



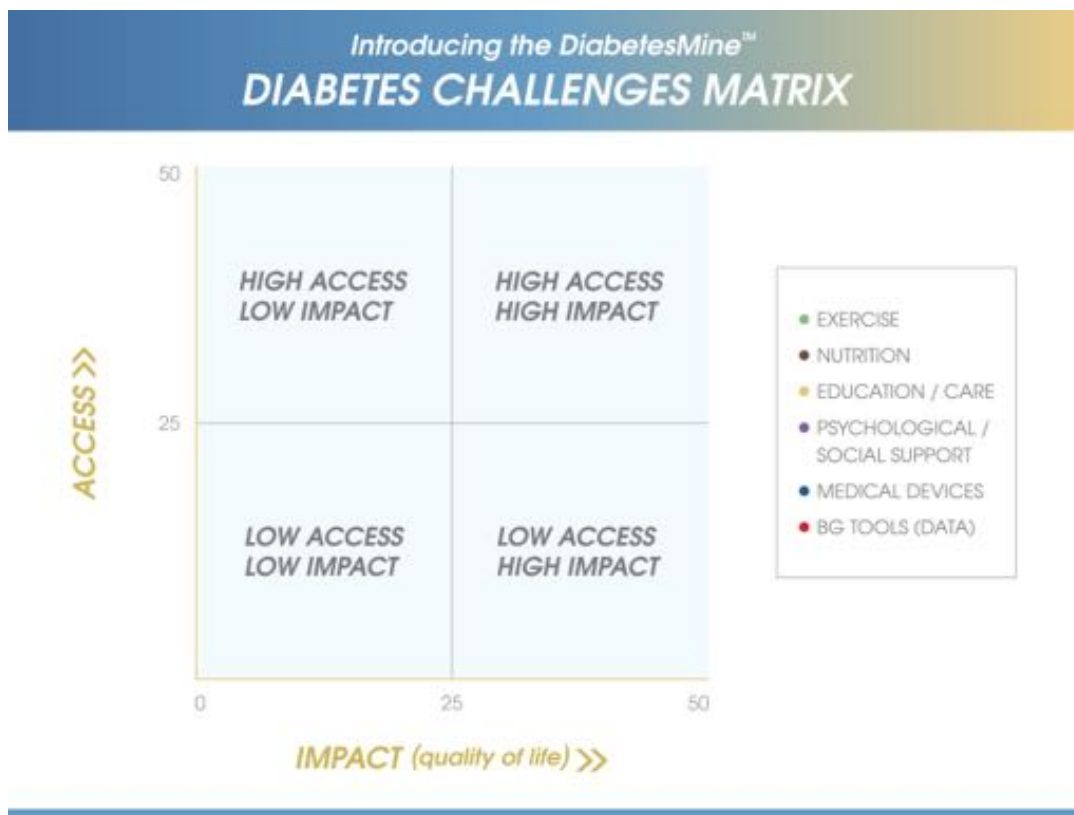
# Diabetes Tools & Services: What Helps Patients Most?

Amy Tenderich

## ABOUT THE DIABETESMINE 2017 IMPACT STUDY


In 2015, we introduced the **DiabetesMine™ Challenges Matrix** to help map the diabetes care landscape with a focus on the needs of people with diabetes (PWDs) and their caregivers.

In essence, it served as a sort of “scorecard” for the patient community to rate all the available diabetes tools and services, along the axes of **IMPACT** and **ACCESS** – the two most critical factors in any offering (product or program) that’s meant to help patients best manage their diabetes.



IMPACT here refers less to clinical efficacy than to how much a given tool or service positively affects personal disease management and Quality of Life for PWDs.

In Spring 2016, we asked the Diabetes Community to use this Matrix approach to rate products and services in six categories: Exercise, Nutrition, Education/Care, Psychological/Social Support, Medical Devices and Blood Glucose Data Tools. Participants were also asked to recommend items they believe should be added to the Matrix, and share their feedback about different products and services in written comments.



The results of that initial study illustrated that IMPACT scores – and the hundreds of rich comments that accompanied them – were the most interesting and ripe for further research.

Therefore in 2017, DiabetesMine conducted an even broader online survey asking patients to rate tools and services on a scale of “Helpfulness” and provide written details to explain their preferences.

We again used this research to inform and guide our new **DiabetesMine™ Usability Innovation Awards** – selecting the winners based on overwhelming positive feedback and standout comments. The results were presented at the 2017 DiabetesMine Innovation Summit at Stanford School of Medicine.

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## METHODOLOGY

Data was collected via an online survey conducted in Summer 2017. A link to the survey was published at the Beyond Type 1 community site, and promoted via DiabetesMine.com and a number of peer sites and networks.

A total of 617 individuals participated, the majority (66%) having had Type 1 diabetes for more than 6 years. The second-largest group of respondents (19%) was caregivers of an insulin-dependent PWD. Approximately 60% of the participants were over 36 years old and approximately 30% were within 19 and 35 years old (with the rest falling between 14 and 18 years old).

The were asked to rate products and services on a scale ranging from “life - changing” to “very helpful,” “helpful,” “of limited value,” or “did not help me at all.” Respondents were prompted to add details in comments, and notably were also ask to make remarks on why they why they may choose NOT to use certain tools. Overall, more than 1,660 written comments were gathered.

Since the data was collected from a convenience sample, the findings represented here are not statistically significant. Nevertheless, the authors of this report believe the findings represent the sentiments of the majority of type 1 PWDs and their caregivers who are very engaged in managing diabetes and are actively engaged online.

## OVERVIEW: WHAT HELPS MOST

The tools respondents chose as the overall most helpful items for living with diabetes were: the continuous glucose monitor (CGM), followed by the insulin pump, and support (via peers, online communities, family and friends, etc.).



Out of 243 comments on the key question of “What Helps You Most?,” 103 mentioned the CGM as being the most influential item in their diabetes management due to the life-saving capability of having constant blood glucose information. Several participants even mentioned that this access to real-time data is “what I have been waiting for my entire life.”

In particular, respondents mentioned how the CGM helps them feel safe from dangerous low glucose episodes overnight, and helps with their mental well-being because they get significantly more sleep.

***“Dexcom takes the fear away, lets patients keep sugar at safe rate which prevents complications. Also saves lives daily.”***

42 comments on this question mentioned the insulin pump, and 41 comments noted the importance of support:

*“You cannot live with a chronic condition without support. It can get the best of you.”*

*“My T1D network (is the most helpful). Life with T1D is so much easier when you've got people who know what's what.”*

*“The people attending the meetings were encouraged and supported to bring up their frustrations with diabetes, or ask questions about management, and we were all able to share our tips and tricks without judgment.”*

## EXERCISE



The above Matrix view shows how patients originally scored items in this category.

### Best Exercise Tools

When asked specifically about Impact in this year's survey, the highest-ranked exercise tools were Fitbit and MyFitness Pal. The running and cycling app Strava

was also suggested as a write-in (not originally in the options list) by multiple participants.



(write-in)

*“The most important thing for understanding exercise is basically the length and intensity – I wear a Fitbit that measures heart rate so it can give me an idea of how aerobic or anaerobic a workout was, and I can make more informed decisions about its effect on my blood sugars.”*

*“Strava... connects me to others locally, and gives supportive feedback.”*

Users mentioned that the effectiveness of MyFitness Pal was largely enhanced by the food tracking component:

*“I love MyFitness Pal because it allows me to create recipes for the food I make and gives me an exact carb and protein count per serving. It is SO much better than guessing! Once I adjusted my macros in the app and went heavier protein and fat and low-carb and combined that lifestyle choice with doing the recommended workout routine... ALL of my insulin doses had to be decreased because I ran lower literally 24/7. My A1c is the lowest it has ever been and stability finally seems possible.”*

### Non-Use of Exercise Tools

The reasons given for non-use of exercise tools were fairly basic:

- Did not know enough about the tools
- Find them too much hassle
- Do not enjoy using them
- Do not exercise (enough) to need them



## NUTRITION



The Matrix view above shows the Nutrition area is sparsely populated, with the least offerings, despite being arguably the biggest challenge that most PWDs face.

### Best Nutrition Tools

The highest-ranked food and nutrition tools were the Calorie King and My Fitness Pal apps, followed by the advice of a healthcare professional (as a write-in).



(write-in)

On Calorie King, participants mostly commented on the carbohydrate counting aspect:

*“The Calorie King book or app has always been the resource we go to since my daughter's initial diagnosis 3 years ago. It's really helpful for carb-counting. My child is getting quite good at estimating her carb intake now, so we rarely need to check the app anymore.”*

Whereas the comments on benefits of MyFitness Pal were broader in nature:

*“MyFitness Pal allows me to create recipes and gives me exact carb and protein counts per serving. This has helped immensely as it takes away the guesswork and enables me to stick to a consistent macronutrient breakdown for the sake of blood glucose stabilization.”*

### Non-Use of Nutrition Tools

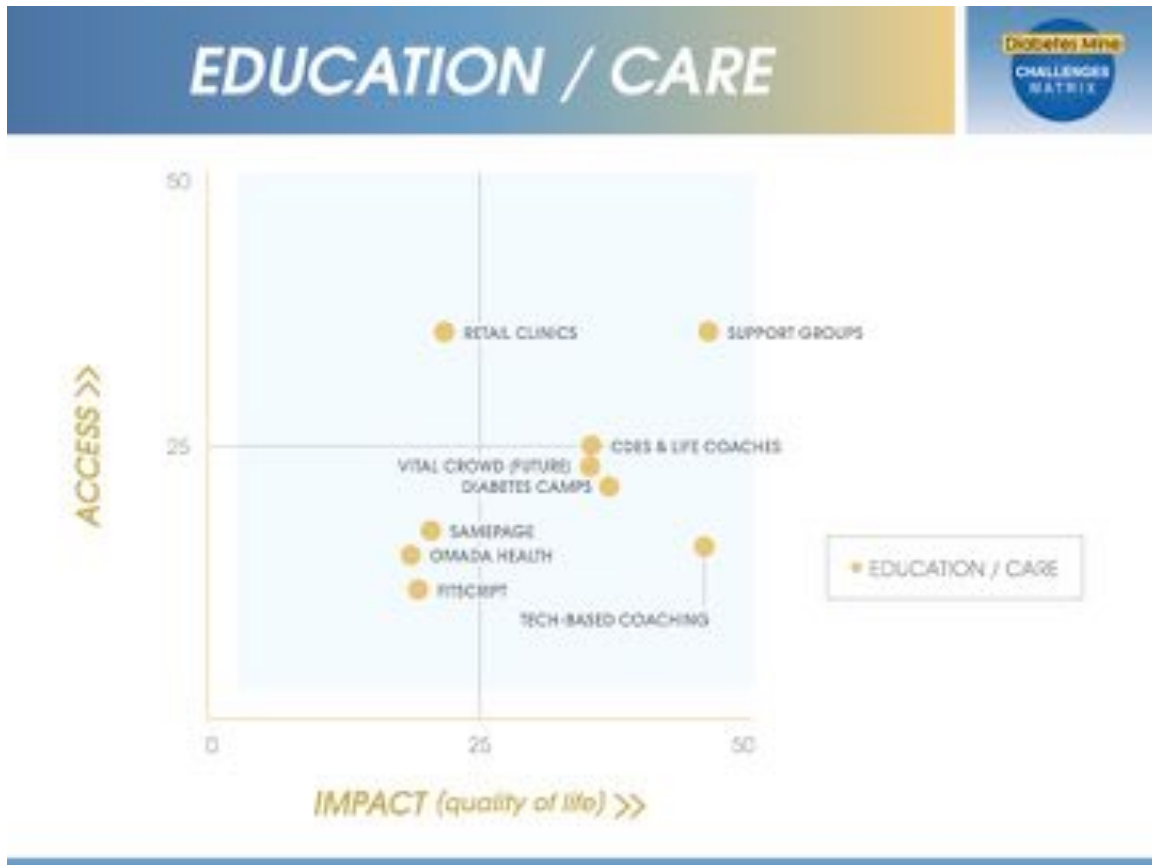
Participants who do not find these tools helpful do not use them because they find them more cumbersome to keep up with than helpful, or feel they are experienced enough in counting carbs by themselves:

*“I have lived with T1 for over 30 years. I can estimate closely enough. Too much information takes away from quality of life. It's a balance for mental health.”*

Others noted that the tools do not have a broad enough food database, or that these tools are not geared towards their specific needs. For example:

*“All the things I've tried focus too much on weight loss. I need an app that's a straight up serving size/carb quantity for as many kinds of foods as possible and I haven't been able to find that yet. If it could have another capability for me to input my doctor-suggested insulin to carb ratio so that I could have the app compute that for me too, then that's great progress.”*

## EDUCATION / CARE



The Matrix view above shows that there are a fair amount of offerings in this area, but you will note that nearly all fall in the lower quadrants on Impact.

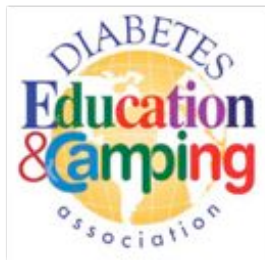
### Best Education/Care Tools

The highest-rated education tool was diabetes camp. Participants commented that diabetes camp is an invaluable learning experience and support system. Having interactions with other diabetics promotes positive exchange of ideas and techniques as well as creates a supportive community where individuals feel they belong:

*“Diabetes summer camp (the completely recreational kind) was wonderful because it exposed me to other diabetics who showed me techniques and mindsets with which THEY managed their disease. CDE appointments are nice for when I have a very specific question about why my body reacts in certain ways or something, but most of the time they’re not needed on a monthly basis.”*

*“I didn't THINK of camp as an educational tool, but the truth is I left 'diabetes training camp' completely renewed and prepared to take care of myself - and I've been doing a great job every since. Practicing healthy habits for a full week with people who share your struggles really makes the difference in follow-through. I've been to many weekend conferences, but by far 7 days of camp was more valuable.”*

*“Diabetes camps have provided emotional and mental health support to me over the years, and I continue to go back as a camp nurse. Additionally, camp is the one place I feel 'at home' or 'normal' amongst all these campers and staff with diabetes.”*



(write-in)

The second highest-rated tool was appointments with a Certified Diabetes Educator (CDE), which participants noted are most helpful for medical training and getting answers to specific questions:

*“CDE was very helpful just in terms of pump training, setting ISF (insulin sensitivity factor) and I:C ratio titration. Where else would I get that info?”*

### Non-Use of Educational Tools/Programs

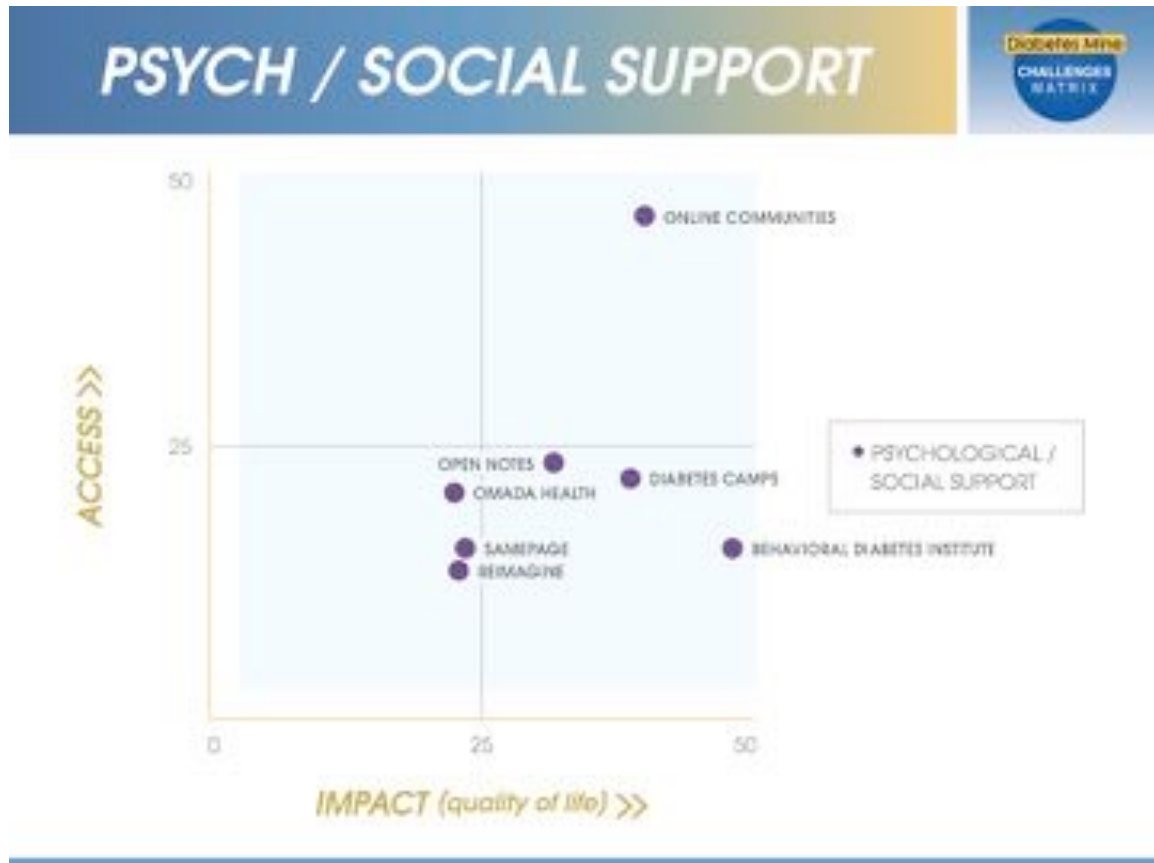
The participants who do not find these tools helpful commented that they are either unfamiliar with the tools, find them too costly, do not find the results helpful, or that they are only helpful in the beginning of the diagnosis.

Others noted that they feel the CDEs do not truly understand or comprehend living with diabetes in the real world, and therefore, do not offer helpful advice. For example:

*“I've been a type1 longer than most CDE's have been practicing... much/most of the educational resources and classes don't actually provide any useful information about how insulin works metabolically, or the various digestive processes our bodies use when*

*eating carbs, fats and proteins... so most all of their info is for beginners and focused primarily on avoiding DKA... not on tight non diabetic a1c control."*

## PSYCHOLOGICAL / SOCIAL SUPPORT



The Matrix view with original scoring indicates that few psychosocial tools and services exist, despite the fact that that mental and emotional well-being arguably provide the basis for any measure of “success” in chronic disease care.

### Best Psychosocial Tools

The highest-ranked tools here were online communities (particularly Facebook groups) and in-person support groups (including local groups, JDRF chapters, and the CarbDM and Diabetes Sisters networks).



Whether finding support online or in-person, participants who use these tools all stated that connecting with others with diabetes has helped them immensely.

These communities are a source of emotional support, education, and inspiration:

*“Conferences/camps/any sort of large gathering of people with diabetes is INCREDIBLY influential. I think the best way to get out of diabetes burnout is to meet others, bond over little things like insulin pumps and the cost of test strips, and be encouraged by the fact that so many others are going through the same exact struggles.”*

*“The accessibility of online Facebook groups or Instagram handles is the most helpful because it's where I go REGARDLESS of diabetes. It brings the day-to-day need to focus on diabetes into my day-to-day need to focus on everything else. It normalizes diabetes and educates/motivates me/challenges me. Every. day.”*

*“CarbDM is a great resource for us, keeping us informed with up-to-date news and events related to T1D. The Dia-Buddies program was a stepping stone for my child to feel more comfortable about opening up to others about her T1D, and now she is mentoring younger kids who may also have a hard time coping.”*

*“TuDiabetes and DiaTribe (online resources) are great for finding out what drugs, techniques, and technology are coming up. Brave Buddies and then CarbDM gave us a sense of community where we could ask questions, support newcomers into ‘our club,’ and give ourselves a sense of control over our situation.”*

*“I find Facebook groups for Type 1s – both informal and formal – to be helpful. They help us connect with others going through the same things, and sometimes it's nice to just be able to laugh about diabetes.”*

*“We have been grateful for the community of Beyond Type 1. It's so nice to connect with others going through the same issues and to get help.”*

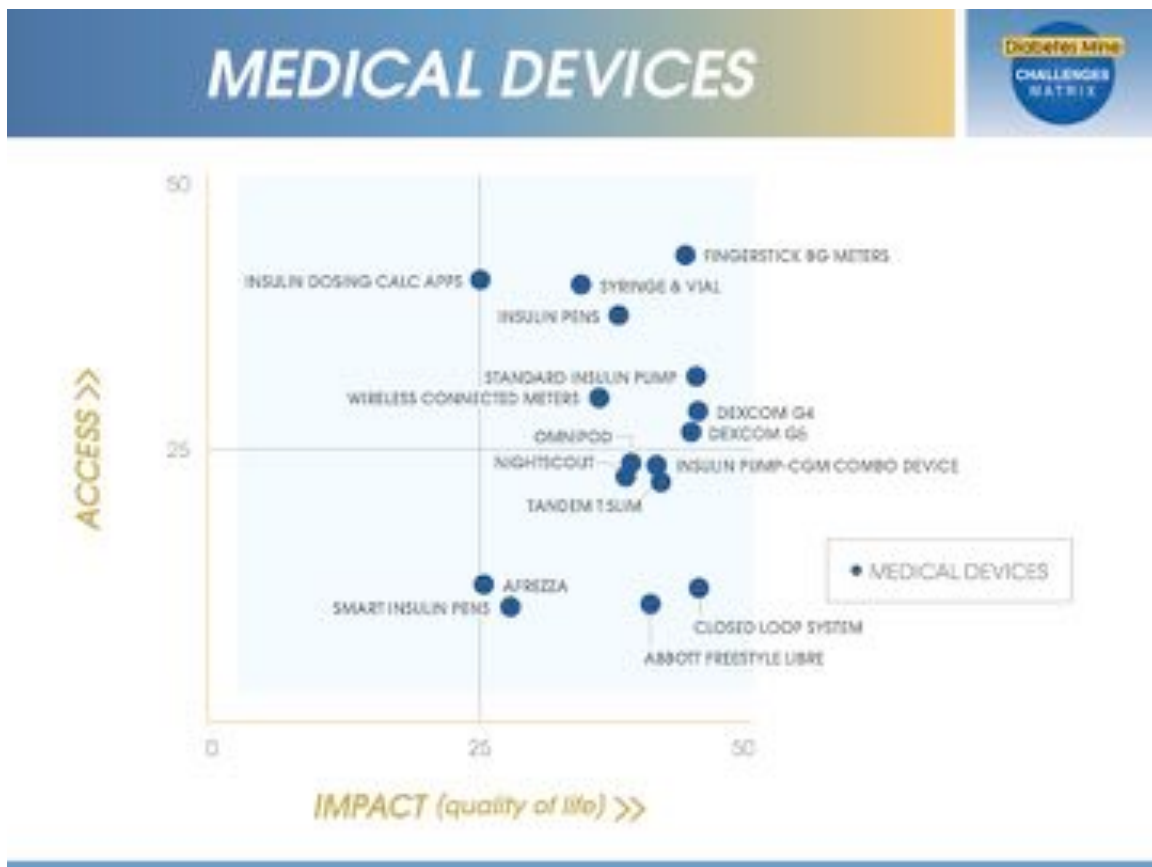
## Non-Use of Psychosocial Tools/Programs

Participants who do not use these types of tools stated that they either had not heard of them, did not have in-person support groups available to them locally, or find it unhelpful and overwhelming to be in these groups.

A few participants also noted that the specific guidance they are looking for is not available. For example, one person wrote:

*“I wish that a psychologist that specializes in diabetes would be available. I've struggled with anxiety and PTSD specifically related to my diabetes and episodes I've had. They don't understand and are quick to give medication vs. working through my thinking and the struggles of the disease...”*

## MEDICAL DEVICES



The Medical Devices category is perhaps the most mature across the Matrix, populated by a wide variety of products and product categories that previously rated high on both Access and Impact.



## Best Medical Devices

When asked in direct terms this year what is most helpful, respondents clearly favored the Dexcom Continuous Glucose Monitor in first place, followed by the Medtronic and Omnipod insulin pumps. A number of write-in suggestions were made that new Tresiba insulin is also very helpful.



*“The Dexcom is invaluable. I have had diabetes for over 20 years and my 3 years with my Dex have been my best. I’ve never been so healthy and I give 90% of the credit to having non-stop information. It helps me make informed decisions, makes my partner feel at ease knowing he can check in on my BG without asking, and keeps me accountable. I’d also like to point out how important the development of degludec (Tresiba) insulin has been. I feel like the better long acting insulin has made tight management off-pump really doable and I prefer to be pump free... so this is a big deal!”*

*“My Dexcom alarms have literally saved my life. Worth every penny and ALL type 1 diabetics should have one. It will save insurance providers more money than the cost of a CGM system and will eventually pay for themselves.”*

*“(Dexcom) has completely changed my emotional and mental outlook and helped me physically to constantly know my blood sugar and to be able to make tiny changes with my pump. I feel much more in control and it is giving me the freedom to live my life much easier”*



*“Tresiba insulin is the best long-acting and it was not on this list – it’s great!”*

## Non-Use of CGM

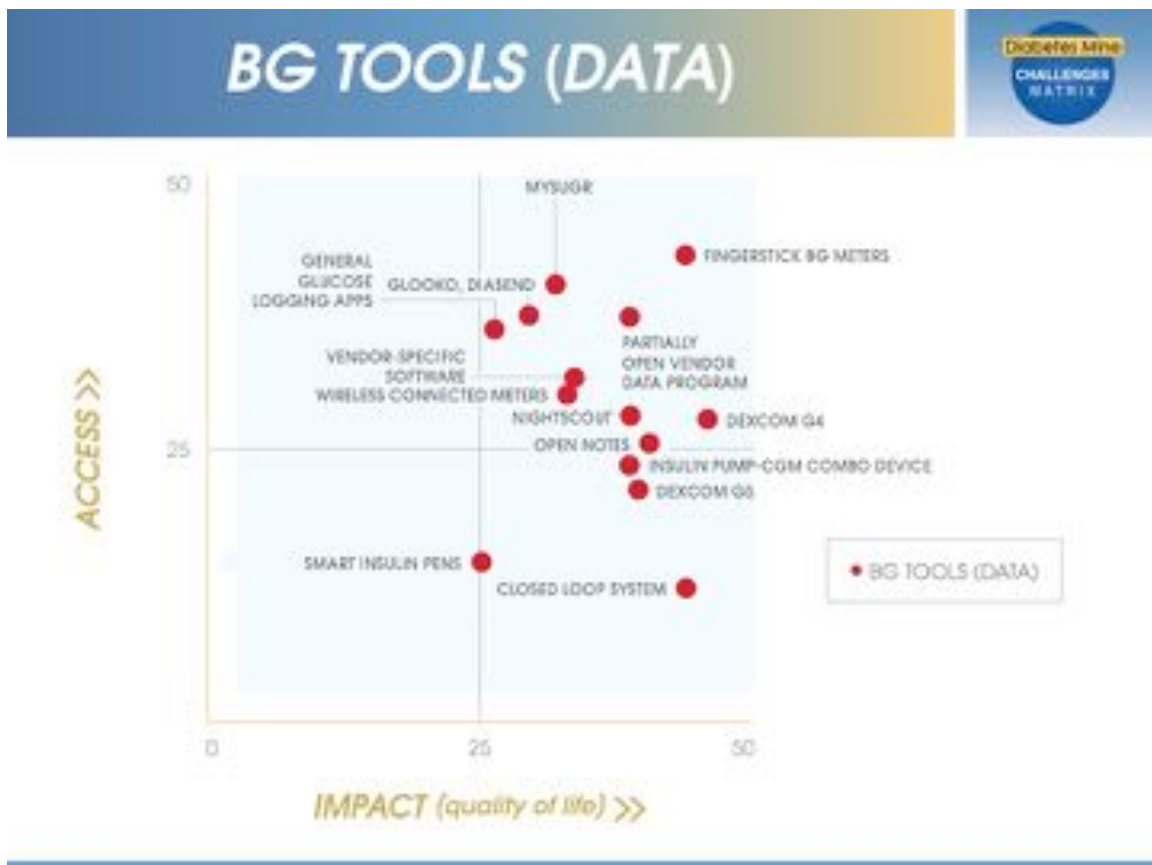
Participants who commented on non-use of medical devices mostly mentioned CGM; typical reasons for non-use were that they find the sensors are not accurate enough, have too much of a lag time, or are too uncomfortable:

*“The CGM is not really useful for dosing. It has a very big time lag from actual BG to Dexy caused panic & REALLY screwed with my OCD. Caused my spouse to obsess over it, too. What’s more is that my little Bichon Frise (lap dog) alerted me to changes in my glucose levels 15-20 minutes before Dexy ever did. So, I decided to stick with my dog, get another one (dog) as backup and ditch the Dexy.”*

*“I’m not a huge fan of the Medtronic CGM because I find it annoying and awkward to inject and tape down and also hard to find a place on my body where it will actually work. If the transmitter moves at all, the calibrations won’t work which is frustrating. It’s also a little inconvenient that the blood sugars only transmit to the pump and not to my phone, which I know the Dexcom does. I also find the Medtronic CGM to be kind of uncomfortable and leaves the injection site feeling sore.”*

Note that we did not get specific comments regarding some of the newest medical devices, that are just beginning to hit the U.S. market at the time of publication of this report (i.e. the Abbott FreeStyle Libre “Flash Glucose Monitoring” system, or the Medtronic 670G as the first “Hybrid Closed-Loop” combo monitoring and insulin delivery system.)

## DATA TOOLS



The Matrix view above shows that Data Tools ranked quite high on Impact in our original survey. (Many obviously cross over with Medical Devices, as they are built-in or outgrowths of a device that generates data readings.)

While there is a plethora of new solutions coming out and a lot of excitement about new data tools, our survey respondents seemed to hone in on the basic items that provide the most value.

### Best Data Tools

The highest-ranked data tool was the Dexcom Clarity App, which provides analysis and reports on Dexcom CGM data. Next up was vendor software (especially Medtronic CareLink), followed by the open-source tools Loop/OpenAPS.



#Loop and #OpenAPS

Users commented that Dexcom Clarity is most helpful due to its simplicity and the ability to easily share the information with their doctor:

*“I have found the Dexcom Clarity app to be helpful for my appointments. It is nice to be able to have an estimated A1c, as well as being able to analyze when I’m running high/low. I love that I can easily sync this at my doctor’s visits, providing me with much more insight for managing my diabetes.”*

*“Dexcom Clarity software has been helpful for me to see my BG data over 2 weeks, 1 month or 3 months, and helps me titrate my settings in my pump.”*

*“Dexcom Clarity app gives me a total picture, weekly, of where my A1C is and helps me fine tune my dosages.”*

*“Loop has allowed me to sleep through the night without significant pump or CGM alarms waking me up every couple of hours because the algorithm in the app is adjusting basal rates in the pump to help keep my blood sugars in the target range I’ve set throughout the day.”*

*“OpenAPS Autotune really helped me understand where I was using basal rates to cover what boluses should have been covered by and helped me eliminate (some) of the unexplained lows.”*

There were also several shout-outs for the popular mySugr app:

*“I feel like I may be unusual, but since I do not wear a pump, logging insulin delivery is SO SO SO helpful and mySugr is aesthetically pleasing enough for me to use it every day. Seeing my TDD and averages and being able to receive positive feedback and send logs to my endo... it’s pretty much marvelous. The only thing it needs is to be able to sync with my Dexcom.”*

## Non-Use of Data Tools

Participants who don't use these data tools say it is because of the time commitment, the amount of manual work involved in inputting data, or the fact that it involves logging into multiple applications or programs on a computer.

Only two people commented on privacy concerns about sharing this type of personal information, while many mentioned that they want the tools to be able to integrate with other tools as well as do more in general:

***“Really need an app w/an algorithm where I can easily enter all my data and it can tell my how to change food/pump settings to achieve better A1Cs.”***

Given our current political and healthcare environment, it is not surprisingly that some participants brought up the issue of access discrepancy to these tools:

***“Not everyone has the resources or access to get/use these tools. They reflect the type 1 white affluent privilege that permeates the diabetes online community.”***

## ADDITIONAL 'LIFE TOOLS'

Participants were also asked to name “any other item – a non-medical or retail product – that helps you in some way with the daily challenges of diabetes, big or small.”

Here write-in comments listed exercising, reading diabetes blogs, and listening to diabetes podcasts as being very helpful. There were also numerous mentions of “seeing other people with diabetes succeed” as an inspiration and help overcoming some of the difficulty of diabetes.

Some participants listed more specific life items, including:

- The Apple Watch
- FRIO insulin cooling packs
- Myabetic and Sugar Medical diabetes carry cases
- Skin-Tac and TacAway wipes
- Sport Beans (glucose for sports)
- The FlipBelt (carry case for sports)

## What Else Helps?



### IMPROVEMENTS WANTED

We asked participants, “If you could change one thing about existing tools available for PWDs (short of a cure or magical access for everyone), what would it be and why?”

Most of the comments here focused on decreasing costs and improving health insurance – in order to increase access to all types of medical tools for everyone:

*“Price. Always price. Even when I’m insured, I’m always fearing for the next time I have a lapse in coverage. Uninsured I just cannot afford to live – or rather my quality of life would decline significantly.”*

*“More affordable access. Because of insurance coverage I had to choose between Omnipod and Dexcom. I chose Omnipod but I believe that if it wasn’t for the total monthly cost of my diabetes I could use this other tool that would decrease my chances of needing higher-cost medical treatment down the road because I would have better control of my diabetes. This would be a win for me and the insurance company.”*

*“As a community, we should apply our efforts towards ensuring all people of diabetes have access to affordable insulin, and affordable*

***testing supplies. All of the discussion about the latest toys, and high-priced gizmos is morally bankrupt if others like us are being hurt or dying because they cannot access the basics.***

One participant pointed out that increasing access also means making these medical tools available for the visually and hearing impaired:

***“All tools and devices MUST BE accessible for people who are both visually impaired/blind or hearing impaired.”***

Quite a few participants also commented on wanting more integrated technology, such as closed loop systems and eventually Artificial Pancreas technology that would be compatible with ALL types of pumps.

Many participants noted that having “one device for everything” or a consolidated app that would collect and analyze all their data all in one place would greatly improve their diabetes management:

***“Make one tool that does EVERYTHING. Enough with 6 different tools and apps – it's too much, even when they work well, and they still never all speak to each other. It just shouldn't be so hard!”***

***“Combine the tools all into one – having a CGM/pump that is combined and Bluetooths to one app that can track all diabetes related things with the option of entering in food and exercise and diabetes nurse and doctor can easily and quickly access.”***

***“Open APIs from all pump and sensor companies to allow for choice of what tools we use. I don't want to wait for a closed loop that works with my Dexcom and, as an example, Omnipod. And even then, I don't want them dictating the changes I make to how it functions. I am an adult. I get the risk. And I don't want 10 different devices and PDA. I have my pump, OK, I have a glucose monitor, got it. Let me do everything else, including monitoring and controlling my pump from my phone, not some other device I have to worry about.”***

A number of participants also commented on decreasing the size of tools, improving the insertion methods, and having longer-lasting sites that do not have to be changed as often.

***“If it's not money, just size of sites. I know we've come a long way, but smaller/ flatter will always make me happier.”***

Other calls for improvement included better resources for mental health support and education, and more in person meet-up events for people with diabetes.

## Improvements, Please

- More **integrated** tech (closed-loop for various pumps)
- A **single app** or device to collect & analyze all data
- Physically **smaller** tools
- Improved **insertion methods** / longer-lasting sites
- Better resources for **mental health** and education
- More **in-person** meet-ups for PWDs



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## MESSAGES TO DECISION-MAKERS

Finally, we asked participants what they would most want to say directly to decision-makers (pharma and device manufacturers, FDA, leading physicians and app developers) given the opportunity?

We received a PLETHORA of comments calling for decreasing the cost of medical supplies (particularly insulin) and increasing access. Just a smattering include:

*“I would ask them to PLEASE make supplies such as test strips, insulins, pump and CGM supplies more affordable. The technology today is so much better than years past and being healthy, having in-range blood sugars is so very important and much more attainable with these supplies, but it's so very EXPENSIVE even with insurance.”*

*“To FDA, Pharmacies, Insurance, etc. – make less hoops to jump through in getting new products that would truly be helpful to PWDs and access more of a level playing field. There's already enough hurdles in managing diabetes on a daily basis, why make it even harder?”*

*“Obviously the ultimate goal is to be cured of the disease. But in the meantime I feel all diabetics should be able to have access to tools that will better the management of the disease at an affordable cost. The less*



*we have to worry about the better, as we already have to worry about our life-altering decisions we make every day when caring for ourselves.”*

*“Think of cost to consumer. Unfortunately, high-priced equipment only benefits a select few.”*

*“Open everything, don't be so obnoxiously proprietary with your systems and apps and devices. Earn money with service, not with things. Think of me a person. Realize that solutions need to be responsibly priced and data from devices should be open source.”*

Or as a few people put it simply:

*“Please don't make us diabetics have to choose between rent and a bottle of insulin.”*

*“Stop putting a price tag on our lives.”*

Many participants also mentioned the desire to accelerate research to speed access to closed loop systems:

*“Continue the progress you are making. Accelerate innovation. FDA (should) leverage technology and allow public input to evaluate investigational devices... Certainly software that can improve communication, control and lessen the burden of diabetes. People with T1D can handle a lot... delay is the one thing we cannot afford.”*

*“Watch the DIY community... they are forging ahead and laying out the ‘feature set’ for your future products. Help them, don't hinder them!!! They will help you make better FDA-approved products. Also give users APIs and make standards for data to share across the apps!”*

Finally, participants emphasized the importance of understanding and listening to PWDs (people with diabetes), who know best what patients really want and need in real life:

*“I wish, in the back of their minds, they would take a look at whatever product they're creating, and ask themselves these questions: -Does this help a person with Type 1 diabetes think LESS about their disease for more time during the day? When a patient is truly on top of their disease, health, fitness and diabetes devices, does their product or service truly help that person too?”*



*“So many doctors can't tell a very fit & active person how to manage the disease. ‘Turn off your insulin’ is NOT the answer. All doctors should know what blood sugar does during aerobic exercise vs. anaerobic exercise. Devices should follow suit.”*

*“Not being able to see the screens of devices in the bright sunlight... is also unacceptable. Test your products for all scenarios! And most importantly, let the user control what alarms and sounds they want to hear – if any!”*

*“Don't judge me, help me. Give me the best advice and tools that will make my management better.”*

*“Think of our little kids – please!!! When designing your products, don't just think about the adults with T1 remember the babies, the toddlers, and the elementary school kids. We are desperate for items that will make our kids lives easier.”*

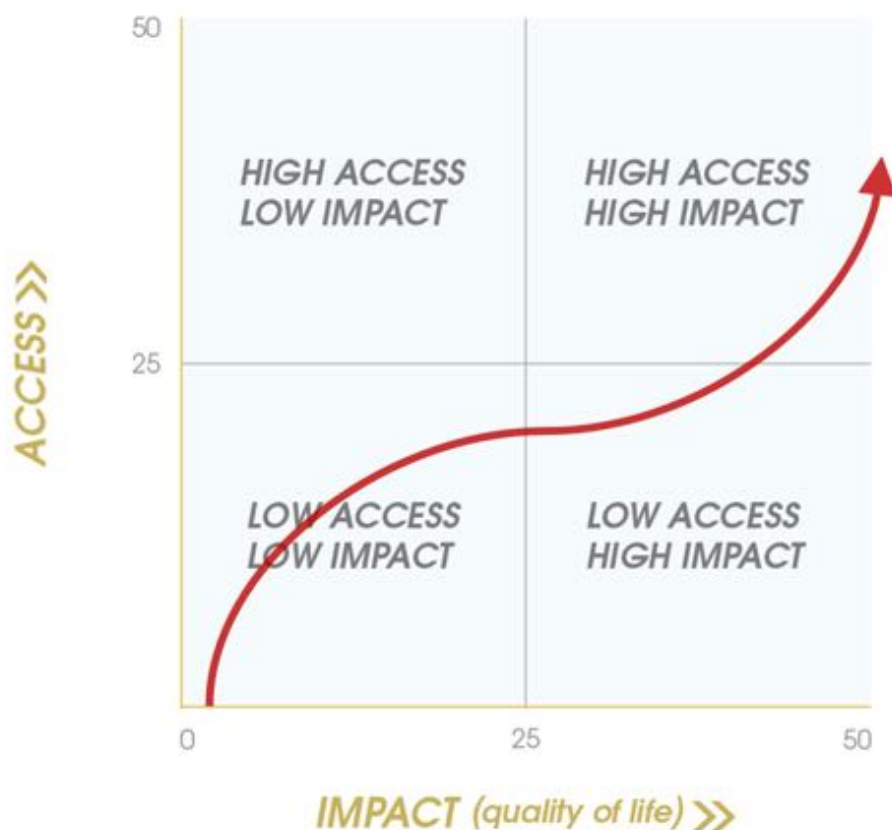
And summing it up:

*“Let people with diabetes design the things that people with diabetes will use so they are the most user-friendly.”*

## SUMMARY / CALL TO ACTION

The DiabetesMine Challenges Matrix was designed as a way to evaluate the challenges people face trying to manage diabetes in the real world – outside the clinical setting, with all the complexity that entails – and the tools and services available to them.

The aim was to provide a baseline from which all the stakeholders can work toward improving offerings on both axes.



Our 2017 study sheds additional light on patient sentiments and current “pain points.”

Interestingly, despite the focus on Impact this year, all roads seemed to lead back to the Access issue – the real-world struggle to afford our diabetes tools and care.

When it comes to the specifics of designing better products, our main takeaway from the 2017 survey is a call to double-down on **Quality of Life Factors**. That means designing for:

- Less hassle
- More comfort
- Fewer moving parts
- Empowering daily decisions
- Providing community/support

Finally, we urge all vendors, clinicians, regulators and other influencers in the diabetes space to work towards finding new and novel ways to **tap into Patient Sentiments and Knowledge** – as we have attempted to do here with the DiabetesMine Challenges Matrix and related research.

As authors Melzi et al. write in their recent paper on “[Patient Knowledge Retrieval](#)” for the Sixth International Conference on eHealth, Telemedicine, and Social Medicine: “These resources are a gold mine for health professionals.”