<table>
<thead>
<tr>
<th>TABLE OF CONTENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong> 2</td>
</tr>
<tr>
<td><strong>Before Engine Searches</strong> 6</td>
</tr>
<tr>
<td>Compuserve 6</td>
</tr>
<tr>
<td>UseNet and the WWW Pioneers 7</td>
</tr>
<tr>
<td><strong>Blogging, Social Media and the D.O.C Boom</strong> 8</td>
</tr>
<tr>
<td>Blogs 8</td>
</tr>
<tr>
<td>Twitter 9</td>
</tr>
<tr>
<td>Instagram 10</td>
</tr>
<tr>
<td>Podcasts 11</td>
</tr>
<tr>
<td>Videos 12</td>
</tr>
<tr>
<td><strong>Diabetes Advocates and the Diabetes Industry</strong> 13</td>
</tr>
<tr>
<td>Industry 14</td>
</tr>
<tr>
<td><strong>Difficult Discussions</strong> 15</td>
</tr>
<tr>
<td>You’re Just My Type 15</td>
</tr>
<tr>
<td>Diversity in the DOC 17</td>
</tr>
<tr>
<td><strong>The Future of the DOC</strong> 18</td>
</tr>
<tr>
<td><strong>Links</strong> 19</td>
</tr>
</tbody>
</table>
Introduction

I had a hard time wrapping my head around this project idea at first.

“A history of the diabetes online community? Like... all of it?”

I’m not the Lorax of the diabetes online community (DOC); I don’t speak for everyone who has diabetes. I’ve written this document through the very specific lens of my personal experiences with this disease, knowing that the ecosystem of diabetes on the Internet is living and breathing and constantly changing. The community I’ve written about here might be unrecognizable in a few years, but to me, today, the DOC is anchored by storytellers.

I’ll talk about diabetes blogs like they are a launching off point for the diabetes community simply because that’s where my pancreas, my heart, and my voice came to rest on the Internet. I started a diabetes blog back in 2005 because I wanted to share more than the lab work and diagnosis stats version of life with diabetes; I wanted people to see the narrative, the life, that diabetes exists within. Blogging gave me the opportunity to show what diabetes looked like in the context of my life, and while diabetes message boards were around well before I was born, the DOC felt like it came to life when people with diabetes opened that kind of digital window into their lives.

This document includes so many organizations that have changed, and will continue to change, the ecosystem of the diabetes community. And I’m sure there are many groups, organizations, and platforms that I’ve neglected to mention, despite trying to be somewhat comprehensive, because I struggle to see the whole forest as a result of being squarely up here in my tree. The DOC is big. And getting bigger.

There’s beauty to that vastness, though. The DOC -- once represented in a message board or two, then in a few discussion boards, then in a handful of blogs -- has become so immense that it’s hard to name everyone and everything. There’s no “one group” or “one voice” that represents our community, and the need for every voice has always been there. This community continues to grow because it needs to, and because there isn’t one someone who tells the story of all of us. We tell our own stories, and the power is found in the collective itself.

One diabetes blog or website or newsletter doesn’t define this community, and the importance of each individual voice cannot be overstated. My hope is that people living with diabetes continue to raise their voices. And continue to tell their stories, no matter the audience size and despite any fear, knowing that their story can make a difference.

– Kerri Sparling, diagnosed with type 1 diabetes in 1986, author of SixUntilMe.com
Kerri / Diabetes (@Sixuntilme) Follower Network Visualization

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Followers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>631</td>
</tr>
<tr>
<td>HCPs</td>
<td>270</td>
</tr>
<tr>
<td>Journalists</td>
<td>62</td>
</tr>
<tr>
<td>Media Outlets</td>
<td>46</td>
</tr>
</tbody>
</table>

27.6K Followers
Online communities of support are, in 2018, never more than a Google search away, and the ability of any person with an Internet connection to connect to peers and experts in a few clicks is one of the unalloyed wonders of the modern age.

This is especially true of the diabetes community, which may be the deepest and oldest of them all. Nearly everyone who lives with diabetes has interacted with the DOC at one point or another, and that ready access makes the whole infrastructure seem almost inevitable.

We’ve done other “Social Projects” at W2O Group, focused on using analytics to understand broad, disparate conversations in a given disease area, but thinking about the D.O.C. by tallying up aggregates misses the magic of this community. All groups online are made up of people, but few have the history of the D.O.C.

Understanding that history seemed like a noble undertaking for this, our first Social Diabetes Project report, so we turned to a person I had always thought of as a pioneer in the community: Kerri Sparling of Six Until Me, who was one of a small group of bloggers that I came to rely on for insight while I was still a journalist, early in the millennium.

But – and this is part of the wonder of the DOC – Kerri was hardly the first wave, and the oral history that follows will provide a sense of not only where the community is going, but where it came from, all the way back to the days of modems that ran off of rotary-dial telephones.

We’re grateful to Kerri for her work, and we hope this will provide lasting value to both the DOC as well as the countless other communities with that share the goal of better living through education, support and good humor.

-Brian Reid
Diabetes Conversation Volume

<table>
<thead>
<tr>
<th>Year</th>
<th>January</th>
<th>February</th>
<th>March</th>
<th>April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
<th>October</th>
<th>November</th>
<th>December</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Before Search Engines

COMPUSERVE

Even if the term “diabetes online community” wasn’t explicitly used, the DOC existed in 1992. This excerpt is from Z*Net International Atari Online Magazine, March 6, 1992, Issue #92-10, about a man named David Groves who had a blood sugar issue while behind the wheel:

“A resident of Miami, Fla., [David] Groves was driving home from his job as a bank vice president when he fell unconscious at the wheel, the result of faulty diabetes medication. He hit another car on the expressway at 65 miles an hour. After his 3 months in a body cast, he spent 9 months in therapy.

So profound was the experience that Groves three years ago established the Diabetes and Hypoglycemia Forum on CompuServe (GO DIABETES) to share the kind of information that could prevent accidents like his.”

Angela Chiffy: In the beginning, [the DOC] was a single discussion group on CompuServe’s Atari Forum. One of the SysOps [Systems Operators], David G. Groves, was recovering from a hypoglycemic-induced car accident, and felt alone. He wanted to know if there were others out there who were experiencing hypoglycemic unawareness, like he was after he switched from animal sourced insulins to human (rDNA) insulins.

What he discovered was there were more people out there, with a wide variety of experiences and who were willing to share with others what they knew. By the time I was diagnosed in March 1993, Dave had outgrown the one message board and had started his own forum on CompuServe. When I started going online in 1994, it was a bustling, crazy group with dozens of SysOps and hundreds of active members.

David Groves: [the DOC] meant more to me than I can express. The time and closeness spent with the staff and our members made the forums a wealth of information and a home away from home for me.

Chiffy: We shared our diagnoses, our treatments, news about current research, our hopes and our fears. We watched as new members and the newly diagnosed came, seeking friendship, solace and knowledge. We all wanted three things: to Educate, Motivate, and Activate others, and that’s what we did. [This picture was] taken in 1995 at the Juvenile Diabetes Foundation conference in Washington, D.C., where we were promoting the Forum.”

1 Chiffy, a person with diabetes (PWD) who knew David from those CompuServe days.
USENET AND THE WWW PIONEERS:

Jeff Hitchcock (ChildrenWithDiabetes.com): While working in the D.C. area on software stuff, I found UseNet stuff related to diabetes, where adults who used UseNet were talking about diabetes. I learned a lot about adults living with type 1 though [Carl Lydick] and others. And then there was a period where no one heard from him. It turned out that he had died from something diabetes-related. And it was that experience that truly made me understand that we are not the enemy, but diabetes was the enemy.

I had access to the very early Internet. We were building webpages for some work projects, and it became clear that this web thing was the place to build a community sharing our experiences raising a child with type 1.

Sometime in the summer of 1995, Yahoo featured CWD on its homepage. And our traffic exploded. Yahoo started indexing sites, and search engines became a thing. People found us.

In 1995, there was no such thing as a hosting company. You bought bandwidth from a telecom company. I ran a server from my den. Originally on a 288 modem, we moved to DSL and I bought a dedicated web server so I could work and not slow everything down. Eventually, that needed to get bigger so I brought and ran eight T1 lines into my house, upgraded our power, and also had to upgrade our AC unit in order to keep everything cool. After time, I got tired of worrying about broken hard drives and we moved to Amazon Cloud.

---

1 UseNet is a bulletin-board system that was created in 1979 and launched in 1980, a precursor to what became web forums and Internet-based discussion boards. Misc.diabetes.health has been cited as one of the first and most widely-read Usenet groups where people with diabetes could go to exchange information back in the early 90s.
2 Hitchcock is the father of a child with diabetes and creator and founder of ChildrenWithDiabetes.com, one of the largest diabetes global communities on the web.
Blogging, Social Media and The DOC Boom

The DOC has grown tremendously since the Usenet years, with blogging platforms such as Blogger and Typepad making the setup for storytelling easier. Those platforms were followed by Twitter, Instagram and Facebook, all enabling people with diabetes to share diabetes details almost effortlessly. Tracking the growth of the diabetes community has become more difficult because there are several platforms where storytelling is happening.

BLOGS

In 2005, when blogging was gaining mainstream traction, there were a handful of diabetes-focused blogs online. Sites like SixUntilMe, ScottsDiabetesBlog, DiabetesMine and Kathleen Weaver’s type 2 diabetes blog were among the first sites to gain a strong following, and those four sites are maintained and updated to this day.

Amy Tenderich (diabetesmine.com):6 [My husband] said, ‘You’re gonna be a blogger. You would be great on this. You can report on this.’ He encouraged me to put on my journalist hat and cover diabetes like it’s my beat. I wanted to share my journey and find peers. One of my first posts was about mail-order medicine and the issues that went with that, like mail-order insulin overheating.

Even on my first post, people were commenting. And what was exciting for me was that it felt like it wasn’t a one-way thing. There was this interaction, and we’d have this conversation and it was super exciting. I would report on something and people would say ‘thanks,’ and then ‘Hey, did you know about this?’

Kerri Sparling (sixuntilme.com):7 Just the promise of maybe finding others was enough to start me down the path of sharing my story.

In 2005, I started blogging, and for me, sharing these stories has made a world of positive difference in my diabetes health, and ultimately my overall well-being. I don’t feel isolated as a diabetic.

When the psychosocial burden of this disease is acknowledged and supported, it’s easier to celebrate the good moments and also to weather any storms. I am proud of, and inspired by, what this community has transformed into over the course of the last 13 years, and the differences we’ve made for one another. I didn’t expect to find others. I hoped to. I didn’t expect to find friends. But I did. And I had no idea how my health would be impacted -- in such a positive way, by strangers on the Internet simply saying, ‘I understand.’ But it was, and continues to be.

Tenderich: If you are diagnosed now, you come into this wonderful world of support. I feel happy and proud that we helped create that environment.

---

6Tenderich is the journalist and PWD who created DiabetesMine.com. The site launched in 2005 after her husband heard about ‘blogging’ at a new media event he had attended.

7This is me: I was diagnosed with type 1 diabetes at the age of 7, and I created SixUntilMe.com in order to find ways to live well with diabetes, instead of reasons why my life would be compromised.
Scott Johnson (ScottsDiabetesBlog.com): I was wrestling with the emotional side of life with diabetes and found that writing about it helped me cope. Sharing my story online connected me with other people living with diabetes. I didn’t know it at the time, but building those connections and being exposed to their diabetes stories provided a sense of normalcy for me, which continues to have huge benefit in my life.

Twitter, which launched in 2006, became a watering hole for people with diabetes who have found their voice on the microblogging platform. Gathering around hashtags like #insulin4all, #beyondA1C, #diabetes, #T1Dlookslikeme, #T1D and #T2D, voices representing diabetes are added to the Twittersphere daily.

@emericle: Twitter is funnier. Need to keep a light-hearted approach to the daily marathon that is T1D. There also continues to be a more productive dialogue on Twitter than anywhere else with regard to pushing everything forward, faster. It’s a good place to put pressure on pharma.

Kelly Close (@kellyclose): Twitter is a key source of goodness for me b/c it’s both a valuable source AND it’s very easy. I love seeing what is resonating w/people I trust who are in the DOC + part of such an important patient support community.

Kristin Ewing (@klewing): I would say that there really aren’t constraints -- you can ask a question at any time and get answers. Also, you aren’t limited to a geographic area. In a way, not being face-to-face also helps prevent initial judgment when meeting people. Humor also exists.

@type1bri: The fact everybody has a voice, ideas and thoughts easily shared and responded to by people who just “get it” The peer support factor is a huge thing too, creates an instant bond like no other.

One of the biggest hashtags remains #dsma, which stands for Diabetes Social Media Advocacy and anchors a global Tweetchat on Wednesday nights at 9 p.m. Eastern Time. Created by Cherise Shockley (diagnosed with latent autoimmune diabetes in adults, or LADA), the chat started on July 30, 2010, and has been going strong every Wednesday since, with dozens, if not hundreds, of people with diabetes logging on to their Twitter accounts to crowdsource answers to questions asked by the @DiabetesSocMed Twitter account.

Another hashtag aiming to make a difference and affect change for people with diabetes is #insulin4all. According to Elizabeth Rowley from the T1International organization, “So many people living with type 1 diabetes struggle to survive because they cannot afford or access their life-saving insulin, blood glucose strips, or basic healthcare. Others are caught in conflict where there is little humanitarian assistance for people with diabetes. The aim of the campaign is to unite as a diabetes and global community to show governments, companies and individuals that we recognize the problems mentioned above. It’s important that we stand together to work towards tangible solutions.”

8 Johnson was diagnosed with type 1 diabetes at the age of 5 and began blogging in 2004. He said he has found that the emotional side of his diabetes management needed some attention, and that’s why he created ScottsDiabetesBlog.com.
9 @emericle, from Nevada, lives with type 1 diabetes and tweets from https://twitter.com/emericle.
10 @kellyclose, founder of Close Concerns and chair of the diaTribe Foundation, tweets at https://twitter.com/kellyclose.
11 @klewing, a PR and social media pro with diabetes, tweets at https://twitter.com/klewing.
12 @type1bri, a marathon runner with diabetes, tweets from https://twitter.com/type1bri.
INSTAGRAM

People with diabetes are employing plenty of pixels to show what life with diabetes is really like, and the community on Instagram is adding to its numbers every day. Launched in 2010, Instagram is a photo and video sharing platform where people with diabetes can show their continuous glucose monitoring graph, their insulin pump infusion site, or how they’re living beyond their diabetes diagnosis. The ability of users to show snippets of their diabetes lives through Instagram stories adds a layer of privacy and protection for users, as the stories disappear from the platform after 24 hours. Simply putting “#diabetes” in the Instagram search function will bring you to a whole community of people sharing visuals of their diabetes lives.

_is.butter.a.carb_: When I was first diagnosed, I googled people with type 1 and went down this black hole of obituaries. It was...dark. And then I found Instagram and saw pictures of people who were alive and active and living their lives...having babies, running marathons, getting married, working and leading normal lives. And there were beautiful women rocking the medical devices that made me so self-conscious...they were wearing Dexcoms and pumps. I didn’t feel so alone and embarrassed and fragile. It made me realize so many things were possible.

_thebarrettgroves_: Yes! Seeing diabetes in the wild and just all kinds of people getting through all the highs and lows day after day! Love seeing the strength and feeling the community! Knowing I’m not the only one either getting my booty kicked by diabetes or doing the booty kicking depending on the day!

_sharechrisman_: For me it’s about the most authentic moments of every day life.

_lizzymae1987_: #hashtags. I have made true friends and diabetes connections through IG. Searching the diabetic pregnancy hashtags during my pregnancies was life changing!!!

_chrisstocker_: I think that it’s more personal than Twitter. I can see pictures, videos and feel more connected to someone. I can see their disease and the common ground we have as opposed to other social networks that may only be text.

_krystalboyea_: Because the photos and Instagram stories make it so relatable. Because with every post you are forced to add a photo. This connects people no matter where they are from. When you live with diabetes, you are curious to see into the lives of others who live with it too. Instagram literally lets you “see.”

---

13Shares her story on Instagram at https://www.instagram.com/_is.butter.a.carb_/.
14Her feed is filled with babies and blood sugars over at https://www.instagram.com/thebarrettgroves/.
15This Instagram is private but if she allows you to follow her, Sharon is at https://www.instagram.com/sharechrisman/.
16Quote from T1D weightlifter https://www.instagram.com/lizzymae1987/.
17Quote from entrepreneur and PWD Chris Stocker, who shares his photos at https://www.instagram.com/chrisstocker/.
18Instagram profile for Krystal found at https://www.instagram.com/krystalboyea/.
Hashtags help converge communities on this platform, too, and many are the same, or similar, to what’s found on Twitter. The #showmeyourpump hashtag came as a result of Sierra Sandison, Miss Idaho 2014 wearing her insulin pump onstage for her pageant competition. Diagnosed with type 1 diabetes just after she turned 18, Sierra helped empower people with diabetes to wear their devices proudly with the #showmeyourpump hashtag as her rallying cry. The hashtag is populated by hundreds of people with diabetes, showcasing their diabetes devices without fear and with pride. The #livebeyond hashtag, made popular by the Beyond Type 1 community efforts, showcases people with diabetes who are living the life they want despite – or because – of a diabetes diagnosis.

PODCASTS

**Chris Snider (Just Talking):** I discovered @SixUntilMe on Twitter and it suddenly hit me that, “Hey, I’m not the only person living with diabetes!” I was five years into my diagnosis, on insulin pens, but … yeah. I found Kerri, Scott and George at the outset, back in January 2009. Up until that point, in the 5 yrs prior, it never occurred to me that other people were living with diabetes. It was a moment of emotional enlightenment.

So I started my own blog. My first blog posts were rooted in anger and in trying to understand my diabetes frustrations and to work through that. I realized I wasn’t alone. I had something to say. [After some time,] the blog became somewhere I didn’t feel was the most effective place for my storytelling. So I started the podcast.

There’s always someone new finding this stuff. You never know who is paying attention, or who is listening, or who knows someone who was just diagnosed with diabetes. If I find a reasonable way to tie in my personal experiences with diabetes to whatever my guest is talking about, I always take that opportunity to tell that story. My podcast is a natural conversation.

**Stacey Simms (Diabetes Connections):** I started Diabetes Connections in 2015, mostly because it was the kind of show I wanted to listen to. My background is in broadcast journalism (local TV and radio news) and I hoped there was a place for a radio style news & interview show about diabetes. Three years and 170 shows later I can say it’s the most rewarding project of my professional career.

My listeners tell me they appreciate my firm but fair questions of healthcare and diabetes tech companies and they want more ‘everyday’ stories along with interviews with celebrities and athletes with type 1. There’s something about audio that is more intimate than reading. Hearing a person tell their own story can be extremely powerful.
VIDEOS

Videos about diabetes can bring a new level of personal connection to someone’s story because you can see their faces, hear their voice, and identify with their experiences -- platforms such as YouTube, Vimeo Vine, and through Facebook, Twitter, Instagram and Snapchat (among dozens of others). Livestreaming video options, like Facebook Live or Periscope, have made the experience even less edited and more personal, letting people into someone’s diabetes narrative real-time.

DiabeticDanica (creator of the DiabeticDanica YouTube channel):21 I initially chose YouTube as a means to share my diabetes story simply because I liked watching other people’s videos. I thought YouTube looked like fun, so when I considered what I’d be interested in talking about, diabetes was the winner! Now I think that video is a nice format because it can be very informal and conversational. When the followers are able to actually see your face and hear your voice, it brings a personal connection where the viewer can really feel like they know you! And of course it is easier to relate to someone that you know!

There are a lot of video options — far too many to list — but here are some jumping off points:

**Daily Diabetics** is a daily video channel where seven different women with type 1 diabetes post a video talking about their personal experiences.

**Diabetic Danica** has a broad slate of content available on her YouTube channel, from diabetes device unboxing videos to busting diabetes misconceptions one by one.

**Beyond Type 1** inherited a robust YouTube channel with its acquisition of the Diabetes Hands Foundation assets, showcasing the older TuDiabetes live chats coupled with the newer Beyond Type 1 celebrity spotlights and programs videos.

Community member **Daniele Hargenrader** has a great series of interviews with folks from the diabetes community, as well as her own take on diabetes, in addition to fitness and wellness advice.

**Phil Graham**, from **Diabetic Muscle and Fitness**, posts regularly about living with diabetes and bodybuilding.

Not all accounts need to be updated regularly to be relevant. Despite the fact that these profiles haven’t added videos in a few years, their insight is still valuable. **Ginger Vieira has a series of videos** ranging from ways to improve the taste of gluten-free bread to breaking up with diabetes. **Mike Lawson explains his life as a pincushion.** You can even find brilliant diabetes-themed parodies of popular songs from **Melissa Lee at the Sweetly Voice Presents YouTube channel.**

21DiabeticDanica has over 21K subscribers and shares her videos at [https://www.youtube.com/user/DiabeticDanica](https://www.youtube.com/user/DiabeticDanica).
Diabetes Advocates and the Diabetes Industry

Once diabetes blogs and the presence of social media had become more ubiquitous and mainstream in terms of patients finding support online, industry became interested. One of the first outreach efforts to the newly-minted DOC came from Roche Diagnostics. The company emailed a number of diabetes online advocates and invited us to Indianapolis for a “blogger summit” in the summer of 2007.

Rob Mueller (Roche Diagnostics): I think we realized early on what a force for the good the DOC was, and we wanted to be part of what was happening. We wanted to understand how we could work with them — where we could work together, and where they wanted us to stay away. That was the real reason; we simply wanted to be part of that powerful conversation early on. It really is what I am most proud of in my professional career.

David Mendosa (journalist and patient advocate): When my invitation first arrived, I didn’t recognize the term ‘social media.’ I now understand it to mean bloggers and other patient advocates, like me, who write about diabetes.

Tenderich: We bloggers and social network aficionados have been calling for the medical establishment to wake up and smell the java, and recognize that we patients have a new place to congregate and a new communal voice on the web. Why don’t they recognize us and engage with us, we ask? Well, Roche was that first big pharma company to do this. Being a manufacturer of popular glucose meters and pumps, the company is listening to us. Not only listening, but they’d like to start building a closer relationship with our online community.

Sparling: It was really a groundbreaking sort of event, with Roche having the balls to invite a pack of opinionated bloggers into their house to talk frankly about social media and pharma -- specifically, THEIR pharma. We talked about ways that pharma can appropriately enter the social media space without being received by a mob with torches and pitchforks.

Dana Lewis: It was exciting to see so many of our d-friends in real life (and in one place); especially since we often communicate by blog posts and e-mails alone! The blogging summit had a wide agenda and hit on a number of topics — but I was most intrigued by the focus to help pharmaceutical companies engage in social media (and with bloggers) the right way.

---

22 For the first Roche blogger summit, the Roche team sent invitations to roughly 30 bloggers and advocates and invited them to its headquarters in Indianapolis. Travel, lodging, and expenses were covered by the company, and expectations were for bloggers to speak freely and to get to the people behind the pharma company.

23 Mueller, Digital Marketing Manager, Strategy and Communications for Roche Diagnostics, was the driving force behind the first Roche summit.

24 Mendosa, who lived with type 2 diabetes, passed away in 2017. The quote comes from his website.

25 Tenderich, along with Manny Hernandez, helped organize the event with the Roche team. This quote comes from her blog.

26 This quote is pulled from SixUntilme.com.

27 Lewis attended on behalf of Close Concerns, a publication about diabetes. The quote from Lewis comes from that site.
Roche, in total, hosted four summits, the last one taking place in 2012. Its decision to invest in relationships with the community became a trailblazer moment, inspiring several other diabetes pharma and medical device companies to engage with the DOC. Lilly Diabetes hosted its first summit back in 2012, Medtronic brought advocates together for an advocacy forum, and other companies in the diabetes space started bringing people together for in-person advisory meetings.

Diabetes companies across the board hosted summits and meetings for patient opinion leaders, looking to engage in discussions about products, perceptions and using social media for social good.

**INDUSTRY**

One advocacy think tank, Partnering for Diabetes Change, was created as a result of a meeting at Johnson & Johnson. It created Spare a Rose, Save a Child, a Valentine’s Day themed effort “that raises money and awareness for the International Disease Federation’s (IDF) Life for a Child program, which provides life-saving diabetes supplies to children in developing countries. The idea behind this effort is simple: people are encouraged to take the typical dozen roses, so popular on Valentine’s Day, and donate the value of one rose to spare the life of a child.” Since the beginning of the campaign, the effort has raised tens of thousands of dollars through small, community-based donations. One woman raised over a thousand dollars on her own by asking families to donate and thanking them with cookies.

**DIY COMMUNITIES**

There are niche-within-niche communities all over the DOC, and one hugely popular and impactful community is the do-it-yourself/hacker community. These groups are taking existing diabetes technologies and, through a dedicated investment of time, resources and an incredible amount of passion, have created ad hoc artificial pancreases and remote monitoring devices. All of these resources are open-source and available for use with all risk assumed by the user.

**Dana Lewis (OpenAPS):** You don’t have to be an engineer, or formally trained, to spot a problem with disease management or quality of life and build a solution that works for you. Who knows – the solution that works for you may also work for other people. We can design the very tools we need to make our lives with diabetes, and other diseases, so much better – and we shouldn’t wait to do so.
Difficult Discussions

YOU’RE JUST MY TYPE

With the diabetes community so broad now, you can actually find your niche community within the niche community. Looking for other pregnant people with diabetes? How about triathletes with diabetes? Or knitters with diabetes?

Chris Snider: That Venn diagram is becoming a bunch of polka dots.

The diabetes community, as it has evolved and changed over the last two decades, has constantly struggled with stigma. And sometimes the tension is within the diabetes community itself. According to the American Diabetes Association, there are 30.3 million people in the United States living with diabetes. Of that number, 1.25 million people have type 1 diabetes while the overwhelming majority have type 2 diabetes. But when you look at the DOC, the stories being shared are mostly from people with type 1 diabetes. What keeps people with type 2 diabetes from sharing their stories online with similar prevalence? Is it diabetes stigma? Shame and blame? The influence of age on someone’s comfort with digital mediums? A combination of these?

Bea Sparks (The Type 2 Experience): For someone with type 2 diabetes, it hasn’t changed much. At first, I felt we were like a token, called up to participate just to make up numbers, but most people weren’t able to see beyond the digit after the word diabetes, and we carry stigma no matter where we go. We’re still fighting to be heard, still struggling to find more voices, not really united, and for the most part keeping to ourselves. Part of it is our personal responsibility, but part of it is that we – I? – just got tired.

DIY COMMUNITIES (cont.)

Nightscout was developed by parents of children with type 1 diabetes and has continued to be developed, maintained and supported by volunteers. There are Nightscout solutions available for Dexcom G4, Dexcom Share with Android, Dexcom Share/G5 with iOS, and Medtronic. The goal of the project is to allow remote monitoring of glucose levels in people with type 1 diabetes using existing monitoring devices.

CGM in the Cloud is a closed Facebook group for those to share their experiences with open source solutions to send data from the Dexcom G4 to the cloud so that it can be accessed anywhere.

Loop is an app template for building an automated insulin delivery system. This site will walk you through the setup of a Rileylink, continuous glucose monitor, Loop application, and insulin pump to create a “closed loop” of basal insulin dosing.

OpenAPS is “is an open and transparent effort to make safe and effective basic Artificial Pancreas System (APS) technology widely available to more quickly improve and save as many lives as possible and reduce the burden of type 1 diabetes.”

#wearenotwaiting is a movement created by the diabetes DIY community and “is the rally cry of folks in the diabetes community who are taking matters into their own hands; they’re developing platforms and apps and cloud-based solutions, and reverse-engineering existing products when needed in order to help people with diabetes better utilize devices and health data for improved outcomes.”

Bea blogs at The Type 2 Experience, alongside several other writers with type 2 diabetes who aim to “boldly redefine type 2 diabetes.”
This dominance of type 1 voices has been problematic since the beginning, despite one of the first diabetes blogs on the web belonging to Kathleen Weaver, a woman with type 2 diabetes. There are several type 2-centric sites – The Type 2 Experience, Type 2 Musings, The Angry Type 2 Diabetic, Diabetes Ramblings and Sweet Success, to name a few – and there are other writers with type 2 diabetes who are raising their voices, sharing on multiple platforms. And the diabetes community as a whole is better for their contributions, because for many years the type 2 voice was missing. With more vocal representation from the type 2 community, the tides of the diabetes community rise in a positive way.

**Chris Snider:** As I consider the various approaches to diabetes advocacy and general patient empowerment, maybe I need to spend some time helping my fellow people with diabetes instead of trying to recruit outsiders. While it’s a small sample, the content of My Diabetes Secret suggests there’s a lot of education that needs to occur within the diabetes community before the outside can take us seriously.

**Sparling:** My lack of perspective used to be rooted in straight up ignorance. Diagnosed with type 1 diabetes as a child, I actively sought to separate myself from my type 2 peers because I didn’t want people thinking ‘I did this to myself.’ And I have to put that statement in quotes because it’s such a crummy one, now that I know so much more about the differences and similarities between all types of diabetes. It’s difficult to talk about how I felt when people lumped type 1 and type 2 together. I’m embarrassed to admit these things. I wish I had been more supportive of my type 2 peers. I wish I had known how they felt.

**ADVOCACY AND ACCESS**

There are several organizations that boost the access and advocacy signal in the DOC. The established non-profit organizations of the American Diabetes Association (ADA) and the JDRF have individual advocacy channels.

The ADA cites supporting government funding for diabetes research and programs, ensuring access to health care, promoting the prevention of type 2 diabetes, combatting discrimination, and much more,” and its “Take Action” hub provides steps that advocates can take to make a difference locally and nationally.

The JDRF Advocates program outlines its policy agenda year to year and highlights opportunities for advocates to take action on the policy stage, through insurance companies, as well as through grassroots channels.

The Diabetes Patient Advocacy Coalition wanted to address the unmet need of policy advocacy through a community lens. CEO Christel Aprigliano said, “DPAC was created to educate our community and the general public about diabetes policy issues and then give them actionable advocacy tools for them to use. We are the only diabetes organization that focuses solely on policy advocacy and the only 501(c)(4) nonpartisan organization, which allows us to directly lobby policymakers. We work with all organizations that align with us for patients’ safety, quality and access to medications, devices and services.”

---

29 MyDiabetesSecret is a website where people with diabetes can submit content and concerns about diabetes anonymously.

30 Quote from sixuntilme.com post on efforts to bring more type 2 stories into the conversation.
DIVERSITY IN THE DOC

In addition to a lack of diversity in types of diabetes represented online, there is also a lack of diversity in age, race and socioeconomic status. While there aren’t any definitive studies that quantify the demographics of the DOC, there are surveys and key opinion leader voices that illustrate a lack of representation of people of color.

Ariel (justalittlesuga.com): When I look at those bold advocates who shamelessly share their stories, I know they are not to blame for the absence of voices of color within the online diabetes space. Rather, a combination of lived experiences coupled with systemic and structural barriers, like social, economic, cultural and environmental ones—help explain the absence of black voices on the web.

Technological and health illiteracy, lack of internet access, and a failure to view social networks as more than a tool for surface-level chatter can also explain the absence of black and brown people sharing their stories of living well with chronic disease and diabetes on social platforms.

Corinna Cornejo (Type 2 Musings): The DOC has grown, but not diversified. There are plenty of people affected by diabetes who don’t seem to show up in the DOC. That’s the unrealized potential of the DOC.

Chelcie Rice (comedian): Good news is the numbers are growing with opportunities to spread the word to more groups that aren’t represented. But the bad news is the flipside of the good news. With more diversity comes a more polarizing environment. Which I believe is caused by the current political and social climate of this country or the world for that matter. When members of a less represented group speak out they’re often times met with complacency or the old “I never thought it was a problem” tune.

In response to a push for more people of color in the DOC, Cherise Shockley (creator of #DSMA) formed the @WOCDiabetes (Woman of Color Living with Diabetes) Instagram account, “A visual collection of stories of Women of Color living with Diabetes (#WOCDiabetes) from around the world.” A @MOCDiabetes account (Men of Color Living with Diabetes) soon followed.

Chris Snider: Social media will continue to be fragmented, but it will continue to be useful. People find their lane, and the timeline to ‘finding their tribe’ will happen faster; they’ll gel with their tribe even sooner.

ADVOCACY AND ACCESS (cont.)

The National Diabetes Volunteer Leadership Council is ‘committed to improving the safety and quality of life for all children, adults and their families who are living with diabetes.” This group, composed of people who have previously served in a leadership position of a national voluntary diabetes-related health organization, serves the diabetes community on a local, state and national level. It has worked to address Medicare Part D, CGM coverage, insulin pump coverage by Medicare, access to insulin, and other policy initiatives important to people with diabetes.

Through advocacy channels and a community uprising, the DOC is working daily to ensure that people with diabetes have access to the medications and resources they need to survive and thrive.

31 Quote from Just a Little Suga.
32 Chelcie Rice is a comedian living with type 1 diabetes.
The Future of the DOC

The future of the DOC is always under review, but therein lies its power – the community and online platforms it lives on are constantly shifting to meet the needs of the people involved.

**Johnson:** It’s hard to know where the DOC will be in the future. And I love that. Five years is an eternity in the fast-moving world of social media, and the needs of the diabetes community change rapidly. Additionally, one of the great powers of the DOC is that it collectively creates whatever it needs at the time. Whether that is a group of blogs, a powerful Tweetchat, a bunch of creative YouTubers, people on Instagram, or some new undiscovered channel or technology.

**Tenderich:** The wave of patient stories and sharing and tech that allows us to have this collective voice is what is so exciting about social media and technology. We’re finding amazing ways to advocate and lobby, to share experiences. That’s going to continue to grow and it’s going to make it impossible for the medical establishment to ignore us. That’s what’s so powerful.

**Sarah Lucas (Beyond Type 1):** I hope what we see is more consolidation and collaboration. Part of why type 1 is further behind as a disease is because there’s a lot of fractured conversations that we could unify. We’re charging forward, trying to accomplish this idea of match-making. If organizations come together and work together, can we be more powerful? If we can do that and people can put egos aside and start to really have some meaningful conversations, I think we’ll be stronger and better in 5 years, and able to capture more attention.

**Sparling:** The future of the diabetes online community will hopefully include more voices and different contexts for diabetes to exist in. Storytellers who engaged in this space decades ago will embrace and support new voices and perspectives. Many of the stories we will hear may not end up as part of a study, or presented at medical meetings or written up in peer-reviewed journals. Instead, they will become mainstream; it will be normal and comfortingly common to find diabetes stories online.

The Internet, for all its change and shift, remains a place where people living with diabetes can come together with their diabetes troubles and triumphs and find community, solace and someone who will give them the “me, too” moment they seek. The Internet is not a replacement for medical advice, but instead a forum to help integrate medical advice within the context of “real life” by connected peers. This peer-to-peer support can be as much a positive influence on health as meetings with medical teams.

And online patient communities of all kinds will continue to support patients and empower them to take control of their health. These anecdotes will become part of the eventual, concrete, “of course it is” proof that peer-to-peer support can contribute to an improved emotional state and improved health outcomes, giving people with diabetes hope that there is a healthy, fulfilling life to be found after diagnosis.
### Links

#### Check out these diabetes blogs:
- Six Until Me
- Scotts Diabetes Blog
- Diabetes Stories
- Our Diabetic Life
- Bittersweet Diabetes
- Diabetogenic
- Diabetosaliciousness
- Just a Little Suga
- JDRF blog
- Happy Medium
- Diabetech
- Diagnosed, Not Defeated
- Type 2 Musings
- Sweet Success

#### Visit these community/news sites:
- diaTribe
- A Sweet Life
- Children With Diabetes
- Diabetes Mine
- Diabetes Daily
- Insulin Nation
- TI Everyday Magic
- Diabetic Living
- David Mendosa
- ConneCtID
- Diabetes Sisters
- Connected in Motion
- Project Blue November
- Riding On Insulin
- Diabulimia Hotline
- College Diabetes Network

#### Listen to these diabetes podcasts:
- Just Talking
- Discovery Diabetes
- Diabetes Connections with Stacey Simms
- Diabetes Daily Grind
- Diabetes by the Numbers
- Beta Cell
- Diabetics Doing Things

#### Advocacy and outreach sites:
- T1D Exchange
- JDRF
- American Diabetes Association
- Beyond Type 1
- Diabetes Patient Advocacy Coalition
- T1International
- iDOCr
- American Association of Diabetes Educators
- The National Diabetes Volunteer Leadership Council
- Life For a Child
- Students with Diabetes
- Sugar Surfing
- We Are Diabetes

#### Technology:
- Tidepool
- Loop Docs
- OpenAPS
- Nightscout
- #wearenotwaiting