



Patients Rate Diabetes Tools & Services

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ABOUT THE DIABETESMINE CHALLENGES MATRIX

DiabetesMine™ Challenges Matrix is a new way of mapping the diabetes care landscape with a focus on the needs of people with diabetes (PWDs) and their caregivers. It was unveiled at the DiabetesMine Innovation Summit at the Stanford University School of Medicine in Fall of 2015.

The Matrix aims to create a systematic new method for monitoring the impact of diabetes offerings in the United States in terms of patient needs, 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.

In essence, the Matrix creates a “scorecard” for the patient community to rate all the available diabetes tools and services.

IMPACT here refers less to clinical efficacy than to how much a given tool or service positively affects Quality of Life for PWDs; while ACCESS addresses cost and availability, as well as scalability to the largest possible swath of eligible patients.

DiabetesMine conducted an online survey in Spring 2016, asking the Diabetes Community to rate products and services in six categories: Exercise, Nutrition, Education/Care, Psychological/Social Support, Medical Devices and Blood Glucose Data Tools. In addition, participants were asked to recommend items they believe should be added to the Matrix, and share their experiences and knowledge about different products and services in written comments.

We used this research to inform and guide our 2016 **DiabetesMine Usability Innovation Awards** – selecting the winners based on overwhelming positive feedback and standout comments. The results were presented at the 2016 DiabetesMine Innovation Summit at the University of California San Francisco Mission Bay.

Contents

ABOUT THE DIABETESMINE CHALLENGES MATRIX	1
METHODOLOGY	3
EXECUTIVE SUMMARY	4
EXERCISE	6
Fitness Wearables	7
Fitness Apps.....	7
NUTRITION	8
Food Tracking & Info Apps.....	9
Dietitians	9
EDUCATION / CARE	11
Diabetes Camps	12
Vital Crowd.....	12
PSYCHOLOGICAL / SOCIAL SUPPORT	13
Online Communities.....	13
OpenNotes	14
Behavioral Diabetes Institute.....	15
MEDICAL DEVICES	16
Fingerstick BG Meters	17
Wireless Connected Meters	17
Insulin Pens.....	17
Insulin Pumps	18
Dexcom CGM.....	18
NightScout	18
Insulin Pump-CGM Combo	19
Closed Loop System.....	19
Medical Devices Highlighted by the Community	20
BG TOOLS (DATA).....	22
Glucose Logging Apps.....	22
Vendor-Specific Software.....	23
Data-Sharing Solutions.....	23
SUMMARY/CALL TO ACTION	25

METHODOLOGY

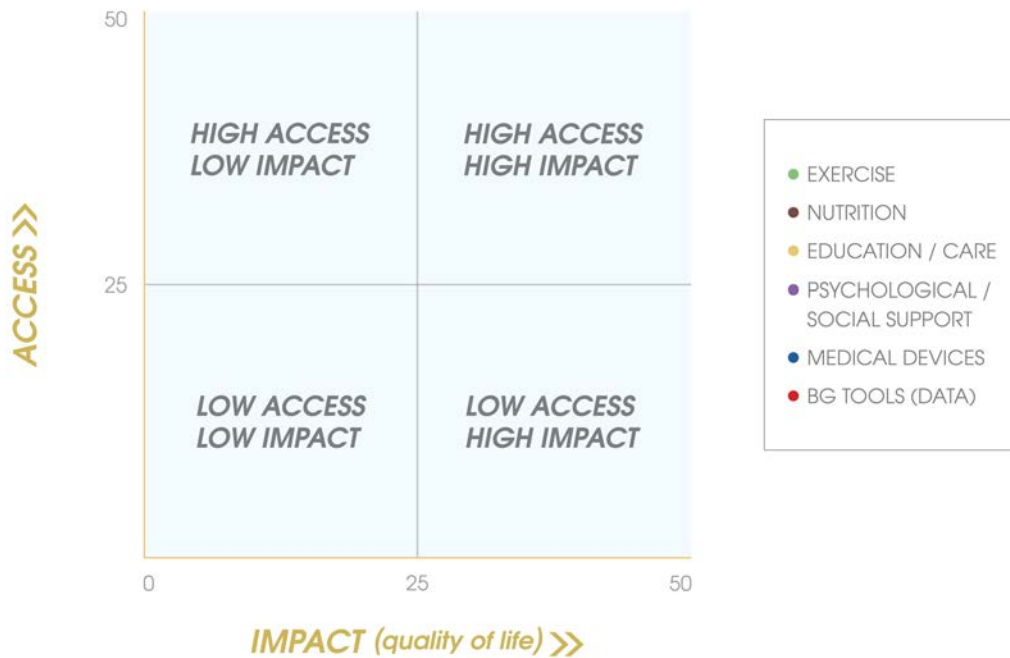
Data was collected via an online survey conducted in the Spring of 2016. A link to the survey was published on DiabetesMine.com and a number of peer sites and networks. A total of 485 respondents participated, giving input to existing ratings of products and services on ACCESS and IMPACT on a scale from 0 to 50. Respondents also added more than 1,000 written comments explaining their ratings.

The majority of respondents reported having had Type 1 diabetes for more than 10 years. The second-largest group of respondents were caregivers of an insulin-dependent PWDs.

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

EXECUTIVE SUMMARY

Introducing the DiabetesMine™ DIABETES CHALLENGES MATRIX



Overall, the original scores of items mapped on the Matrix by the DiabetesMine team were generally adjusted downward on both ACCESS and IMPACT by our survey respondents. This may be an indication that we (as journalists, advocates and researchers) have an overly enthusiastic view of available tools, i.e. the wider patient population struggles with ACCESS and IMPACT more than we realize.

Along those lines, the comment trends were eye-opening. A great deal of frustration was communicated.

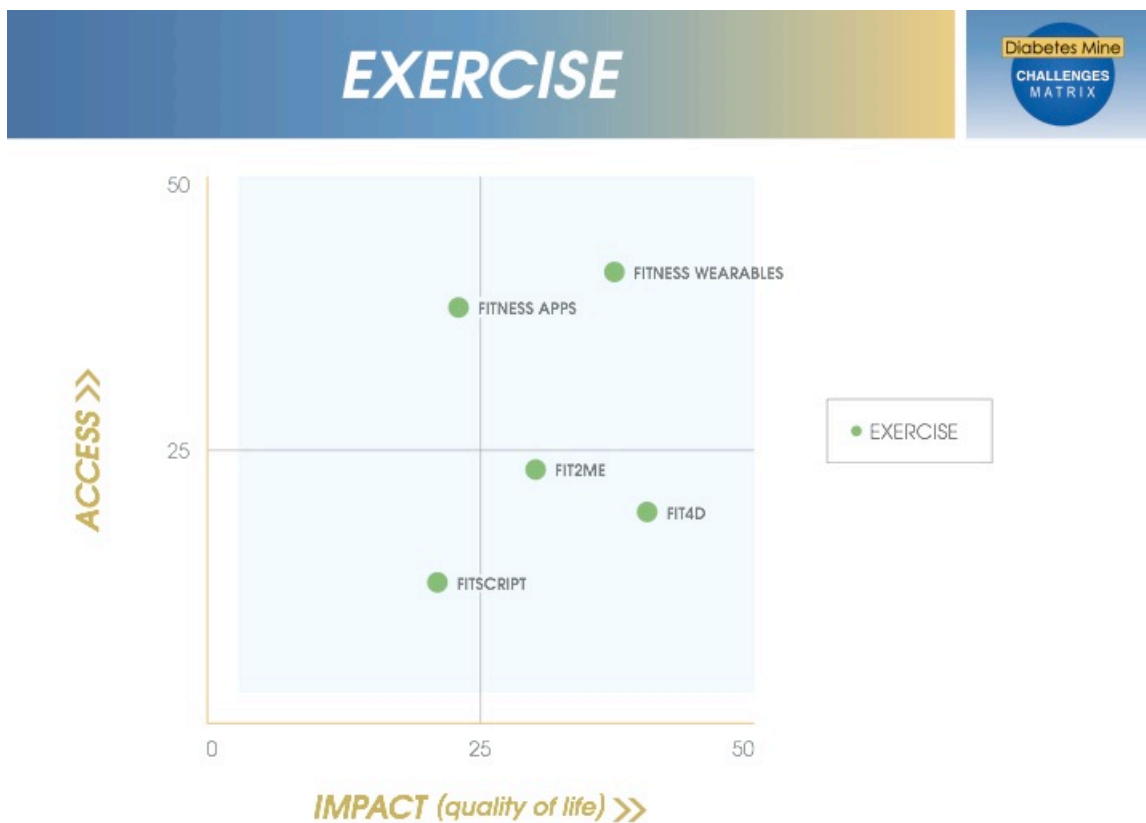
To summarize, the comments reflected clear calls for three things:

- **Interconnectivity** of products and services, urging technology vendors to forgo proprietary systems for the benefit of the patient community. This mirrors the call for Interoperability that has been the rally cry of the grassroots #WeAreNotWaiting movement.

- **Improved education for healthcare providers (HCPs)**, including diabetes educators, to give them a better grasp of the challenges of life with diabetes “in the real world.” Our respondents expressed a great deal of frustration that HCPs still generally take a “text book” approach that does not recognize the realistic challenges patients face.
- **Patient empowerment** was named repeatedly, with specific calls for improvements in:
 - Cooperation between healthcare providers and PWDs, that truly allows for a partnership approach to care.
 - A greater emphasis on peer support/informational online patient communities (such as TuDiabetes, DiabetesMine and DiaTribe). Respondents noted that an introduction to these resources should be “part of the prescription” for newly diagnosed patients.
 - Patient Community Input into the design of tools and services, and into research efforts about their disease – via crowdsourcing efforts, etc.

The remainder of this report describes respondents’ specific feedback in each of our six life challenge categories.

EXERCISE



You can see that this category is sparsely populated overall. There are essentially two groups of offerings that appear – pure technology tools that let people track and record their physical activity (seen above the middle horizontal axis), and programs that combine the technology with a coaching component (seen below).

It's no surprise that the pure technology items score higher on ACCESS, because all one needs is a cell phone or a small budget to purchase, whereas enrolling in a coaching program is often dependent on geographic limitations or access through a clinic or employer.

This group of Type 1-focused respondents also balked at the idea of using exercise as a key means to manage blood glucose (BG) levels, as people on insulin often experience the opposite problem: they must work hard to managing BG levels so that they can exercise safely and effectively. Controlling BG levels during and after a workout can be highly complex and challenging.

“I find the idea that I can manage my diabetes just with exercise almost laughable. Exercise has a marginal effect on managing my diabetes, carb restriction is much more important.”

Fitness Wearables

Interestingly, Fitness Wearables did not originally appear on the Matrix, because our previous research indicated they were not top-of-mind as diabetes tools. But this year, we had multiple write-ins for Fitness Wearables and they were ranked particularly high on both ACCESS and IMPACT. People liked the notion of receiving real-time actionable data, as well as visualization of their efforts and the interactive aspect of these tools.

“These help increase activity by gamifying our lives. We see the results and know when we need to be more active. We have a visual reminder of what we are accomplishing, with limited additional work on us (other than the exercise).”

“Automatic logging of activity. The better ones can also tag heart rate, distance, effort, etc. These can be accurate enough to provide a timeline to counter-pose other biometric timelines (glucose levels, food, sleep, blood pressure, etc.) used to determine a patient's health.”



Fitness Apps

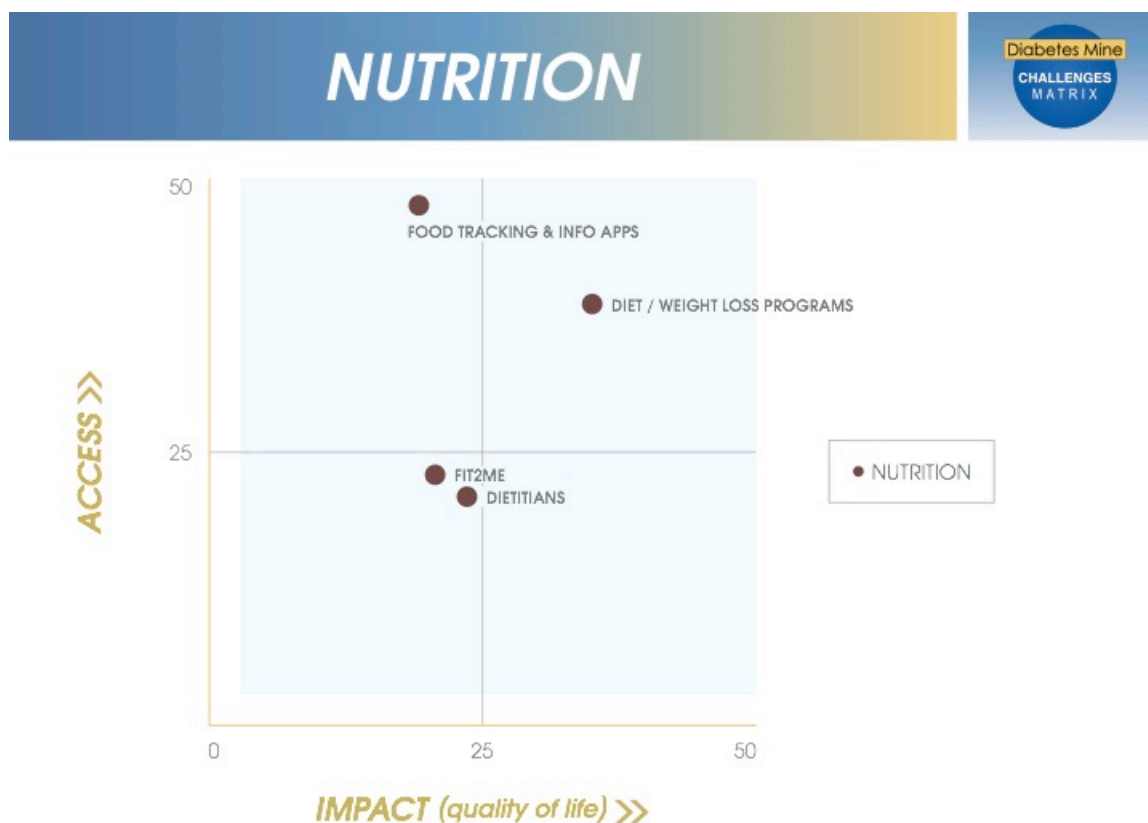
The category of fitness apps was rated surprisingly low on IMPACT, while ACCESS took a hit for being limited by the need for smartphones paired with generous data plans.

One barrier for IMPACT is the necessity for manual data entry – which in turn impacts motivation to use the app consistently. While many consider fitness apps to be overwhelming and demotivating, others point to their value as a cheap method for tracking activity and often nutrition.

Meanwhile, they're seen as offering basic assistance when individual exercise coaching is hard to come by:

“Generally one-to-one services are either very poor, or cost too much, which is why automated devices that assist us are so important.”

NUTRITION



This is the most sparsely populated category, with the least offerings, despite being arguably the biggest challenge that most PWDs face. This area is ripe for innovation.

Existing apps score high on ACCESS because they're relatively easy to get, but do not score impressively on IMPACT.

A number of respondents recommended adding mainstream weight loss programs to the Matrix, such as Weight Watchers and Jenny Craig. These are seen as relatively impactful, even though the programs are generally linear with a specific weight-loss goal.

Food Tracking & Info Apps

Respondents demonstrated moderate excitement for this category, considering them most useful for PWDs who eat out often in mainstream restaurants. The apps are considered less impactful for people who regularly prepare their own meals or eat at non-chain restaurants.

But they noted that as with all apps, much of the effectiveness depends on users' motivation to continue app use, tap into the information provided and change behavior accordingly.

ACCESS is restricted primarily by the need for a smartphone with a sufficient data plan.

The Calorie King app in particular was called out as very useful for carb tracking when eating out, especially at chain restaurants.

“Although some are clearly better than others, the portability and availability of so many apps makes carb-counting away from home almost a non-issue!”

“These tools are useful to the newly diagnosed and to those who mostly eat out and eat packaged and processed foods. I probably eat 90% of my meals prepared at home from whole ingredients, so these apps are of little help.”



Dietitians

Collectively, dietitians were criticized for being poorly educated, teaching “one size fits all” and “old school” plans and/or being advocates of one particular diet without being open to new approaches.

The service dietitians provide was criticized as “not personalized” or tailored to the needs of individual diabetes patients, but instead solely focused on achieving weight loss goals.

ACCESS to dietitians is restricted by insurance providers and usually limited to sessions shortly after diagnosis, with only very few sessions per year afterwards.

Some respondents noted that Certified Diabetes Educators (CDE) could also be added in the Nutrition category – stating that they often provide more value

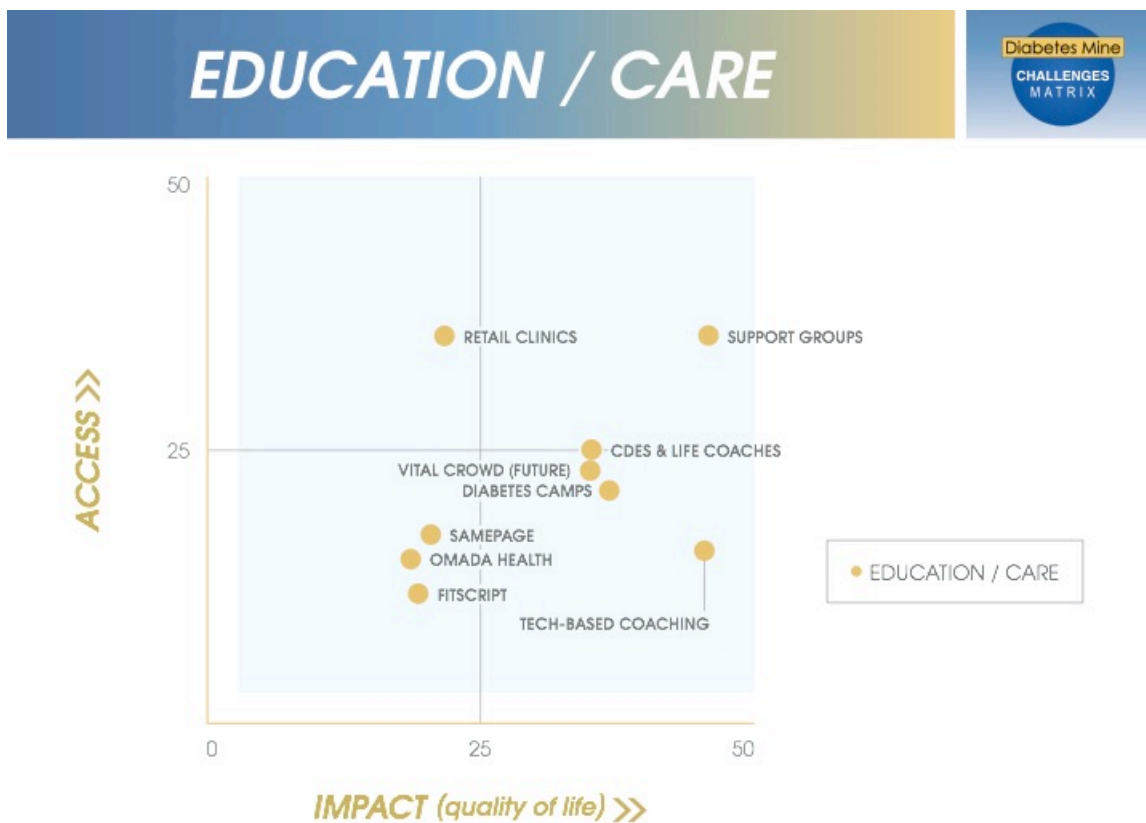
helping patients with food choices and are more commonly covered by health insurance than dietitians.

“Not all dietitians are CDEs. I think there is a difference between simply seeing a dietitian and seeing somebody who can educate more on all aspects of diabetes management education.”

“Covered by many insurance companies where nutritionists are less likely to be. Seems they could be great resources for nutrition info.”



EDUCATION / CARE



There are a fair amount of offerings in this area, but you will note that nearly all fall in the lower quadrants on IMPACT.

Interestingly, the most low-tech item of all, Support Groups, ranked highest on both ACCESS and IMPACT, pointing to the value of peer camaraderie and ongoing learnings from fellow PWDs.

Retail Clinics – a new wave of options starting to crop up around the country – scored high on ACCESS by our respondents for that reason, yet scored low on IMPACT. Respondents voiced skepticism about their commercial nature, whether they are trustworthy in regards to discretion and privacy, and the fact that they likely lack expertise, especially about Type 1 diabetes.

CDEs, life coaches and tech-based coaching all scored high on IMPACT, showing that a “personal touch” is highly valued. Yet those programs are challenged on ACCESS in terms of scalability and affordability.

Diabetes Camps

Diabetes camps scored high on IMPACT – with some caveats – but low on ACCESS.

Camps are seen as particularly suited for children and teenagers as they have the potential for boosting confidence and educating younger PWDs about self-management. Yet commenters point out that IMPACT differs strongly by which camp you attend.

ACCESS to diabetes camps is limited by cost and location, as they're not offered everywhere. Respondents also lamented the lack of camp programs for adult Type 1 PWDs, who they feel could also greatly benefit.

Vital Crowd

Vital Crowd is a new crowdsourcing platform allowing patients to give input to help design research studies. It's being created by the Scripps Translational Institute and was debuted at the 2015 DiabetesMine Innovation Summit.

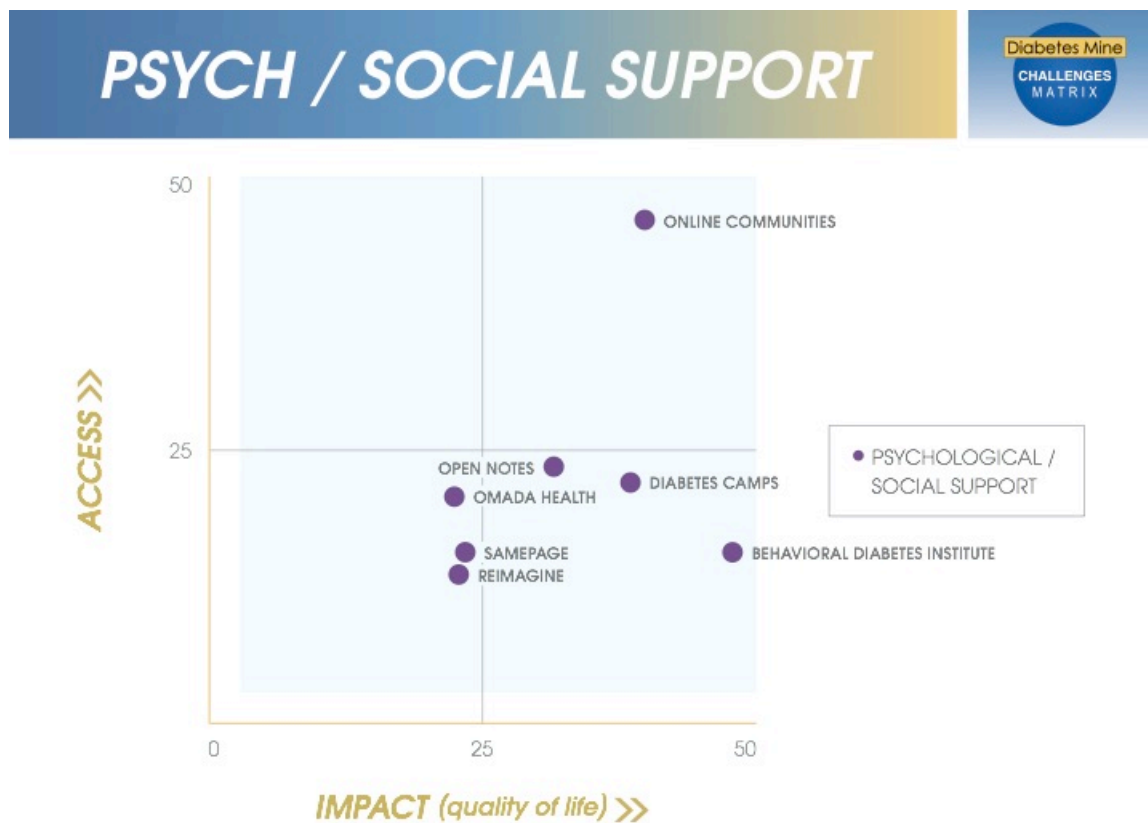
Although still in beta phase, the program scored high on ACCESS due to its simple online presence.

It also ranked surprisingly high on IMPACT by those who took the effort (as it's still lesser known in the community, comparatively few people ranked it). But those who did leave positive comments, were enthusiastic about the potential for a channel allowing patients to have a voice in clinical study design.

“Vital Crowd has a lot of potential. The current implementation leaves a lot to be desired, but the basic idea of not just involving patients in research, but -- more importantly -- of allowing them to suggest research based on their own day-to-day insights into the condition that they constantly live with, struggle with, and devote mindshare to, is critical to the future of medicine.”



PSYCHOLOGICAL / SOCIAL SUPPORT



This category is very sparsely populated despite its documented benefits. It's a challenge area that was traditionally neglected, yet arguably provides the basis for any measure of "success" in chronic disease care; without the necessary psychosocial support, patients will not achieve a sense of well-being – without which they are *very unlikely* to make healthy choices and be diligent in their diabetes management.

Thankfully, online offerings have added value here.

Like Nutrition, this area is ripe for innovation.

Online Communities

Web communities such as TuDiabetes, Diabetes Daily, DiabetesMine and DiaTribe scored very high on both ACCESS and IMPACT. This is not entirely surprising, given that the survey was promoted in an online community and therefore drew respondents who would naturally be fans.

The high marks on ACCESS are notable, in that having free and easy 24-hour patient support at your fingertips these days is truly revolutionary compared to the patient experience just ten years ago.

For some people, these online communities have clearly become the “hub” of their diabetes world.

“Online support groups are where we get our primary social support.”

“Finding others in the same boat is worth its weight in gold, and at little to no added expense! Whether its a well run, moderated chat group format (TuDiabetes especially), or reading peer-reviewed (in a casual sense) storied/articles from reputable sites

(DiabetesMine, diaTribe) they both have a lot to offer in a way that is totally relatable and can turn a bad day or a frustrating problem on its head.”

Separated by Miles, United by a Cause



OpenNotes

OpenNotes is a national program to allow patients’ access to their doctor’s appointment notes online. It is a portal where they can view these notes and keep their own records of their health and doctor-patient interactions.

Respondents rated it relatively high on both IMPACT and ACCESS, although commenters point to the fact that not nearly enough clinics across the country have implemented the program. They love the concept, but recognize that health institutions and in particular physicians themselves, need to buy into OpenNotes for wider accessibility. Also, doctors must commit to using language that is understood by PWDs.

“I LOVE seeing the doctor's notes from my daughter's visits. It's really helpful in furthering a beneficial relationship to see how the doctor views the same visits.”

“I've rated impact as high because this sort of patient empowerment is critical.”

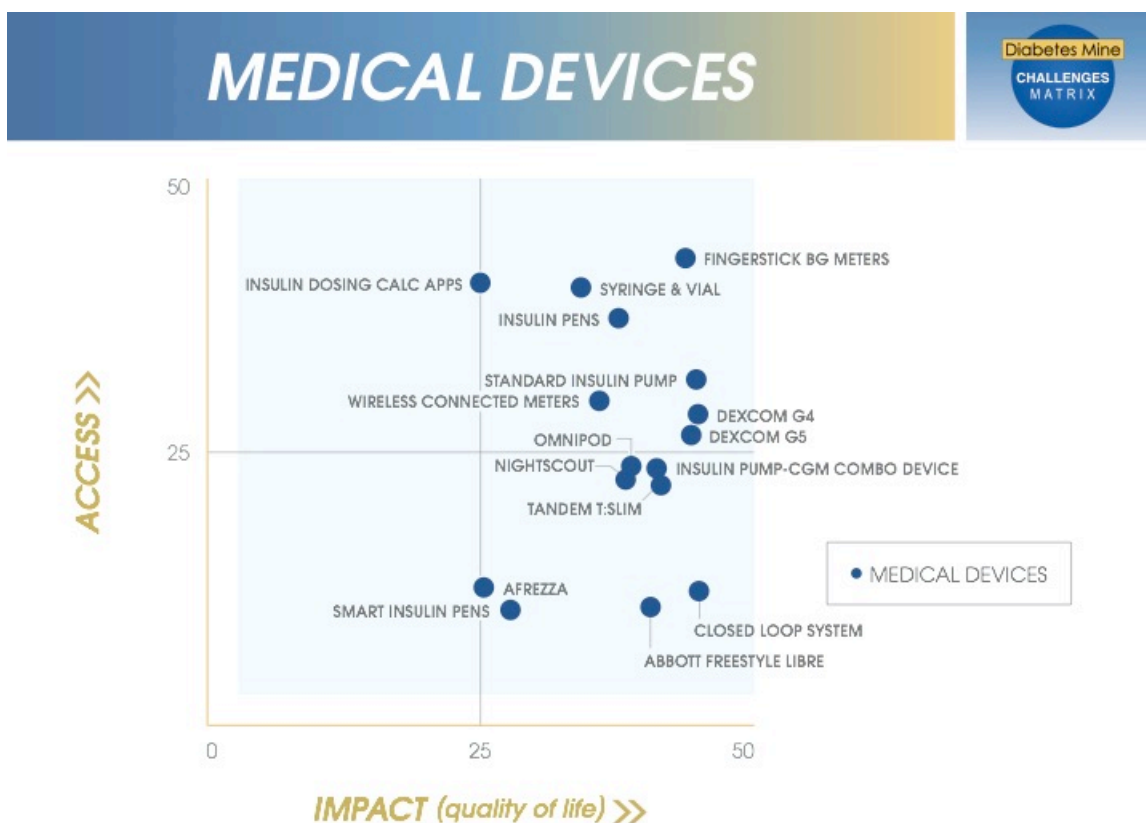
“Being able to see what your PCP or specialist is saying about your care and progress is crucial to being an active participant in ones care. Access us limited to having Internet and dependent on your provider participating in the program.”

Behavioral Diabetes Institute

This San Diego, CA-based educational institute focusing on the psychological needs of PWDs scored spectacularly high on IMPACT – the closest to the maximum value of 50 among all products and services ranked in the Matrix.

At the same time, it scores almost as spectacularly low on ACCESS due to its regional nature. This points clearly to the need for replicating the Behavioral Diabetes Institute’s care model across the United States.

MEDICAL DEVICES



The Medical Devices category is perhaps the most mature across the Matrix. It's populated by a wide variety of products and product categories that appear in the most desirable upper right quadrant, which indicates high scores on both ACCESS and IMPACT.

Good news: this is where innovation is exploding at the moment, making devices more powerful.

In recent weeks, the first commercial pre-Artificial Pancreas system from Medtronic (670G) was approved by the FDA – an exciting milestone for automating glucose control.

Nearly all the devices shown here are aimed at insulin-dependent patients (Type 1s) who are potential candidates for an Artificial Pancreas.

But there are some devices that can potentially impact care for the broader (Type 2) community. Those include “smart” glucose meters that help patients recognize trends, and new efforts like the Abbott FreeStyle Libre and other more mainstream

devices on the horizon to bring the value of continuous glucose monitoring (CGM) to broader diabetes populations.

Fingerstick BG Meters

Not surprisingly, traditional fingerstick glucose meters received a high number of responses, and rate very high on both ACCESS and IMPACT. While perceived as essential and very useful products – especially for Type 1 patients – respondents expressed concern about measurement accuracy. They further criticize that insurers don't provide enough test strips, especially for people with Type 2 diabetes. As high prices limit ACCESS for some, commenters also demanded ample supply of test strips at little to no cost to patients.

In addition, they noted that test strip containers are typically round, which makes it difficult to pull out one strip at a time. Commenters suggest a design shape resulting in a rectangle-shaped container. This is an interesting example of a product that would be even more useful if PWDs were able to weigh in on the design of the packaging. (NOTE: in October 2016, Roche launched the new Accu-Chek Guide meter that includes the first-ever spill-resistant test strip vial.)

Wireless Connected Meters

Many respondents agree that wireless connected meters bring value in making record-keeping easy – another major step forward over log books. Respondents commented on limited ACCESS due to high price combined with limited insurance coverage, not only for the meter but also for the necessary test strips to use it. In addition, these more modern “smart meters” are typically not covered at all for Type 2 diabetes patients.

“Helpful but insurance is not willing to pay extra for wireless features as a convenience for patients.”

“Even with coverage the out of pocket cost can still be prohibitive.”

“I wish I had access to something like this, but they're not available to people with type 2 diabetes.”

Insulin Pens

As a product group, insulin pens score high on IMPACT because they provide a portable and easy way to administer insulin on the go. At the same time, respondents noted ACCESS issues because the insulin cartridges for pens are more expensive than insulin vials – an added cost that some insurers dispute. Many

respondents report using insulin pens for emergencies only, and therefore state that while the overall IMPACT on their diabetes might be low, their “emergency IMPACT” is extremely high.

Insulin Pumps

The quality of life improvement associated with the use of standard insulin pumps is undisputed and echoed by the community. As a next generation device, the Tandem t:slim is lauded for its user-friendly interface combined with its modern design.

However, limited insurance coverage combined with high out-of-pocket expenses limits the accessibility of insulin pumps across the board.

Dexcom CGM

Respondents agree that the Dexcom Continuous Glucose Monitoring (CGM) system has been the biggest milestone in diabetes treatment in recent years and that future innovations will likely be based on this technology.

While ACCESS is significantly limited by insurance providers, the community expressed a great level of excitement over the Dexcom CGM.

“With current/avail tech, the Dexcom CGM has had the greatest impact since the pump.”

“Dexcom is an amazing tool and newly diagnosed people should leave the hospital with one.”

“I wish every friend and relative and neighbor and person with diabetes had access to these.”

“Accurate, relatively comfortable CGM is transformative. All future innovation in technology rests on this foundation. Cost remains a barrier.”

NightScout

The homemade and community-supported “CGM in the Cloud” system called NightScout invoked an abundance of strongly opinionated comments – both very positive AND very negative.

The pro-NightScout camp loves the vision of this non-profit and are urging for more support from healthcare providers and technology companies. Those

opposing strongly disapprove of the product and its lack of data security. Some express concern over making kids with diabetes more obsessive and dependent rather than independent with their condition.

ACCESS to NightScout is limited by the need for certain technological skills and the costs associated with implementing this do-it-yourself diabetes technology.

NOTE that neither NightScout nor the newer homemade “OpenAPS” system are FDA-approved; both are open source, DIY projects that allow patients to create their own system with real-time access to CGM data via personal website, smartwatch, or apps and widgets available for smartphones.

Insulin Pump-CGM Combo

As the industry moves towards a full closed-loop Artificial Pancreas system, a number of vendors have launched “combo systems” comprised of an insulin pump that communicates with a CGM. Heralded as the first major step toward the AP, these systems rank very highly on IMPACT. However, product evaluations differ by manufacturer. It is clear among our commenters that the Dexcom CGM is preferable to Medtronic’s.

Commenters do complain that current devices are limited by inaccuracies, troubles with calibration, painful insertion, and falsely setting off “awful sounding” alarms.

ACCESS is hampered by strong insurance coverage restrictions combined with high out-of-pocket cost even for those whose insurance does cover it. Another limiting factor is the significant learning curve for PWDs new to the combined devices.



Closed Loop System

Although no fully closed loop system was yet available at the time of this report, we added it to the Matrix as a touchpoint for the near future.

Respondents are very enthusiastic about closed loop systems and rank IMPACT very high, referring to the category as a “game changer.” At the same time, some voice concern that closed loop technology will widen the gap between the privileged, well-insured and less well off patients in regards to their diabetes care.

Medical Devices Highlighted by the Community

In the area of Medical Devices, we received numerous suggestions to add new items to the Matrix:

Insulin Dosing Apps (Rapid Calc, PredictBGL)

Several smart phone apps offer the same insulin calculation feature included in insulin pumps. Respondents noted that these are of high value to patients on shots.

“It’s the coveted ‘bolus wizard’ without the expense and hassle of a pump. As a former pump user, I’ve found that I can almost duplicate my BG results with syringes as long as I use an app to help calculate and track IOB.”

Modern Basal Insulins like Tresiba

In the mind of some respondents, newer insulins that work faster or offer smoother curves of action constitute a “medical device” in their toolbox for diabetes care.

“After multi-decade pump use, I’ve transitioned to Tresiba and a rapid acting analog, both in pens, and my control and quality of life both went up.”

Abbott Freestyle Libre

This new type of “Flash CGM” is a simple, easy to use system that many believe has huge potential to help Type 2 patients. It is available commercially in Europe now, and the “Pro” version for healthcare providers was FDA-approved in Fall of 2016. Respondents commented enthusiastically on this up-and-coming technology.

“It’s approved for dosing insulin, doesn’t need calibrations, it’s affordable and doesn’t require a prescription.”

“This is an essential forward step in providing CGM-like capabilities for managing hyperglycemia in real time, at reasonable (insurable) cost for T2Ds at low risk for hypoglycemia.”

“Why the hell is available in many, many countries but not in the U.S. where it was developed and made? I’d buy one tomorrow because I know it would be a great help for my Type 2 and MDI.”

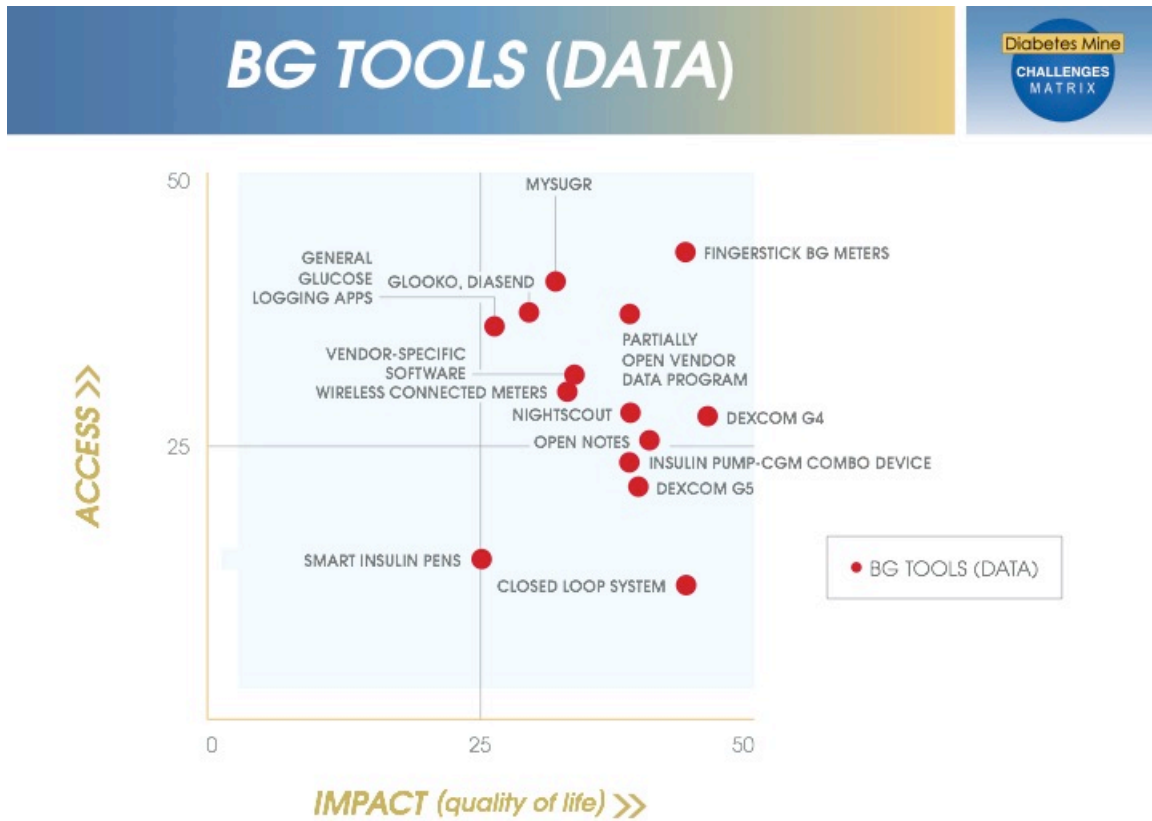


Encapsulation, etc.

There are a number of companies working on technology that would implant insulin-making cells into the pancreas, techniques for transplantation, etc. Everything is still experimental, but the potential is interesting.

“VARIOUS stem cell projects, such as encapsulation, cell conversion (stomach lining cells to beta cells), etc.”

BG TOOLS (DATA)



The area of Data Tools is the nucleus of innovation in diabetes at the moment. You can see a highly populated chart with nearly all items scored in the upper right quadrant for high ACCESS and IMPACT.

Many data tools 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 diabetes data sharing, our survey respondents remind us that “data overload” can be a problem, and that identifying trends and making real-world therapy suggestions trumps all.

Glucose Logging Apps

Logging apps are seen to be potentially impactful because the data they provide can be used to take proactive steps, however commenters note that the actual IMPACT greatly depends on whether people consistently use the app and change

behavior based on the information provided. This is of course influenced by the user interface and the experience people have using the app.

While the technology itself resonates with respondents, many criticize that these first-generation record-keeping apps are limited in their functionality, design and ease of use for data entry.

ACCESS is considered limited by the need for a smartphone with a generous data plan. It's also worth pointing out that logging apps are basically obsolete for PWDs using CGM systems.

Vendor-Specific Software

This category refers to the proprietary data-logging software that device manufacturers offer with their glucose meters and insulin pumps (such as Medtronic's CareLink, Roche's Accu-Chek 360°, etc.)

As a category, these software programs for data download are generally viewed as time-consuming, difficult to use, with too few software updates and lacking compatibility across devices.

But respondents also noted that the usefulness differs significantly by vendor, and also by desktop versus mobile offering.

Some said that "if used regularly and properly," these programs can be very useful for PWDs and their physicians/educators, as they do help reveal patterns over time that can translate into actionable insight to trigger changes and adjustments. As such, these programs have the potential to be a conduit to fostering patient-doctor relationships.

Data-Sharing Solutions

Vendor software comes closer and closer to obsolescence as a new generation of independent data platforms and mobile apps evolves. These are able to capture and combine data from multiple devices, as well as input from the users on carb and insulin intake, activity, etc. The data can also be shared and viewed on a variety of platforms (computer, phone, tablet, smartwatch).

Data-sharing solutions are summarily viewed as the next generation technology that respondents would like to see more widely used. Not surprisingly, some data security and privacy concerns are expressed in regards to saving data in the cloud. There were also some complaints that even these newer data solutions are not as user-friendly as they could be.

“Enjoy using Tidepool, and Glooko could be a contender. Combined viewing is the future. Single device systems are second-rate.”

“Glooko + Omnipod + Apple Health Kit = the very first time we could see Dexcom + Omnipod in one report. It's unacceptable that it took so long to get this functionality.”

“Potentially useful, but VERY poorly implemented.”

SUMMARY/CALL TO ACTION

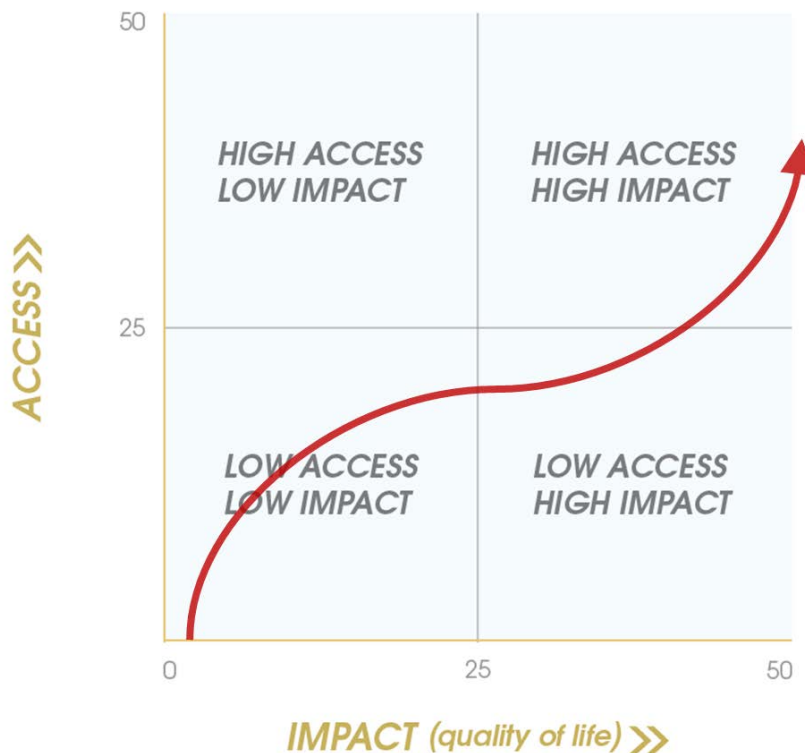
There's an axiom used in design and elsewhere: "Do More of What Works."

In the case of diabetes care, the first step is to identify what the patient community believes to be helping them most, and then concentrate on building those items out.

Our purpose in creating the DiabetesMine Challenges Matrix is to take a broad look at 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.

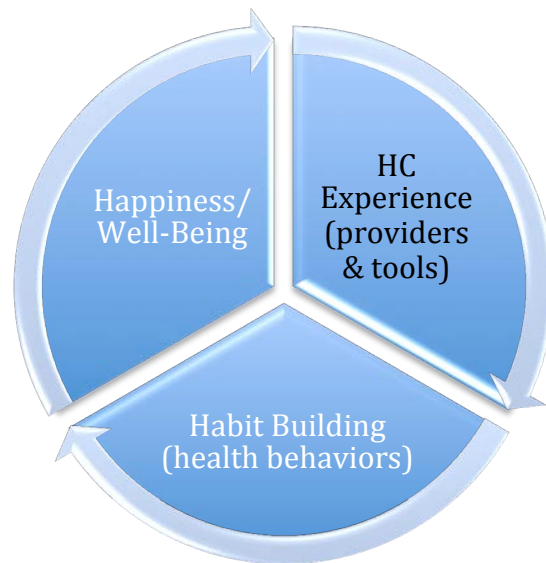
The question we've put to patients over the past several years with various research efforts is: What Helps Most?

What can be accomplished with the information gathered here is working to increase the ACCESSIBILITY of the most impactful items, and to increase the IMPACT of the tools and programs that are already most widely accessible.



The Matrix provides a starting point to measure where we stand on offerings designed to help PWDs achieve the best possible health outcomes.

It is our belief that there are three vital components of “success” for patients:



First is a focus on Quality of Life that assures well-being and happiness – without which no amount of devices or treatment plans can help.

The second – addressed here in the Matrix – is the overall experience that patients have with the healthcare system, from the atmosphere at the clinic to their doctors’ demeanor to the tools and services they must use for their disease care. It is vital that these experiences are positive and productive if they are to achieve the third vital component... establishing healthy behaviors that become lifelong habits.

In the interest of making the tools and services offered to patients the best they can be, we urge vendors to:

1. **Take a Systems Approach:** Remember that each product / service is part of the larger diabetes equation
2. **Think IMPACT & ACCESS** rather than brand loyalty & “Engagement” via Marketing
3. Keep in mind: It’s all about the real-life **Usability Experience!**

Our hope is that the DiabetesMine Challenges Matrix sheds some light on those Usability Experiences and patients’ sentiments around current tools.