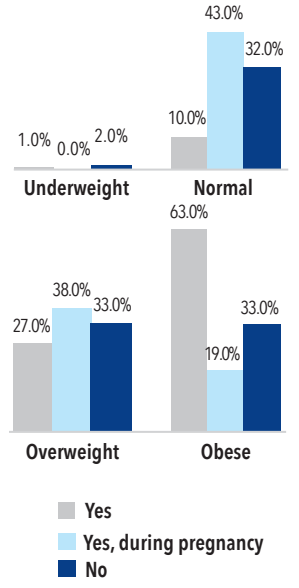
MAP of Obesity Prevalence Rates



Pre-Diabetes status by BMI Categories



Diabetes status by BMI Categories



ACCESS TO HEALTH CARE AND FOLLOWING TREATMENT RECOMMENDATIONS ARE KEY TO SUCCESSFULLY MANAGING DIABETES.

More than three-quarters of the respondents indicate that they have a regular healthcare provider and 78% said they had a check-up in the past year. Almost all respondents had some form of health insurance, either through an employer, self-pay, Medicare or Medicaid. However, 11% of the people report that they didn't see a doctor when they needed because of the cost.

Comments from patients in the focus groups and interview reveal a number of concerns about the expense of diabetic supplies and prescriptions. Many plans only cover one type of blood sugar monitor while other plans limit the number of strips. Patients found their insurance coverage confusing, in terms of what it will cover and when.

"We have insurance but we still have to pay a portion for any of the medicines. For a long time I did not buy the medicines because of the cost. [Patient] *"*

"The cost of needles and test strips is ridiculous. It depends on which insurance company you've got. [Patient] *"*

"Then the insurance company called this physician then this one had to call another physician to get it okayed. [Patient] *"*

Providers repeatedly stressed how social determinants of health interfered with their ability to treat patients' diabetes effectively. Specific social determinants of health included financial barriers, low education levels, food insecurity, housing issues, transportation barriers, limited or no insurance coverage, lack of diabetes specialists in the region, and minimal social support.

"Affordable insulin, number one. Affordable medication, period. The only thing that's affordable is basically sulfonylureas and metformin, and about 20% of people can't handle metformin. Everything else is prohibitively expensive, and formularies change all the time. [Physician] *"*

"Education, I think that's a barrier. A lot of ours don't have cars. A lot of our patients don't have homes you know, so they're hopping around. So hopping around trying to find food, trying to find you know how they're going to get from place to place. Most of them don't have jobs. The majority of patients here in our free clinic don't have jobs, so everything's a barrier for their diabetes. You know they're noncompliant. They care more about what their family is going to eat than whether or not they're going to take their insulin. [Nurse Practitioner] *"*

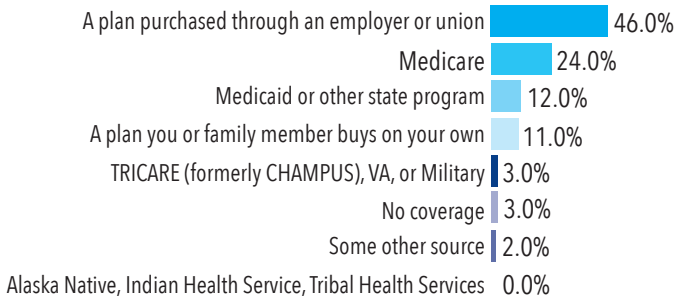
Do you have one person you think of as your personal doctor or health care provider?

76.0% YES **24.0% NO**

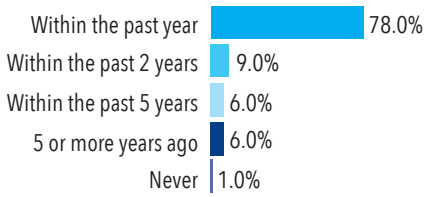
Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

11.0% YES **89.0% NO**

What is the primary source of your health care coverage?

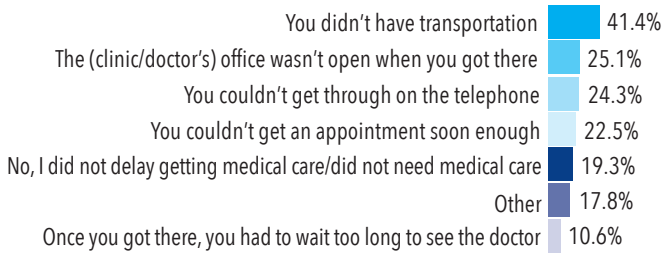


About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

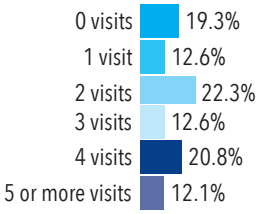


The following responses are from only those patients with diabetes.

Other than costs, there are many other reasons people delay getting needed medical care. Have you delayed getting needed medical care for any of the following reasons in the past 12 months? (Diabetes = "Yes")



About how many times in the past 12 months have you seen a doctor, nurse, or other health professional for your diabetes?



DIABETES EDUCATION

Nearly 70% of the patients who participated in the interviews or focus groups indicated that they had taken a class to learn how to manage their diabetes, compared to only 48% of the respondents on the phone survey. Most of the focus group/interview participants talked about the class being one of the most helpful things they had done in terms of learning how to manage diabetes, both physically and emotionally. They also noted that education needs to be ongoing, and a refresher course or the support of a community coalition can be very valuable.

Patient Quotes

"The key to diabetes in one word and that is EDUCATION. But it doesn't start with us. It has to start with the doctors who just tell you 'stay away from the white fluffy stuff, see you later.' There is a lot more to it than that!"

"Taking a diabetic class, that's the biggest thing. I got a lot more information from that than anything else that I've done. I don't like reading. I learn more from hands-on or going to a class where we talk about it."

"Her [the endocrinologist] education classes made a big difference. Her nurse had a lot of information. And the way it was presented to me and my willingness to listen. Because, for the longest time I had the opinion that diabetes doesn't have…I don't have diabetes, diabetes has me. And I didn't like it but I just, I took medicine. I tried to diet. I tried the exercise. I would kind of…I would be up, I would be down. Emotionally up and down, as well as with my numbers being up and down. Once I took the class it has changed greatly. My last few readings, both me checking my sugar at home or my labs, my A1Cs, things have greatly improved."

Providers requested culturally sensitive diabetes education material designed specifically for patients living in southeastern Ohio and western West Virginia. Providers suggested these materials be tailored to low literacy families and include recipes for well-known Appalachian meals as well as images for how diabetes affects different parts of the body. Providers also recommended a regional telemedicine network of specialists to address the shortage of specialists and transportation barriers in the region.

Provider Quotes

"I want a dietitian student to make Appalachian cookbooks. These church cookbooks, and go in and nutritionally analyze them and then improve them. Cut out the saturated fat, and put in a substitute. [For example], the simple thing would be for instead of mashed potatoes have mashed cauliflower. [Endocrinologist]"

"You could have telemedicine. You could have telemedicine for individuals, you could have telemedicine for groups. You could have group visits in offices, you know, get ten diabetics there with their significant others, and have an educational thing happen. You could have it at a center someplace, where there are 50 people. But the education has to be consistent across all of those modalities. [Family Physician]"

LIFESTYLE CHANGES

While 65% of survey respondents noted they were physically active, this was only once per week or once per month, 45 minutes at a time, not meeting the recommended physical activity levels suggested by the US Department of Health and Human Services. Likewise, consumption of fruits and vegetables falls far below current recommendations with nearly half of participants not eating any dark green or orange colored vegetables in the past month and just over one-third not eating any fruit.

Patients stated an understanding of the importance of healthy food choices and being physically active in managing their diabetes, but also noted barriers to making changes in their current lifestyles related to food and exercise. The financial burden of purchasing the types of foods they thought they should be eating was frequently mentioned as an obstacle. Additionally, finding a location that was both safe and affordable for physical activity was a concern.

Diet Challenges

"The cost of the food is usually a big factor. Availability, whether it's really good fruits and vegetables or whether it's wrinkled and moldy."

"Probably the biggest challenge that I face is food. I like to eat. I like to cook. And it shows, because I'm not in any kind of a physical shape to say that I'm at all on track with that."

"Your food bill is going to go up and there are a lot of people who just say 'Ok, Do I buy my medicine or do I buy the diabetic food I need to keep my numbers down.'"

Exercise Challenges

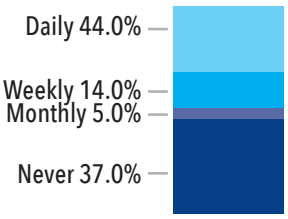
"There's no place close to here to exercise."

"It would be nice if everybody had a place where they could walk in the winter time inside. We don't have that here in XXX County."

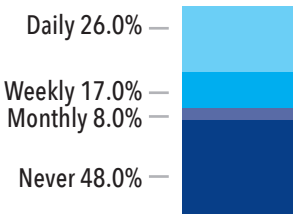
"They had a swimming pool in there where we could go. It was real warm and they had a woman there that ran a class where they run us through exercises in the water and stuff. But it's so far away…we done it a couple times. You pay $35 for six weeks or something and went down twice a week. But we done it a couple times then they raised it. But it's far to drive down there."

Life Style Choices

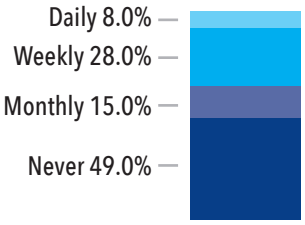
During the past month, not counting juice, how many times per day, week, or month did you eat fruit?



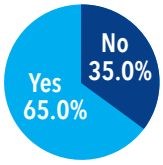
During the past month, not counting juice, how many times per day, week, or month did you eat dark green vegetables?



During the past month, how many times per day, week, or month did you eat orange colored vegetables such as sweet potatoes, pumpkin, winter squash, or carrots?



During the past month, other than your regular job did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?



How many times per week or per month did you take part in this activity during the past month?
Median number of times = 1

When you took part in this activity, for how many minutes did you usually keep at it?
Median number of minutes = 45

RECOMMENDATIONS

The comprehensive look at the burden of diabetes in southeastern Ohio and western West Virginia provided by the diabetes needs assessment highlights several opportunities for future action.

FREQUENT AND ONGOING ASSESSMENT: The burden of diabetes in our region is understudied and underestimated. This diabetes needs assessment clearly shows that rates of diabetes in this region are substantially higher than the Centers for Disease Control estimates, emphasizing the need to conduct ongoing assessments that engages both the patient and healthcare providers.

DIABETES EDUCATION: Patient and provider education was identified as a critical need. The development and subsequent provision of diabetes education materials that are culturally appropriate and easy to understand would be of great benefit to both patients and providers. Further, providers requested access to a network of diabetes specialists to enable them to better serve their patients and overcome barriers such as transportation and the lack of specialists in the region.

"And they've taught us in classes, you know, to read the labels and so forth. And now, when I go to the stores, that's the first thing I look at."

IMPROVING ACCESS: Strengthening the connection between community and clinical providers will help ensure that those living with diabetes and other chronic conditions have access to resources that support healthy lifestyle changes, which are critical in the prevention and management of diabetes. Identifying key stakeholders with a vested interest in diabetes prevention and education throughout the region to facilitate these linkages will be key moving forward.

"My other difficulty is specialists in the area. I don't have endocrinologist in Hocking County…Athens is my closest [endocrinologist] and transportation is an issue for my patients that need it. [Nurse Practitioner] *"*

The Diabetes Institute will strategically align its focus areas to address these recommendations. Strengthening existing partnerships while establishing new collaborations throughout the region will be essential in this work. Building on the assets of all partners will create the most impact as we address the burden of diabetes in this region of Appalachia.

Ruhil, A., Johnson, L., Cook, K., Trainer, M., Beverly, E., Olson, M, Wilson, N., Berryman, D. *What Does Diabetes Look Like in our Region: A Summary of the Regional Diabetes Needs Assessment Study, 2017*. The Diabetes Institute, Ohio University Heritage College of Osteopathic Medicine, Athens, OH www.ohio.edu/medicine/di/needs-assessment.cfm

In 2012, the Ohio University Board of Trustees approved the formation of the Diabetes Institute as a combined effort of the former Diabetes Research Initiative, the Appalachian Rural Health Institute and the Diabetes Endocrine Care Center. This facilitated the evolution of a unit that reflects a broader scope of activities than what each entity could provide alone. The Diabetes Institute strives to reduce the diabetes burden regionally, nationally and globally through basic and applied research, clinical care, academic and professional training, and community outreach each working in partnership toward the institutes's vision of A Diabetes-Free Society.