

# DiabetesSistersVoices: Creating a Patient-Centered Agenda to Enhance Research and Improve Outcomes



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## OVERVIEW

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Engaging women living with diabetes is crucial to inform and improve patient-centered research, advocacy and healthcare delivery. Women with diabetes are an important, high-risk population with unique health concerns across the life course- reproductive health to pregnancy to menopause, elder years and beyond.

DiabetesSisters, a national non-profit organization representing women with all types of diabetes, partnered with a diverse Stakeholder Advisory Board, clinical researchers from the Johns Hopkins University and the University of North Carolina at Chapel Hill, and TrustNetMD, an established innovative team of website developers, to develop, refine, and launch DiabetesSistersVoices. DiabetesSistersVoices is an on-line national community for women with diabetes to engage with one another and share their perspectives on how to improve their care through patient-centered research and health services delivery.

In this report, we:

- Describe the process for developing the online community with feedback from our Stakeholder Advisory Board
- Summarize our methods for engaging women with diabetes to join the website and research study
- Characterize the use and the users of DiabetesSistersVoices online community during the pilot study phase over 6 months
- Highlight priority topics for research and advocacy that were frequently discussed on the site by study participants.

# BACKGROUND

## *Women with diabetes have unique health concerns*

Diabetes is common in women and its prevalence is increasing along with the obesity epidemic (1). Despite the high prevalence of diabetes in women, there is limited evidence about what women identify as their highest priority research and healthcare needs.

Type 1 and 2 diabetes are associated with multiple complications including cardiovascular disease, nephropathy (kidney disease and failure), peripheral neuropathy (pain and numbness in hands and feet), and retinopathy (eye disease and blindness) (2). Women are disproportionately affected by diabetes, with greater risk of heart attack and stroke compared with men with diabetes (3-6). Little research has addressed the reasons for these sex differences, including disparities in access to care and diagnostic testing, and differential benefits or receipt of preventive treatments (e.g. statins to prevent stroke and heart attack) (7). Compared to women without diabetes, women with diabetes have unique health concerns across their life course, including preconception health, pregnancy and postpartum care, and the transition into menopause. Women with diabetes experience higher rates of eating disorders, pregnancy complications and adverse outcomes, and sexual dysfunction (8-10). Additionally, women with a history of gestational diabetes mellitus are at high risk for developing type 2 diabetes following their pregnancies (11).

## *Engaging patients is critical for patient-centered research*

Engaging patients about what is most important to them is crucial to direct researchers, consumer organizations, policy-makers, health systems leaders, and funders toward clinical research and health system improvements that are patient-centered and meaningful (12). There is an urgent need to request and elicit feedback from patients in a manner that will optimize time and resources and enhance partnerships. Technology involving patients, doctors, and other healthcare providers "crowdsourcing" their thinking about topics of interest, research, and healthcare priorities is currently available using Web 2.0 technology. There is a need for patient-centered advocacy organizations to use web-based tools to engage their stakeholders in the research process.

## *DiabetesSistersVoices: An online community for women to share research and healthcare priorities*

This report is a product of strong partnerships between women's health and diabetes researchers, DiabetesSisters, TrustNetMD, and the Stakeholder Advisory Board members to share a common vision for providing a voice for women with diabetes to inform future research and healthcare priorities.

Through these partnerships, our team created an interactive, engaging website for women with diabetes to provide perspective on what is important for research and healthcare to improve their health and social and emotional well-being.

This online community is called **DiabetesSistersVoices**. In this report we first describe the process for developing the online community with feedback from our Stakeholder Advisory Board. We then summarize and provide results for the six month pilot study, including our methods for engaging women with diabetes to join the website and research study, characterizing the website users and their online website usage and engagement over 6 months and finally, sharing the high priority topics that the online community identified as important for research and advocacy.

# METHODS

## *The Stakeholder Advisory Board Composition*

A cornerstone of the development and launch of DiabetesSistersVoices was the input and constructive feedback from the members of our stakeholder advisory board. We believe the diverse experiences, perspectives and incredible knowledge range of our stakeholder advisory board members reflects the study's commitment to meaningful, authentic stakeholder input in the planning and conduct of the DiabetesSistersVoices project. As shown in **Table 1**, members of our board represent 5 stakeholder groups including patient partners, a national diabetes advocacy organization, national women's health and general patient advocacy groups, and nursing and community-based researchers in racial minority communities.

**Table 1. DiabetesSistersVoices Stakeholder\* Advisory Board**

Patient partner, advocacy	Anna Norton (Lead)	Lead for the Stakeholder Advisory Board (SAB) Patient living with Diabetes and CEO of DiabetesSisters
Health educator, social worker (Alias: the Coach's Coach)	Angela F. Ford, PhD, MSW	Health Program Manager, Black Women's Health Imperative (BHWI), <a href="http://www.bwhi.org">www.bwhi.org</a>
Nurse, community researcher, advocacy	Adelita Cantu, PhD, RN	National Association of Hispanic Nurses, Associate Professor, Nursing, University of Texas Health Sciences Center-San Antonio
Advocacy, organizational leadership	Marcy Fitz-Randolph, DO, MPH	Manager, Research Operations, PatientsLikeMe, <a href="http://patientslikeme.org">patientslikeme.org</a>
Advocacy, research	Aimee Gallagher, MPH, MS	Former Scientific Programs Manager, Society for Women's Health Research
Patient partner	Karen Graffeo	Patient living with diabetes, Member, DiabetesSisters, DSVoices on-line moderator
Patient partner	Alejandra Marquez	Patient living with diabetes, Member, DiabetesSisters
Patient partner	Evelyn Savido	Patient living with diabetes, Member, DiabetesSisters

\*Stakeholder groups are based on categories developed as part of the PCORI Engagement Rubric.

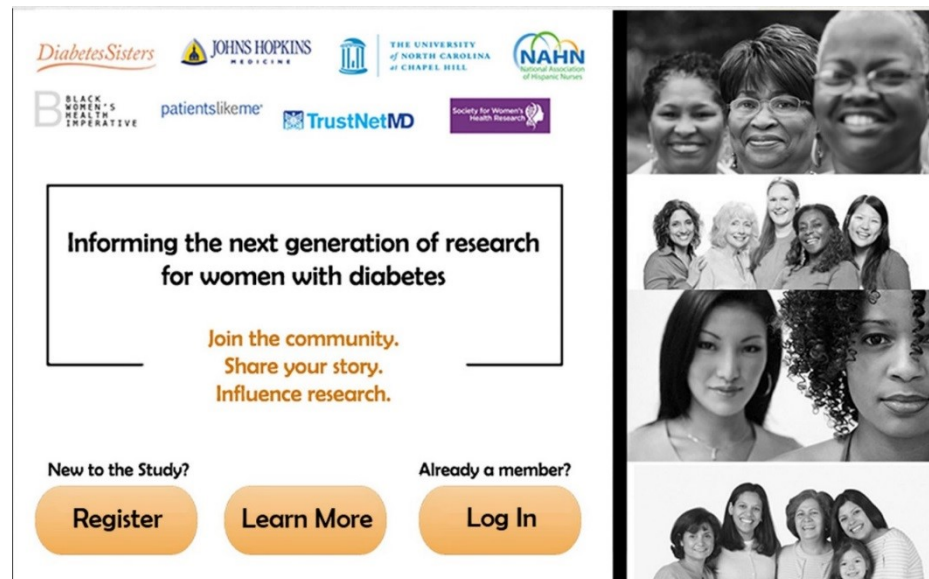


## *Role and engagement of stakeholder advisory board members*

Stakeholder Advisory Board members were engaged in all aspects of the research study, including 1) creation of the on-line community and development of participant strategies; 2) recruitment and enrollment of participants to the on-line community and 3) dissemination of research results. After the initial design of DiabetesSistersVoices by the web developers (TrustNetMD), we sent the stakeholder advisory board members links to the website to explore the usability and functionality of the site. We then conducted an initial video-conference call for the entire group of stakeholder advisory board members followed by one-to-one video conference calls to engage in an in-depth fashion with each individual member and get their feedback to improve the site. These calls were attended by members of the research team and the web developers. The series of calls were crucial to the development and refinement of the on-line community.

## *Development of DiabetesSistersVoices through in depth interviews with stakeholder advisory board members*

Our goal was to introduce an online experience that would allow women with any type of diabetes to traverse the website in a seamless fashion to ask questions, talk about their experiences, or join an ongoing discussion. We conducted 'hands-on' semi-structured interviews with



each board member who were led primarily by a trained interviewer (Akimi Smith-now a first year public health student at Emory University) and a member of the research team. Interviews lasted approximately 60 minutes. General questions were posed to elicit feedback from the board members and included the following: i) how easy was it to follow the layout of the web-based program, including font size, formatting, and ease of transition between screens; ii) functionality of the program; and iii) clarity and completeness of enrollment instructions and guidance on how to provide comments on the site.

## *Development of participant engagement and re-engagement strategies for the DiabetesSistersVoices online community*

Stakeholder advisory board members were also engaged in the development of strategies to engage and re-engage online participants. They provided comments and feedback on all recruitment materials. With feedback from the stakeholder advisory board members, we created an “Engagement Toolkit” which contained Facebook posts and Twitter tweets that we had developed and which were IRB approved for recruitment into the pilot study.

Recruitment materials included the following:

- Social media promotion through Facebook and Twitter and monthly e-newsletters from DiabetesSisters Facebook posts were boosted to showcase the posts to more users, centralizing it to female users in the United States with interests in diabetes-relevant topics.
- Printed brochures, posters, and postcards were distributed for in-person recruitment. These materials were shared with churches, health clinics, and conferences, such as World Diabetes Day and the American Diabetes Association Expo in New York City.
- A toolkit which included a partnership invitation, a description of DiabetesSistersVoices, a description of collaborative organizations’ mission and vision and funding sources, and promotional materials including flyers and postcards. Examples are below in Figure 1.

**Figure 1: Examples of Social Media and Recruitment Materials Used**





The stakeholder advisory board members and research team developed and employed a wide range of recruitment/engagement strategies and activities in a committed effort to attract women to the site across age, racial, and socioeconomic strata. **Table 2** lists selected engagement activities by members of our stakeholder advisory board and research team aimed at advertising the study to many women with diabetes and engaging them to join the community.

<b>Table 2. Select Engagement Activities</b>		
<b>Stakeholder Groups</b>	<b>Engagement type</b>	<b>Description</b>
<b>DiabetesSisters Leadership and Constituents</b>		
Evelyn Savido		Patient living with Diabetes & Member, DiabetesSisters
Alejandra Marquez		Patient living with Diabetes & Member, DiabetesSisters
Karen Graffeo	Social Media, In-Person	DiabetesSistersVoices online forum moderator and manager of DiabetesSistersVoices Twitter account
Anna Norton	Social Media, In-Person, Guest posts	Lead promoter for DiabetesSistersVoices in various events and community engagements
<b>National patient and advocacy groups</b>		
DiabetesSisters	Twitter, Facebook, Weekly Digest, Magazine Interviews, Journal articles, Guest Posts, Podcasts	DiabetesSisters is the main community partner for the DSV project and engaged in a variety of social media strategies to recruit and retain women in the study.
<b>PatientsLikeMe</b>		Website where people can share their health data to track their progress, help others, and change medicine for good.
<b>Black Women's Health Imperative(BWHI)</b> and affiliated organizations (Black Women for Wellness; Collins Wellness Center, Fundamental Health Solutions, Indiana Minority Health Coalition, Urban Health Resource)	Webinar	A one-hour online webinar was provided for the BWHI National Diabetes Prevention Program partners to encourage participation and buy-in to the study from each organization's participants.

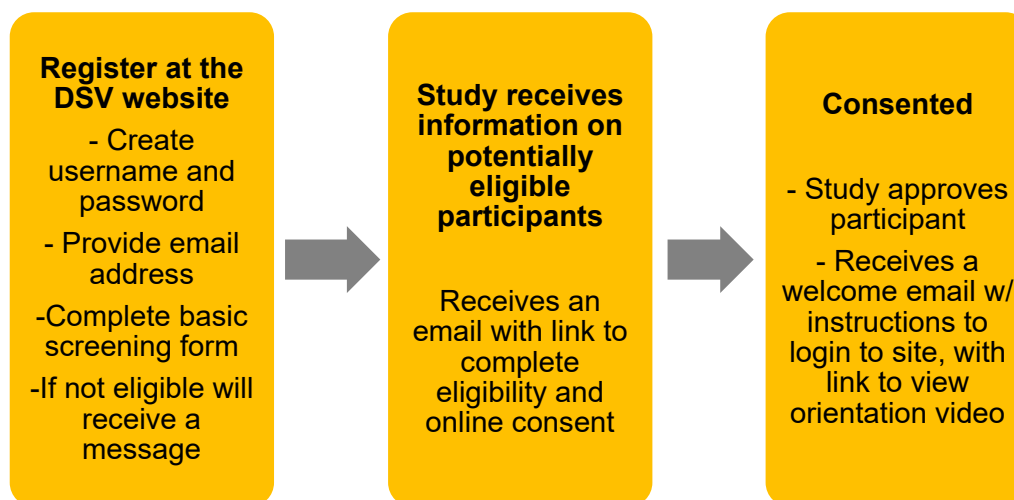
<b>Table 2 continued. Select Engagement Activities</b>		
<b>Physician groups</b>		
UNC Diabetes Center – John Buse, Sue Kirkman, Laura Young	Email, flyer and brochure distribution	UNC investigators met with UNC Diabetes Center leadership and developed a partnership to promote the DSV study within the Diabetes Center patient population through flyers, social media, and brochures.
UNC Family Medicine – Katrina Donahue	Email	Email sent to Katrina Donahue, who is a UNC family medicine doctor serving women with diabetes in her everyday practice
John Hopkins Diabetes Center	Flyer	
John Hopkins Clinic	Flyers posted in clinic	JHU investigators posted flyers and met with staff, including dieticians, to discuss the study
Baltimore Podiatry Clinics serving people with diabetes	Flyers in waiting rooms	JHU investigators provided flyers at registration desks and in waiting rooms
<b>Patient Registries and communities</b>		
Penn State PRO Wellness and Next-D patient partners	Listserv Email and patient partner webinar	JHU investigators presented the project to patient partners at the Penn State Next-D study, and they advertised the study through their newsletters
UNC Diabetes Center	Listserv Email	The Diabetes Center sent an email promoting the DSV study to over 1,000 eligible women within its listserv.
<b>Community and state advisory groups</b>		
Diabetes Advisory Council, North Carolina Chapter– Ronny Bell	Email	Email sent for potential partnership. The council works to reduce the burden of diabetes through coordination among the many stakeholders in diabetes control in North Carolina.
<b>Community Organizations</b>		
North Carolina Churches Bulletin	Posted Advertisement	Ten churches in the North Carolina area with a history of promoting UNC health initiatives and minority health were contacted to promote the DSV study
Maryland Chapter of the American Diabetes Association – Research Conference for Patients	Invited small group leader	JHU investigators shared research and findings with patients at a local conference.
Baltimore African American Churches involved with diabetes-related research and projects	Posted Advertisement	Local churches posted flyers and included brochures in Sunday service schedule.
<b>Institutional events</b>		
Johns Hopkins World Diabetes Day	Provided educational and study materials at a Table.	JHU investigators were invited to share information about the study
American Diabetes Association- San Diego Conference -	Moderated Poster Session by Anna Norton and Wanda Nicholson	DiabetesSistersVoices was granted a moderated poster session presentation, and members of the team presented findings to conference attendees in a 10-minute talk.

DiabetesSisters posted on Facebook about the study and each month they “boosted” the post to increase the number of women who saw each post.

<b>Table 3. Facebook Boost Summary</b>		
<b>Boost Date</b>	<b>Target</b>	<b>Boost Statistics</b>
12/15 /2016	women, ages 18 - 65+	4,046 people reached, 148 reactions, comments and shares
01/09/2017	women, ages 18 - 65+	4,541 people reached, 201 reactions, comments, and shares
02/22/2017	women, ages 18 - 65+	6,272 people reached, 189 reactions, comments, and shares
03/28/2017	Women, aged 50-65+	5,127 reached 229 reactions, comments and shares
05/04/2017	40+, US, prediabetes, African American, insulin resistance, type 2 diabetes, diabetes awareness, diabetes management, Hispanic (any of applied)	1,177 People Reached; 44 reactions, comments, and shares
06/06/2017	18-65+, type 1 diabetes support groups, type 2 diabetes awareness, Diabetes awareness, Managing Diabetes or Diabetes Health	3,115 reached, 192 reactions, comments, and shares

### *Recruitment for the Pilot Study, Eligibility and Enrollment*

We used a wide variety of advertising and recruitment strategies as described above, including Twitter posts, Facebook posts and boosts, printed materials and advertising to patients via newsletters.



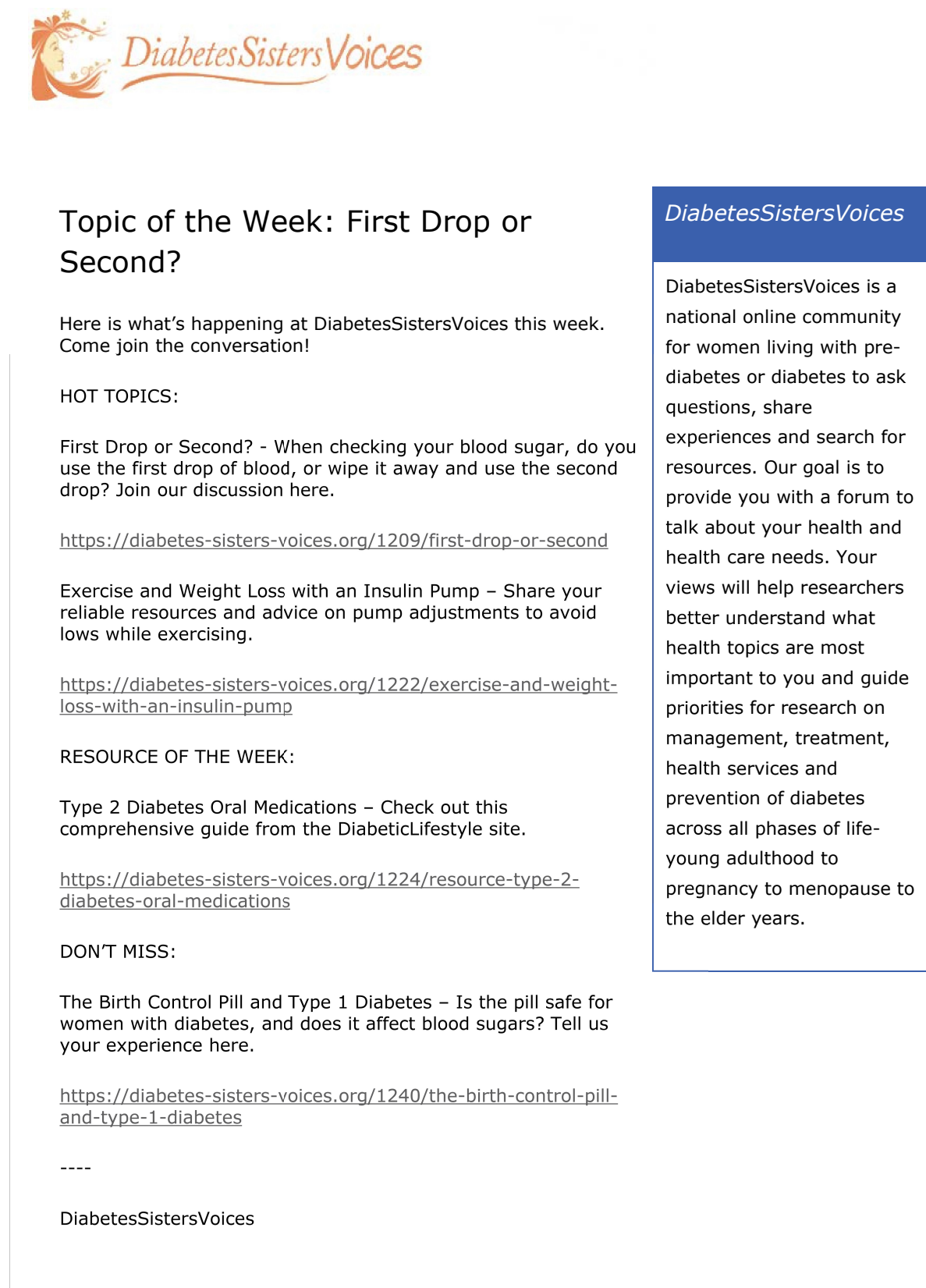
**Figure 2. Screening and Enrollment Process**

**Figure 2** shows the registration and enrollment process. Interested participants were able to register at the DiabetesSistersVoices website by providing their name and e-mail address and basic screening questions. Once registered, we e-mailed them a link to an online survey that assessed further eligibility. Inclusion criteria were all of the following: Female sex; Age 18 or older; Type 1, 2, prediabetes/at risk for diabetes, or GDM history; Currently residing in the US. Once deemed eligible, participants completed an online consent process, which involved reviewing and saving the pdf of a Consent Form, and answering affirmatively to consent awareness questions to acknowledge that she knows that this is a research study, that her participation is voluntary and that she knows how to contact a study staff member with any questions.

### *Website engagement and moderation*

DiabetesSistersVoices had a trained site moderator who worked closely with the project team on stimulating conversations and engaging users. The moderator posted on the “Wall” of new users to welcome them to the site and invited them to introduce themselves. She also created weekly newsletters that highlighted topics of the week (Figure 3).

**Figure 3. April newsletter with topics of the week**





## *Data collection*

### **Development and Administration of Online Surveys**

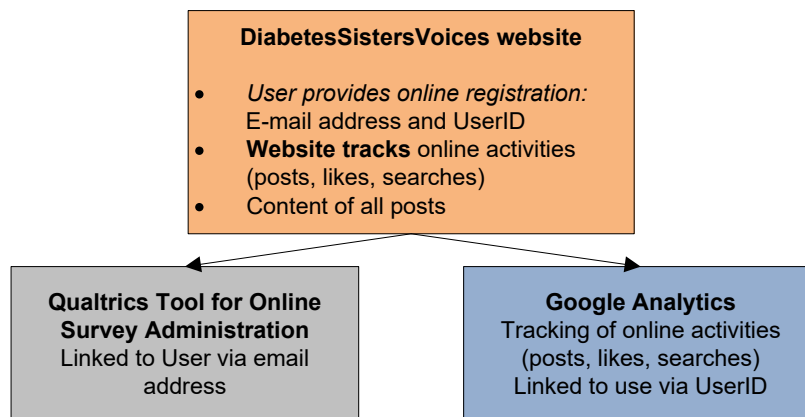
Online surveys were administered when women joined the study and at the end of the study. Surveys contained questions about sociodemographic characteristics, health status, internet use, and health-related quality of life. Demographics questions were adapted from standard measures including the Centers for Disease Control Behavioral Risk Factor Surveillance System (BRFSS) and the Pew Study of Internet and American Life (13, 14). MOS Social Support Survey Instrument will assess emotional and informational social support (15). We used the PROMIS scale v1.2 Global Health survey instrument to assess users self-reported health status (16). We used Qualtrics to administer all online surveys.

### **Google Analytics and Website Post File**

We used Google Analytics, a web analytics service, to track and report DiabetesSistersVoices website traffic. All users' online activities, such as the time of individual sessions, download, page views, tag clicks, and likes were captured by this application. We also used website log files as supplements for the Google Analytics report so online activities would be captured if they existed in either. We used the website post file for documenting each user's post and associated tags.

### **Data Linkages**

**Figure 4: Data Structure and Linkages**



We created a unique user identification number for each participant, which was assigned by Google Analytics at the time of registration. Participants' full name,

user name, user ID, and email address were captured by website user file, which serve as the data linkage (Figure 4):

### **Definition of online engagement levels**

Using website usage data, we created three categories to measure the level of engagement on the website:

1. “Never Users” - Women who registered for site but never logged-in
2. “Observers” - Women who logged into the site at least once but did not post
3. “Active Users” - Women who posted in on the site at least once

## *Data Analysis*

### **Description of Participants Enrolled in the 6 month pilot study**

We described characteristics of participant enrollment overall and within specific time periods. Participants socio-demographics were retrieved from Qualtrics baseline survey, including age, education level (less than high school or GED, HS or some college, college degree and above), race (Caucasian and non-Caucasian), diabetes diagnosis (type 1 and type 2), frequency of email use (daily, every few days, less than weekly), and use of social networking site (ever, never). We counted the cumulative number of participants over time and by race, diabetes type.

We described enrollment and engagement with the website. All online activities (post, like, tag click and search) were retrieved from Google Analytics and website log files. To see the trend of online engagement activities, we calculated the accumulative proportion of participants who engaged in each of the activities at least once bi-weekly.

We described these characteristics and engagement outcomes by three categories of engagement level on the website: never users, observers, and active users (see above for discussions). We described these statistics by mean and variance (for continuous variables) or by number and proportion (for categorical variables).

### **Content Analysis of Online Discussion Topics**

We used an active iterative approach to developing and creating “topic” categories. The site was “seeded” with the initial categories including “type 1 diabetes,” “diet food nutrition” and “gestational.” Study participants were able to create their own topic labels and the study moderator combined and created new topics depending on the content of the conversation. For example, the topic, “emotional wellness”, was created when a participant was also describing struggling with “feeling burned out.”

We identified the most frequently used topics and assigned frequency counts for them based on the number of times the topic was assigned to a new post. We identified representative quotations that the team and the Stakeholder Advisory Board members agreed upon.

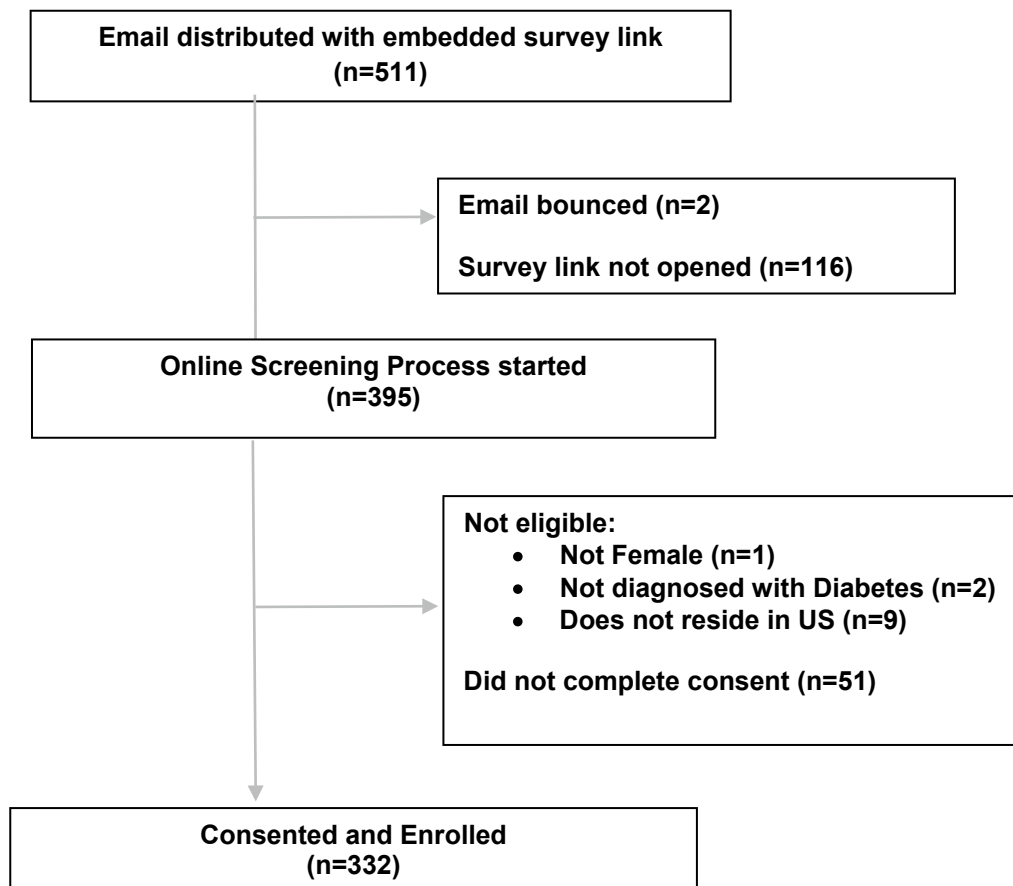
The next step of this project is to conduct an in-depth qualitative analysis to identify themes and quotations that elucidate common topics shared on the site.

# RESULTS

## DiabetesSisterVoices' Enrollment

**Figure 5** shows the enrollment process for participants to engage in the study. Women interested in the project registered on the DiabetesSistersVoices website with an e-mail address. From these registrations, 511 confirmation emails were sent with an embedded survey link. 395 women began the process of screening process using the survey link to determine whether they were eligible for the project. Among these, 332 (84%) completed the consent form and enrolled in the study.

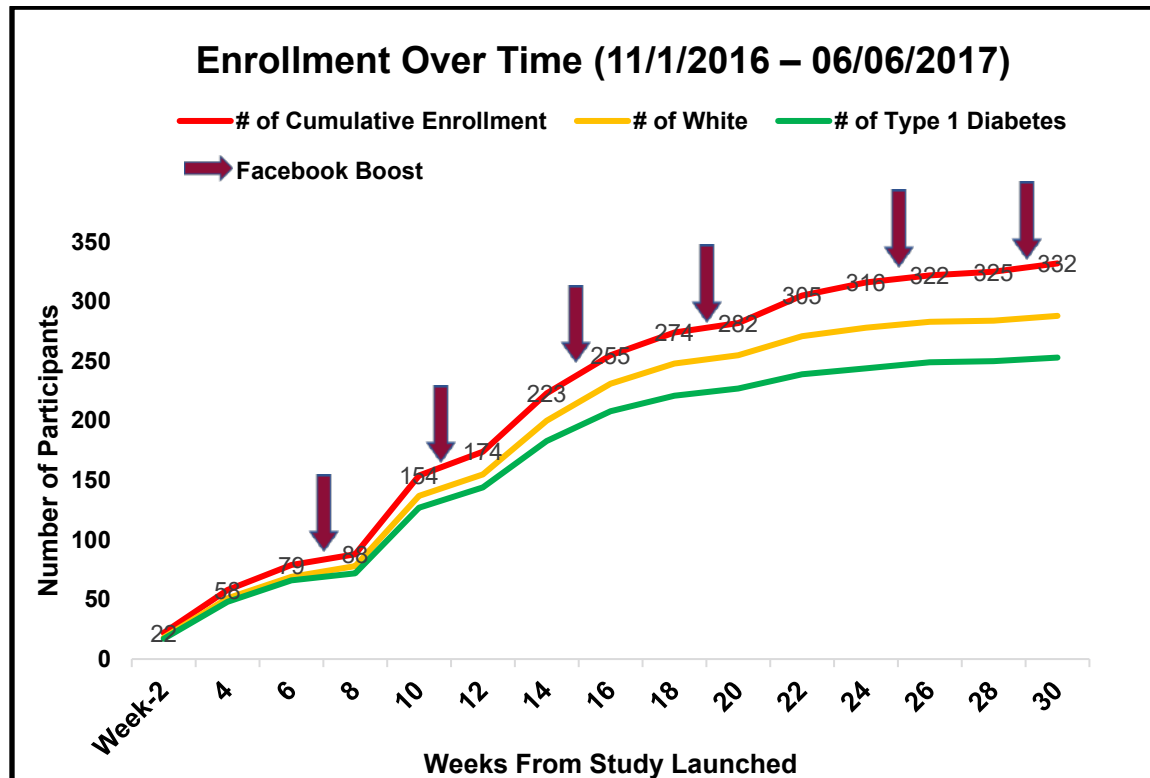
**Figure 5: Enrollment Flow into the Study**



## *Enrollment into the DiabetesSistersVoices study over time*

**Figure 6** demonstrates the total number of participants who joined the study over 6 months (30 weeks) by week. The figure shows cumulative enrollment over time, as well as showing the number of Caucasian and women with type 1 diabetes who joined the study over time. Initially, all participants were Caucasian and had a diagnosis of type 1 diabetes; however, over time and expansion of engagement methods, the diversity of study participants increased. The study was boosted on Facebook multiple times, targeting female users in the United States with interests in diabetes-related topics. Boosts drew the greatest increase in registration.

**Figure 6: Enrollment Over time – Overall, by Race, and Type of Diabetes**





## Participant characteristics and online activities

**Table 4. Characteristics of Study Participants**

Mean (standard deviation) or n (%)	All users (n=332)	Never users (n=74)	Observers (n=120)	Active users (n=138)
Age	49 (13.8)	46 (14.1)	48 (13.8)	51 (13.4)
Education				
Less than high school or GED	4 (1.2)	2 (2.7)	0 (0)	2 (1.5)
HS or some college	100 (30.4)	29 (39.2)	31 (26.1)	40 (29.4)
College degree and above	225 (68.4)	43 (58.1)	88 (74.0)	94 (69.1)
Race/ethnicity				
Caucasian	287 (86.5)	61 (82.4)	104 (86.7)	122 (88.4)
Black	21 (6.3)	8 (10.8)	7 (5.8)	6 (4.4)
Asian	3 (0.9)	2 (2.7)	0	1 (0.7)
Hispanic	11 (3.3)	2 (2.7)	5 (4.1)	4 (2.9)
Diabetes Type				
Type 1	253 (76.2)	53 (71.6)	90 (75.0)	110 (79.7)
Type 2	73 (22.0)	20 (27.0)	26 (21.7)	27 (19.6)
Email use				
Daily	297 (90.0)	60 (82.2)	111 (93.3)	126 (91.3)
Every few days	30 (9.1)	11 (15.1)	8 (6.7)	11 (8.0)
Less than weekly	3 (0.9)	2 (2.7)	0 (0.0)	1 (0.7)
Ever use social networking site	295 (89.9)	61 (84.7)	110 (93.2)	124 (90.0)
Website engagement				
Number of session, median (IQR)	3 (1.0-5.5)	NA	2 (1.0-4.0)	5.5 (4.0-12.0)

GED=General Education Diploma; HS=high school; IQR=interquartile range

**Table 4** shows the sociodemographic characteristics of the participants in the study, overall, and by use of the website.

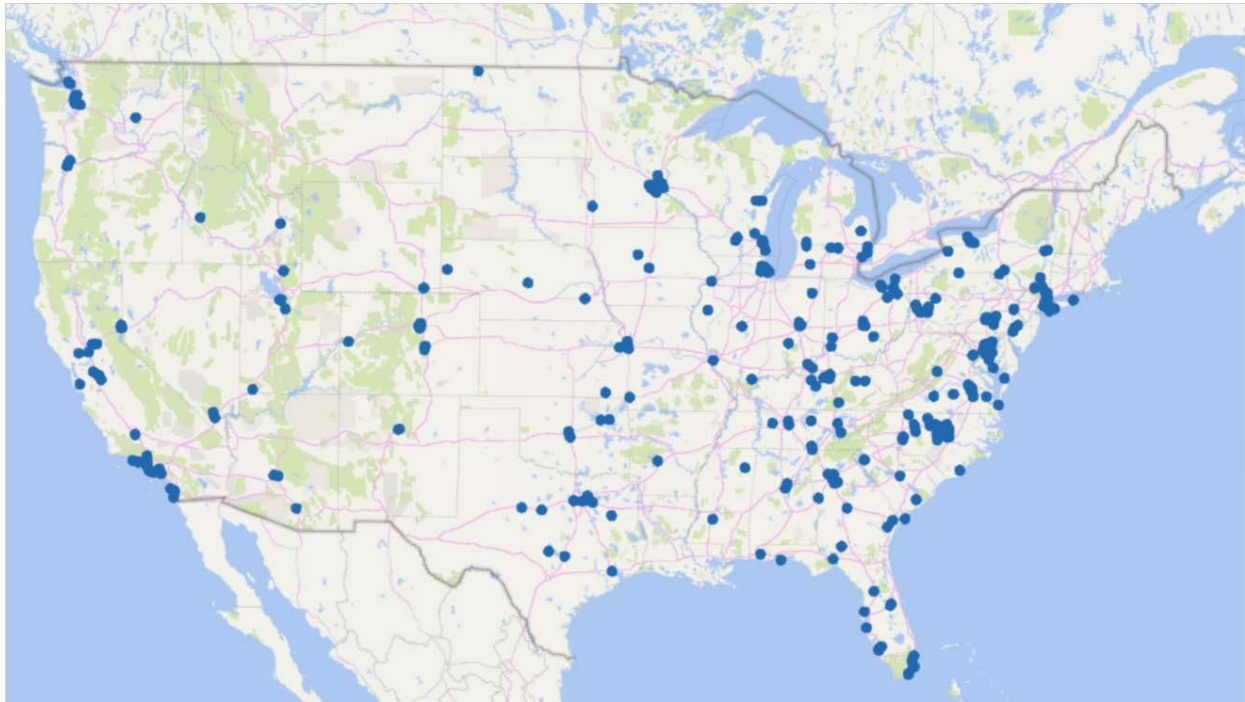
As described in the Methods, “Never Users” were defined as women who registered for site but who never logged in (n=74, 22%), “Observers” were defined as women who logged into the site at least once but did not post (n=120, 36%), and “Active Users” were defined as women who posted on the site at least once (n=138, 42%).

The racial makeup of women on the site was primarily Caucasian (87%). The mean age was 49 years old and most women had a college degree or above (68%). The majority of website users had type 1 diabetes (76%). Most women used email at least once daily (90%) and used social networks such as Facebook (90%). Caucasian women were younger (mean age 48 (13.7)) compared to non-Caucasian women (mean age 51 (13.9)). 52% of the 44 non-Caucasian women had type 2 diabetes compared to 17% of the 287 Caucasian participants. Similar proportions of

Caucasian and minority women, and women with type 1 and type 2 diabetes were active users on the site.

### **Regional distribution of participants**

**Figure 7: The Geographic Distribution of Participants**

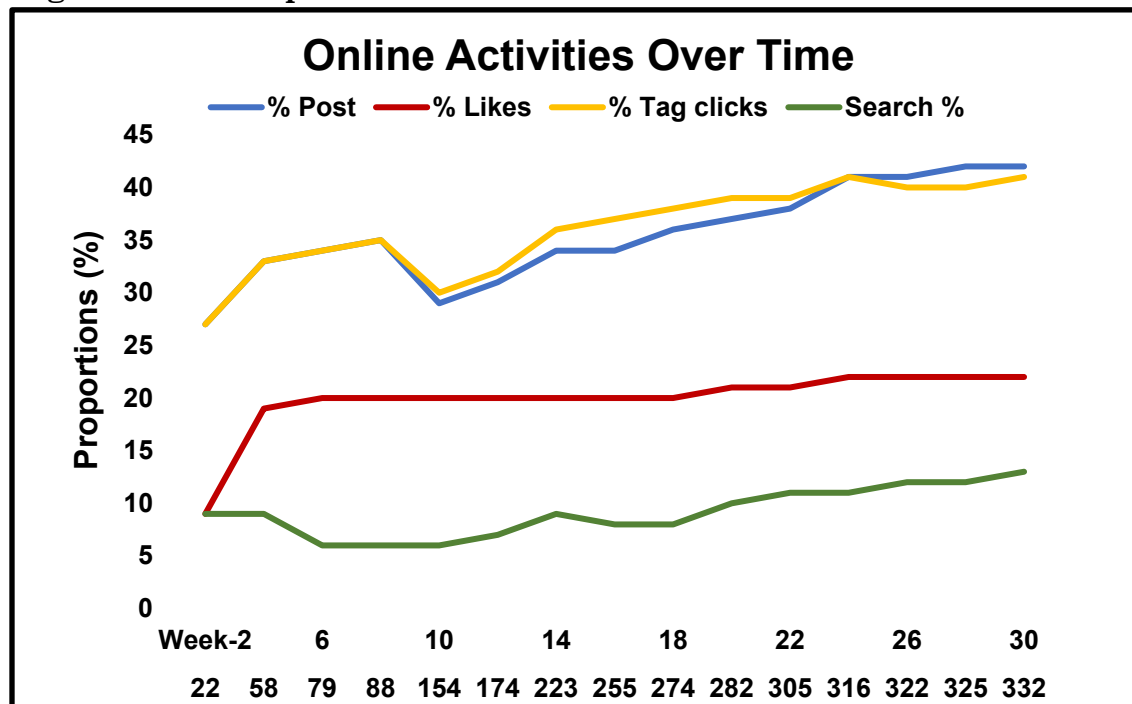


The majority of website users were from the Eastern part of the United States, with fewer in West or Midwest (Figure 7). This difference in geographical distribution may reflect, in part, the distribution of DiabetesSisters membership and also the fact that the two key institutions leading the study are located on the east coast.

## Online activities on DiabetesSistersVoices

Overall, study participants clicked topic tags 497 times, posted or replied on the site 872 times, voted for posts 540 times, searched for resources 167 times and downloaded resources 671 times. Figure 8 shows participants online activities over time. With increasing enrollment over time onto the website, engagement was constant with about 1/3 of all enrolled women posting or clicking a topic tag on the site each month. Fewer women “liked” posts on the site (~20%) or performed searches (<10%).

**Figure 8: Participants’ Online Activities Over Time**



## *High priority topics on the DiabetesSistersVoices community*

We identified 11 high priority categories of topics (identified as a “tag” under a Question-Discussion-Resource page) that were discussed on the DiabetesSistersVoices community. These overarching categories are listed in Table 5, along with the topics that were included within each category.

**Table 5: High priority categories and Topics discussed on the DiabetesSistersVoices online community**

Category	Topics
Emotional wellness	Emotional wellness, relationships and intimacy, diabetes burnout, stress, motivation
Psychosocial support and coping	Psychosocial support, support, community, connections, needing encouragement, stigma, blame, what not to say, popular websites, diabetes treatments and art, disability
Diabetes Complications and Co-morbid health conditions	Complications, diabetes and other conditions, heart disease, eating disorders, retinopathy, macular edema, type 1 and autoimmune disease, celiac, macular degeneration, neuropathy, breast cancer, lumpectomy, chemo
Food, diet and nutrition	Diet food nutrition, carbohydrates carbs, healthy living
Exercise and physical activity	Physical activity and exercise, type 1 and running, personal training, weight lifting
Weight / weight management	Weight, weight loss, body image, underweight, bariatric surgery
Diabetes in pregnancy / pregnancy planning	Pregnancy, gestational, type 1 pregnancy communication, diabetes and fertility treatments, pregnancy with multiples, birth control
Insulin and Insulin Delivery, including Pump	Insulin, insulin pump, devices, wearable location of pump, insulin resistance, closed loop system, Medtronic, travel
Glucose self-monitoring and CGM	Glucose monitoring, continuous glucose monitoring, hypoglycemia
Type 2 DM and other non-Type1 treatments	Treatment, oral medications, medications, treatments and side effects
Older women and diabetes	Aging, 62+, advanced duration diabetes, menopause

Table 8 displays the category, representative quotations identified from the online discussions, and implications for future research and advocacy to improve care for women with diabetes. We also showed the number of times discussed, either as part of a new post or a reply to a post. Below are the preliminary results showing the categories, frequency that they were discussed, quotations from the discussion and implications and research questions to guide future research. Next we will be conducting an in-depth qualitative analysis to identify themes.

Table 8. DiabetesSistersVoices Discussion and Implications for research			
Category	# times discussed	Representative Quotations from the DiabetesSistersVoices online community	Questions and Implications for next steps in research to improve health and care for women with diabetes
Emotional wellness	43	<p><i>"I have always hated hearing the hate term 'better diabetic' because I do not like being labeled as a 'diabetic'. It reminds me of my mother admonishing me 'You have to be a better diabetic or else ...'" – conniet1d</i></p> <p><i>"For the most part I count my T2 as a blessing. Even though I was a healthy eater, exercised regularly and was not overweight, my dx allowed me to tweak my diet i.e. eliminated carbs and sugars. In return, I feel better!" - donna</i></p>	<ul style="list-style-type: none"> <li>• Influence of language, terminology (e.g. being labeled a "diabetic") and diabetes stigma on emotions wellness of people with diabetes</li> <li>• How "positive outlook" and wellness impacts diabetes outcomes</li> </ul>
Psychosocial support and coping	55	<p><i>"Sometimes, I just need an outlet. A good rant helps me feel better" – jennhouchins</i></p> <p><i>"Some days I hate having to constantly think about what did I eat, how many carbs, can I exercise now. It feels like you can't just do something without having planned everything you do." - Pump1fun</i></p> <p><i>"I find a great support system in my immediate family and closest friends even though they don't entirely understand but I see that they truly try." - theartisticgypsy94</i></p>	<ul style="list-style-type: none"> <li>• What are effective coping strategies and support for people with diabetes that improves mental health outcomes?</li> <li>• Characterizing the emotional weight of daily diabetes tasks</li> <li>• What are the best methods of social support specifically for women with diabetes</li> </ul>



Diabetes Complications and Co-morbid health conditions	66	<p><i>"I got nearly monthly yeast infections for the first 20 years of my diabetes. It was frustrating, uncomfortable, embarrassing, and none of my friends had ever had one. Mine also seemed to happen when I was stressed from work or other things, high blood sugars, or having a sickness like a sinus infection." – Skoshi</i></p> <p><i>"I've had not one, but TWO frozen shoulders! I had never been told it was a fairly common diabetes complication until I was diagnosed with the first one. With the first one, I chose to treat it with physical therapy, OTC pain relievers, and patience. It got better very slowly, but after a couple of years was back to normal. With the second one, I did not want to go through all that again, so I chose surgery and physical therapy. Three years after the surgery, I still do not have full use/extension of that shoulder." – bayleafbroker</i></p> <p><i>"Having had T1D for over 40 years, I know complications can happen. In fact, I've had them. used to get very wrapped up in the what-ifs, but have worked to not live in fear. I can't go back and change anything from the past that may impact my future/ complications. Instead I focus on the day to day, and know if something does come up, my healthcare team will help me through it." - phyllisk</i></p>	<ul style="list-style-type: none"> <li>• What conditions (that aren't considered "complications") that women with diabetes have increased risk for – such as musculoskeletal issues.</li> <li>• Best strategies to educate women about risks without having constant fear of them</li> </ul>
Food, diet and nutrition	67	<p><i>"I use fresh oranges and grapefruit to treat lows. I like the real fruit much better than juice. Sometimes I also buy fresh cut-up pineapple in the produce section and that works well also." – Laddie</i></p> <p><i>"I have a digital scale that I use to weigh the portion size listed on nutrition label, helps with carb counting too." - SandeeK</i></p>	<ul style="list-style-type: none"> <li>• What are effective and also healthier options for treating hypoglycemia?</li> <li>• What are most effective methods for carb counting?</li> </ul>
Exercise and physical activity	20	<p><i>"I struggle with having to "feed" the lows that are a result of exercise. Is there a chart or graph or formula for adjusting insulin with a pump to manage exercise? I'm looking for some reliable resources" – Tanya</i></p> <p><i>"The power of any movement for glucose control is amazing. It does not matter what you do, just get more of any activity you can to lower blood sugars. Be prepared for lows with carbs ahead of time or a reduced basal rate or bolus for the meal prior to exercise." – hanavank</i></p>	<ul style="list-style-type: none"> <li>• What are strategies for managing blood sugar during exercise using an insulin pump?</li> </ul>

Exercise and physical activity, continued		<i>"Because of all the variables such as how much insulin is on board, the time it takes for your insulin to absorb, what your blood sugar is when you start, the status of your infusion site, how recently you have eaten, how much you ate, how strenuous the exercise, the length of time you exercise, whether it's that time of the month, and about a million other things, it is difficult to have an exact formula for how to adjust your pump." - janmosso</i>	
Weight / weight management	11	<p><i>"I work so hard at exercising and eating better, and the number on the scale does not move. Like ever. Last summer I started going to Camp Gladiator workouts - that has done AMAZING things for my blood sugars and I've lowered my A1C over a full point in the last 3+ months. I've lost inches. And I know the number on the scale shouldn't matter, but it does. I have a range I want to be back in, and I have not budged in almost 2 years. But I'm now taking 1/2 of my daily insulin that I was before and I'm eating so much better. But still not losing weight." – aggim0m</i></p> <p><i>"I am a 67 year old underweight type 2 female diabetic. I was diagnosed last year. I have seen the one recent article on this issue, but I am very interested if anyone else has anything to share on this matter." - jcorlette</i></p>	<ul style="list-style-type: none"> <li>• What are facilitators and barriers to weight loss with diabetes?</li> <li>• Reinforce other ways of measuring success of positive lifestyle changes (beyond weight loss) (e.g., BMI, BMR, body measurements)</li> <li>• What are weight and health concerns and treatments for underweight people with type 2 diabetes?</li> </ul>
Diabetes in pregnancy/pregnancy planning	28	<p><i>"I was told when I was dx'd in '92 that I'd not be able to have children. But I've since had 2 healthy pregnancies - the most recent of which was with twins. :) All 3 healthy baby boys. I only wish I'd had resources back then, like DiabetesSisters, to know I wasn't alone." – aggim0m</i></p> <p><i>"With the help of my incredible medical team with once or twice weekly appointments we were able to keep my levels under control with multiple insulin injections throughout the day and checking my levels at least 8 times a day. Throughout most of my pregnancy I was able to keep my A1C level around 5.3-5.7. We made it to 38 weeks before I was induced." -lennemane</i></p>	<ul style="list-style-type: none"> <li>• Guides to successful and healthy pregnancies with diabetes</li> </ul>

Insulin and Insulin Delivery, including Pump	61	<p><i>"So I want to discuss insulin resistance in Type 1s. I can't be the only one who has experienced this, and I'm pretty much at wit's end as to how to manage it." - natsera</i></p> <p><i>"For whatever reason, though, I can't quite get myself to commit to a pump. I am a bit intimidated by all the learning curve that pumping requires and a bit apprehensive about the risk of occlusions." - TortieGirl</i></p> <p><i>"I don't wear tight clothing, but it (edit: the pump) still sticks out quite a bit. Wearing it inside my bra doesn't work well for me, it just seems too inconvenient to pull it out frequently. Does anyone have any tricks to share?" - Tillyseattle</i></p>	<ul style="list-style-type: none"> <li>• What is the overlap and management for Type 1 DM and insulin resistance?</li> <li>• What are the (emotional and other) barriers to starting an insulin pump</li> <li>• What are the best educational guides for wearing insulin pump?</li> </ul>
Glucose self-monitoring and CGM	35	<p><i>"None of my practitioners has talked about ketones with me or recommended getting ketone strips." - TortieGirl</i></p> <p><i>"If I do not take insulin when I get up and especially if I skip breakfast, my BG will go up steadily until mid-morning. It takes more insulin to keep my BG in range if I do not eat than if I do." - Laddie</i></p> <p><i>"I use it exactly as it's name implies - I "monitor" my blood sugars with it, and look for trends. When I first got it, it was definitely hard not to overreact to every up or down arrow, and I certainly did stack insulin. Patience is really key with a cgm!" - ctgirl54</i></p>	<ul style="list-style-type: none"> <li>• What are patient education methods about the importance of ketones?</li> <li>• What are the implications for meal timing, like skipping breakfast or eating meals late?</li> </ul>
Type 2 DM and other non-Type1 treatments	20	<p><i>"This daily maintenance is hard and I had been told that I had reversed my "prediabetes". However, that is only if I follow my diet and exercise plan strictly." - cs81953</i></p> <p><i>"I'm nervous about the possibility of Metformin. I'm worried about the side effects." - DiabetesRamblings</i></p>	<ul style="list-style-type: none"> <li>• What does it mean to reverse or cure type 2 diabetes?</li> <li>• How do you prevent diabetes in people with prediabetes?</li> <li>• What are the psychological barriers to starting new diabetes medications and insulin in people with type 1 and 2 diabetes?</li> </ul>
Older women and diabetes	18	<p><i>"I think there are way TOO MANY of us over 50 to be honest. I am 58 years old and have had type 1 for 34+ years. Life IS hard with this disease, but I am learning that I am still healthy and can live a terrific life in spite of something I have to monitor 24/7. It's nice to know we aren't in this alone! &lt;3" - bndtnana</i></p>	<ul style="list-style-type: none"> <li>• What are unique health issues for older women living with diabetes?</li> <li>• What are best ways to engage older women with diabetes in the diabetes community?</li> </ul>

# DISCUSSION

We were able to engage a diverse stakeholder advisory board to help to develop and refine DiabetesSistersVoices. Through in-depth interviews and video-conferencing, we were able to refine a website to facilitate participation across racial/ethnic, socioeconomic, age and geographical strata. Our results show that an on-line, interactive website can be a portal for adults with disease conditions to express their opinions, share experiences and resources and verbalize what research topics are most important to them.

Our goal was to initiate engagement across the broad population of women living with diabetes and to identify strategies to re-engage participants. Specifically, our goal was to enroll participants and to encourage them to return to the website regularly to voice opinions and concerns, read the comments of others and provide resources. As DiabetesSistersVoices is an on-line community, we primarily focused on social media strategies as a method of engagement. We found that our highest recruitment/enrollment yields to the site occurred via social media activities of our primary stakeholder, DiabetesSisters, as well as Facebook boost. The success of these two strategies are likely due to the well-established advocacy and communication infrastructure of DiabetesSisters and the broad use of Facebook by adults across demographic strata.

We successfully enrolled 332 women with 42% of them posting at least once on the site over 6 months of use. Although the majority of women were Caucasian with type 1 diabetes, we successfully engaged and sustained women with diabetes in an online community. As time went on, more women with type 2 diabetes joined the study.

The content analysis of the study provides an opportunity to summarize women's perspectives on their current care, their perceived barriers to or limitations of current therapies and what knowledge they need to live healthier lives. Our findings (Table 8) contribute to the care of women with diabetes in two important ways. First, we developed and refined a venue by which women are able to express their views in an on-going iterative fashion. This method to engage participants differs substantially from traditional focus groups in which participants have only one opportunity to express their opinions. To our knowledge, DiabetesSistersVoices is one of the first on-line communities specifically for women with diabetes and with the focused goal to gain input from women with diabetes on priorities for research.

### *Limitations*

There are limitations to this study that deserve further attention. It was challenging to recruit and enroll a racial/ethnically diverse group of women. The majority of our participants were Caucasian women with type 1 diabetes. It is possible that women with type 2 diabetes may have been reluctant to share their experiences due to concerns about being stigmatized for their diagnosis. From a public perspective, type 1 diabetes is considered to be a non-preventable condition, while type 2 diabetes is thought to be preventable and largely occurs in adults with overweight or obesity. We were also limited in older women ( $\geq 65$  years) who may use the internet for information, but not as a method for social interaction with peers.

## CONCLUSION

Our study findings suggest that an on-line community can be an engaging and efficient tool for women with diabetes to interact with each other and provide their perspectives about diabetes care to inform the next generation of research questions. We identified multiple approaches to engage women to share their perspectives on a range of topic and interest related to diabetes. Finally, we were able to summarize, preliminarily, their perspectives on knowledge gaps in health care delivery. Further study is needed in a larger cohort of women with type 2 and gestational diabetes, as the majority of study participants has type 2 diabetes. Also, future studies might consider targeting aspects of diabetes care (e.g. fertility, menopause) that are specific to women and address conditions across the woman's lifespan.



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# APPENDICES: Screen shots of the DiabetesSistersVoices online community

## Table of Contents

A. DiabetesSistersVoices homepage
B. “About Us”
C. Online Help Videos
D. Forums
E. Conversations
F. Resources
G. Shaew

## A. Homepage



[Home](#) [Share](#) [Forums](#) [Resources](#) [Conversation](#) [Topics](#) [Admin](#) [Users](#) [About Us](#) [Contact Us](#) [Help](#)



### Share Your Experience

*Share experiences or questions about living with diabetes*



### Join a Forum for Conversation

*Let's discuss your health, diabetes and healthcare*



### Find a Resource

*Search for helpful resources and information*



### Explore a Topic

*Pick your favorite topic from the topic list*



DiabetesSistersVoices is an online community for women living with diabetes, pre-diabetes or known to be at risk for to ask questions, share experiences and search for resources. Our goal is to provide you with a forum to talk about your health and health care needs. The voices from this community have been helping researchers to better understand what health topics are most important to women living with or at risk for diabetes and guide priorities for research on management, treatment, health services and prevention of diabetes across all phases of life - young adulthood to pregnancy to menopause to the elder years.

[Site Orientation Video](#)

[About Us](#)

[Study Participation](#)

The creation of the DiabetesSistersVoices online community was made possible through a research partnership between DiabetesSisters, Johns Hopkins University, University of North Carolina, TrustNetMD and an advisory board of diabetes advocates, with funding by the Patient-Centered Outcomes Research Institute.

#### Popular Topics

type 1 and lada type 2 resource healthy living diet food nutrition






q&a complications diabetes and other conditions

glucose monitoring emotional wellness newly diagnosed

physical activity and exercise gestational devices insulin pump

insulin treatment psychosocial support healthcare prediabetes

## B. About Us



Home Share Forums Resources Conversation Topics Users About Us Contact Us Help

### About Us

**DiabetesSistersVoices is a national online community of women with diabetes to be responsive to their needs, perspectives and preferences. The members of DiabetesSistersVoices are making a difference for themselves and other women living with diabetes.**

[Register to join the DiabetesSistersVoices project.](#)

**Mission**

To improve health outcomes and care for women living with diabetes

**Vision**

Through the collaborative power of DiabetesSistersVoices, we will transform research on diabetes to meet the needs and preferences of women living with diabetes.

**Who we are**


DiabetesSistersVoices was made possible through a partnership between DiabetesSisters, physicians at the Johns Hopkins University and University of North Carolina, TrustNetMD and a Stakeholder Advisory Board composed of women and diabetes advocates. Your DiabetesSistersVoices team members are dedicated to care of women with diabetes at every phase of their lives.

**Goal of the DiabetesSistersVoices Project**

The project has provided an interactive, engaging website for women with diabetes to discuss what research they believe is most important to improve their health, well-being and health care to guide the research community in setting future research priorities

**How can you help us to achieve this goal?**

The Voices from this community have been helping researchers to understand what health topics are most important to women living with or at risk of diabetes, and what types of research is needed to improve the health and health care of women living with diabetes.



On behalf of Ms. Anna Norton, CEO of DiabetesSisters, Inc, Drs. Wendy Bennett and Wanda Nicholson and Peijin Han, Thank You for visiting the DiabetesSistersVoices website and taking the time to learn more about our efforts. If you are a woman living with diabetes, then DiabetesSistersVoices is the website for you. After reading our mission and vision, we hope that you will join our team!

We bring women with diabetes together to share their struggles and accomplishments, ask questions and discuss health and health topics that are important to their daily living. We need you to help us make a difference for all women with diabetes.



## C. Online Help Videos

The screenshot displays the DiabetesSistersVoices website interface. At the top, the logo "DiabetesSistersVoices" is accompanied by social media icons for Facebook, LinkedIn, YouTube, and Twitter. A navigation bar includes links for Home, Share, Forums, Resources, Conversation, Topics, Users, About Us, Contact Us, and Help. Below this, a section titled "Help Videos - Click to play" is visible. The main content area is titled "Site Navigation Help" and features a smaller version of the website layout. This layout includes a red callout box stating: "Use the top menu links to navigate the site...". The navigation bar in the smaller layout lists Home, Share, Forums, Resources, Topics, Users, About Us, Contact Us, and Help. The main content area of the smaller layout is divided into two columns. The left column contains four green buttons: "Ask a Question" (with a speech bubble icon), "Join the Conversation" (with a speech bubble icon), "Find a Resource" (with a magnifying glass icon), and "Explore a Topic" (with a heart icon). The right column features a photo of five women and a text block describing the community's mission. Below the buttons, a "Popular Topics" section lists "type 2", "type 1 and lada", and "resource". At the bottom of the screenshot, the text "Resources Help" is visible.

**DiabetesSistersVoices**

Home Share Forums Resources Conversation Topics Users About Us Contact Us Help

**Help Videos - Click to play**

**Site Navigation Help**

**DiabetesSistersVoices**

Home Share Forums Resources Topics Users About Us Contact Us Help

Use the top menu links to navigate the site...

**Ask a Question**  
Questions about

**Join the Conversation**  
Let's discuss your health, diabetes and healthcare

**Find a Resource**  
Search for helpful resources and information

**Explore a Topic**  
Pick your favorite topic from the topic list

**Popular Topics**

type 2 type 1 and lada resource

**DiabetesSistersVoices** is a national online community for women living with pre-diabetes or diabetes to ask questions, share experiences and search for resources. Our goal is to provide you with a forum to talk about your health and health care needs. Your views will help researchers better understand what health topics are most important to you and guide priorities for research on management, treatment, health services and prevention of

**Resources Help**

## D. Forum





[f](#)[in](#)[yt](#)[tw](#)

HomeShareForumsResourcesConversationTopicsAdminUsersAbout UsContact UsHelp

Select a forum to join


RecentHot!Most likesMost repliesMost views


Diabetes and You



Women living with diabetes can face multiple challenges in managing their condition, meeting family and work commitments and making time to focus on their health and well-being. In the Diabetes and You forum, select a topic below or [create a new topic](#) to discuss how you live with diabetes.


[type 2](#)[type 1 and lada](#)[pregnancy](#)[pre-diabetes](#)


Healthy Living



In the Healthy Living forum, you can talk about your goals for adopting or maintaining a healthy lifestyle. Share your views about what research needs to be done to help you live healthier and happier. Select a topic below or [create a new topic](#) to discuss in this forum.

[healthy living](#)[heart disease](#)[diet food nutrition](#)[weight](#)[62+](#)[minority health](#)[physical activity & exercise](#)[relationships & intimacy](#)

Resources and Education



New research discoveries are important to helping you a healthier life with your diabetes. Use the Resources and Education forum to discuss information that has helped you with your journey with diabetes and any gaps in health care information that you believe you need to live a healthier life with diabetes.

[resource](#)[research](#)[popular websites](#)

Researchers across the U.S. have recognized the need to include patient voices in clinical research.


DiabetesSistersVoices hears your voice and has served as a pathway for members to express their opinions and perspectives on the next generation of research priorities.

Popular Topics

[type 1 and lada](#)[type 2](#)[resource](#)[healthy living](#)[diet food nutrition](#)[q&a](#)[complications](#)[diabetes and other conditions](#)[glucose monitoring](#)[emotional wellness](#)[newly diagnosed](#)[physical activity and exercise](#)[gestational](#)[devices](#)



## E. Conversations






[f](#)[in](#)[yt](#)[tw](#)

HomeShareForumsResourcesConversationTopicsAdminUsersAbout UsContact UsHelp

Recent posts and replies in Conversation

RecentHot!Most likesMost repliesMost views

Please check out Karen's video blog post...  
Dealing with Endo visit anticipation... share your **Endo nerves** experiences!



0likes0replies2views

**Type 2 diabetes and metformin**  
posted 2 days ago in **Conversation** by **Madelyn** (130 points)  
type 2oral medicationsmedications

0likes0replies2views

**Question: Type 1 Diabetes and PCOS**  
posted 2 days ago in **Conversation** by **JusttJay** (120 points)  
type 1 and lada pcosbirth controlpmspregnancydiabetes and other conditions

0likes0replies1view

**Summer Hydration**  
posted 2 days ago in **Conversation** by **KarenG** (14,590 points)  
healthy livingdiet food nutrition

+1like5replies22views

**Update on Underweight Diabetic**  
answered 2 days ago in **Conversation** by **Cweems89** (370 points)  
type 1 and lada weighttype 2

+1like3replies14views

**Small dose of insulin after high fat meal?**  
answered 3 days ago in **Conversation** by **AllisonG4** (180 points)  
diet food nutritioninsulintype 1 and ladaclinical trials

+1like1reply15views

**Summer Food Carb Counts**  
answered 3 days ago in **Conversation** by **janmosso** (1,260 points)  
diet food nutritioncarbohydrates carbstype 1 and lada type 2

0likes0replies3views

**Keeping Insulin Cool?**  
posted 5 days ago in **Conversation** by **KarenG** (14,590 points)  
insulininsulin pumprecommendationstravel

Knowledge is the power to learn to live well with diabetes, or manage pre-diabetes. This Resource page provides educational materials, such as research publications, trusted patient care sites and links to other diabetes support sights that have been provided by your peers on the site and your DiabetesSistersVoices team.

Popular Topics

type 1 and lada

type 2 resource

healthy living

diet food nutrition

q&a complications

diabetes and other conditions

glucose monitoring


emotional wellness

newly diagnosed

physical activity and exercise

gestational devices

## F. Resources






[f](#)
[in](#)
[yt](#)
[tw](#)

[Home](#)
[Share](#)
[Forums](#)
[Resources](#)
[Conversation](#)
[Topics](#)
[Admin](#)
[Users](#)
[About Us](#)
[Contact Us](#)
[Help](#)

### Recent posts and replies in Resource

[Recent](#)
[Hot!](#)
[Most likes](#)
[Most replies](#)
[Most views](#)

Please check out Karen's video blog post...  
Dealing with Endo visit anticipation... share your **Endo nerves** experiences!

0 likes	0 replies	1 view	<b>RESOURCE: 5 Ways to Wear an Insulin Pump with a Prom Dress</b> posted 4 days ago in <b>Resource</b> by KarenG (14,590 points) insulin pump devices resource body image
+1 like	0 replies	6 views	<b>RESOURCE: Tests to Confirm Which Type of Diabetes You Have</b> posted Jul 4 in <b>Resource</b> by KarenG (14,590 points) type 1 and lada type 2 resource healthcare
0 likes	2 replies	17 views	<b>RESOURCE: 35 Tips for Travel with Diabetes</b> answered Jun 28 in <b>Resource</b> by Cweems89 (370 points) type 1 and lada type 2 resource travel
0 likes	0 replies	8 views	<b>RESOURCE: Women and Diabetes: Frequently Asked Questions</b> posted Jun 27 in <b>Resource</b> by KarenG (14,590 points) resource type 1 and lada type 2 gestational q&a
+2 likes	0 replies	15 views	<b>RESOURCE: Healthy Summer Picnics</b> posted Jun 13 in <b>Resource</b> by KarenG (14,590 points) resource type 1 and lada type 2 healthy living diet food nutrition
+1 like	0 replies	8 views	<b>RESOURCE: Glossary of Health Insurance Terms</b> posted Jun 8 in <b>Resource</b> by KarenG (14,590 points) resource type 1 and lada type 2 prediabetes
0 likes	3 replies	13 views	<b>RESOURCE: What are diabetes complications?</b> answered Jun 7 in <b>Resource</b> by ConnieT1D (580 points) resource complications type 1 and lada type 2

Knowledge is the power to learn to live well with diabetes, or manage pre-diabetes. This Resource page provides educational materials, such as research publications, trusted patient care sites and links to other diabetes support sights that have been provided by your peers on the site and your DiabetesSistersVoices team.

### Popular Topics

type 1 and lada

type 2 resource

healthy living

diet food nutrition

q&a complications

diabetes and other conditions

glucose monitoring



emotional wellness

newly diagnosed

physical activity and exercise

gestational devices

## G. Share



Home Share Forums Resources Conversation Topics Admin Users About Us Contact Us Help












































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


































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