



EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

MODULE 2 SUMMARY
& HIGHLIGHTS





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AGENDA

MODULE 2: HONING PATHWAYS FOR CHANGE

Tuesday, May 25, 9:00–12:00 PDT/12:00–3:00 EDT – Zoom

-
- 9:00 AM** OPENING REMARKS
Welcome Back for Module 2!
-
- 9:15 AM** BREAKOUTS AND SHARE-BACKS
Flash Visioning
Imagining a future beyond diabetes stigma
-
- 9:45 AM** ALL VOICE CHECK-IN
Mapping Our Interests in the Stigma Fight
Where does stigma-busting intersect with your existing commitments/passion projects?
-
- 10:15 AM** Break
-
- 10:30 AM** PRESENTATION/Q&A
Action Updates
Research, website, strategy, and more!
-
- 10:45 AM** BREAKOUTS AND SHARE-BACKS
Action Planning Working Groups
There are many threads of strategic action we've identified that we'd like to move forward with your support—Research, Website Launch, Network Development, HCP Engagement, Media Advocacy, and more—*See pre-reader for details, and let us know if you have passion project ideas you are called to lead!*
-
- 11:45 AM** CLOSING REMARKS
Highlights and Reflections
-

Welcome Back to d21

Jim Carroll – CEO, diaTribe Foundation

Jim Carroll started off Module 2 by welcoming all the participants and thanking the event's generous sponsors, including One Drop (Presenting Sponsor), Abbott (Silver Sponsor), and AstraZeneca, Dexcom, and Sanofi (Bronze Sponsors). Carroll provided a short history of the dSeries as an event where intelligent experts and influencers in the field of diabetes convene to explore new approaches to solving the most pressing issues in the field of diabetes.

Brooking Gatewood – Co-Founder, The Emergence Collective

Brooking Gatewood explained how Module 2 would explore the intersection between participants' personal interests, professional capacity, and core stigma-busting strategic action areas. After she provided an overview of the day's agenda, Gatewood introduced Eileen Opatut, who spoke about her personal experience with stigma.

Grounding in the *Why*

Eileen Opatut – Realtor & Former Television Producer

Transcript of Eileen Opatut's moving personal experience with stigma:

I started struggling with my weight in college. And as you might expect, I have felt stigmatized for being overweight since that time.

Fast forward to my thirties. Pregnant with twins, I contracted gestational diabetes and the diabetes didn't go away. I was ashamed. Everywhere I looked, society told me that diabetes was a condition that was not treatable, was about lack of discipline, was very uncomfortable to discuss and above all, very, very sad. But I found the perfect excuse – it was gestational! Not my fault! And I've been using that cover ever since.

And it wasn't just the media or societal prejudices. It was also my doctors. When I was first diagnosed, they didn't tell me much at all other than to check my feet. I'm a well educated woman, but because I couldn't see its long-term effects and only took a little metformin, I ignored it. I didn't realize what it was doing to my nerve endings, my healing time, my GI system, all my organs. And because my doctors didn't take the time to educate me properly, I didn't take it seriously myself. Obituaries said people died of complications from diabetes, and I kept asking "What does that mean?"

One well-regarded Park Avenue doctor took a different approach. He threatened me with bariatric surgery if I didn't take the little black pills that would keep my body from absorbing the fat I consumed. They made me hallucinate. It was awful, but he didn't believe me when I told him. Instead, he scolded me. I spoke with another endocrinologist about losing some weight. He was clear. Don't focus on that; in fact, he said, most of the meds you take will keep you from losing weight. Is that true?

I went to the Pritikin Center. That actually worked with weight loss and most importantly, blood sugar control. But it was extremely difficult to maintain.

I was in charge of all the programming on Food Network for a decade. I tried my best to include content about healthy eating, diet, and diabetes. It was the perfect platform. Crickets. Viewers wouldn't watch. Advertisers didn't want it. No surprise that everyone wants to watch baking competitions. I call it food porn. So I suppose you could say I've suffered from stigma professionally as well.

And the diabetes still progressed. My body doesn't produce insulin anymore. I have been on insulin for eight years. Is it because I didn't treat this with enough seriousness? *Maybe. Maybe not.*

Here's what did change. About five years ago, during a casual lunch with my thin, athletic older brother, he took out some metformin. He had diabetes too! He had been too embarrassed to tell me. It was a big day. On that day, I could finally say, "It's not my fault." I had a genetic disease. And I could get to the business of educating myself and taking ownership of my disease. *My disease*, not the shameful outcome of not taking care of myself or my lack of discipline — all those stereotypes that haunted me for decades.

I'm much better now. In every way. But in our society, the stigma about diabetes and obesity runs deep. And that's why I decided that I should help.

Flash Visioning

Participants broke into small groups to explore a world without stigma and the specific questions below. Discussions allowed some common themes to surface, which are represented visually below.

Imagine we now live in a world where diabetes and obesity are not stigmatized....

1. What does this world look like; how is it different from today?
2. What becomes more possible for people with diabetes?
3. How would your area of work be affected; what might become easier?





Mapping Our Interests in the Stigma Fight

Gatewood then invited participants to share, one by one, where they felt their personal work, interests, and passion most closely aligned with areas of the stigma fight – even if that area was not one of the five core areas diaTribe identified. Though many participants coalesced around research, the stigma information hub, network development, healthcare provider engagement, and media advocacy, they also identified gaps where attention could be focused, including storytelling, and community engagement. Although not specifically mapped in this exercise, we know that policy is another area of interest for dSeries participants.



In the graphic above, participants are grouped by primary area of interest; colored squares list the areas that participants mentioned as being most aligned with their work and expertise. The [public Miro board](#) of this information may reflect additional people and/or updated interests as they arise.

Collective Action Strategy and Updates

Brooking Gatewood

Gatewood provided an overview of what work diaTribe has done based on insights and feedback collected after Module 1. She shared the revised dNetwork mission statement and pathways to enacting this mission, and the key elements of change the dNetwork will focus on to get there:

dNetwork

Reducing the impact of diabetes on society and improving the lives of people with diabetes by fostering understanding of the disease, eliminating misplaced blame, and ensuring access to care.

Prevention: Reducing New Incidence Rates for Diabetes



Care: Improving Lives of People Living with Diabetes



Reduce Diabetes Impact on Individuals & Society

HOW ARE WE DOING THIS?

1. **Getting Smarter Together.** Bringing leaders together to better understand the world of diabetes through the annual dSeries Executive Innovation Labs, training in best practices and commissioning research to fill gaps in the skills / knowledge needed for change.
2. **Working to reduce misplaced blame by shifting messaging** in our individual and collective spheres of influence with evidence-based stigma-busting language and frames.
3. **Activating others.** We're building a movement and leveraging our influence to engage more and more leaders across levels to change behavior, culture, policies, and ultimately systems.

Elements of Change



Matthew Garza – Associate, diaTribe Foundation

Matthew Garza then clarified what diaTribe, as a small nonprofit, can provide moving forward as a convener and coordinator of the dNetwork as well as what is hoped for from dNetwork participants:

- diaTribe's Priority Actions – diaTribe will build the infrastructure to act by publishing a research agenda, building the stigma information hub, and securing staffing and funding for network and campaign development.
- Participant Priority Actions – Participants will utilize diaTribe's work to change mindsets, messaging, and policy. This will be done by developing a healthcare provider engagement plan, growing the network through outreach and marketing campaigns, and launching media campaigns and policy actions.

Action Planning Working Groups

Gatewood then transitioned the group to the main working block of d21. Our participants were split into five project-specific action planning groups. Each group had unique discussions led by a facilitator designed to help move the specific work forward in that project area. The following are summaries of the discussions and insights. We will use these summaries to inform official action plans moving forward in each respective track.

Research: Providing input into the research agenda development

Facilitator: Jim Carroll

Participants: Ananta Addala, Rebecca Pearl, Rebecca Puhl, Kelly Close, Kelly Brownell, Urmimala Sarkar, Richard Wood

The slide deck for this group can be found [here](#).

Carroll began with outlining the what, who, and why of the research agenda

- **WHAT is it?** Create and publish a research agenda to serve as a roadmap, developed by experts in diabetes and related fields, for guiding academic research and funding on diabetes stigma.
- **WHO is it for?** Researchers (in academia, government, or industry), granting organizations, and other funding sources.
- **WHY do this?** Existing studies, though useful, do not lay a sufficient foundation for documenting the scope and breadth of the problem of diabetes stigma in the USA: its prevalence, impact on individual health, and impact

Carroll then presented dQ&A survey results showing the real impact of stigma on people's healthcare

	Diabetes Type					
	Total		Type 1		Type 2	
	Count	Column %	Count	Column %	Count	Column %
Have you ever felt that your doctor, nurse, or other professional in a healthcare setting blamed you for having diabetes?						
Yes	33	26%	10	20%	23	29%
No	94	73%	39	80%	55	69%
I don't know	2	2%	0	0%	2	3%
Total	129		49		80	
Did your experience(s) with diabetes-related stigma ever keep you from seeing your healthcare provider?						
Yes	15	45%	3	30%	12	52%
No	18	55%	7	70%	11	48%
I don't know	0	0%	0	0%	0	0%
Total	33		10		23	
Have you ever made a decision to delay an insulin injection or bolus because you were afraid of being judged by the people around you?						
Yes	38	36%	20	41%	18	32%
No	66	63%	29	59%	37	66%
I don't know	1	1%	0	0%	1	2%
Total	105		49		56	
Have you ever made a decision to not wear a diabetes device (e.g. a CGM or pump) because you were afraid of being judged by the people around you?						
Yes	22	32%	9	23%	13	43%
No	46	67%	30	77%	16	53%
I don't know	1	1%	0	0%	1	3%
Total	69		39		30	

Caroll then opened the group up for discussion on crafting a research agenda, other study topics, and next steps from the group

- **Research will be vital to our efforts.** It can be a very convincing way to help people realize how prevalent the problem is. It also allows us to say there are clear and important impacts that the community needs to talk about. It is also important to figure out how to harness research to get the change you're looking for such as figuring out who the change agents are and how we could speak to them.

- **Further studies beyond just establishing prevalence are needed.** These could be large studies that look at what language people feel most comfortable using, or studies that identify HCP attitudes, what they see as barriers, and what things need to improve, and studies that specifically test the success of interventions. There is also an opportunity to connect with researchers doing large and long-term epidemiological studies to see if we can partner with them, adding questions to interviews and surveys that specifically look at diabetes stigma.
- The participants agreed that **figuring out a method to fund the research is vital**, whether that be through grants, philanthropic efforts, corporate sponsorships, or some other way.
- Since diabetes stigma intersects with countless other stigmas such as weight, race, and socioeconomic status, **it's important to identify how these stigmas intersect and figure out ways to measure the impact of diabetes stigma** (and the interventions used to address it).
- The participants agreed to work asynchronously over the coming weeks to develop a cohesive roadmap or research agenda that can be used to guide this project area moving forward.

Stigma Information Hub: Providing input to the web design team

Facilitator: Chris Barnes

Participants: Alan Moses, Karen Talmadge, Scott Johnson, Jennifer Hahamian, Marjorie Sennett, Virginia Valentine

The slide deck for this group can be found [here](#).

Barnes began with an overview of the stigma hub website development plans and then led an engaging discussion focused on outstanding questions, helpful tools, the motivation behind using this site, and what success looks like

- **What other questions or ideas about our plans are on the top of your mind?**
 - Getting people to change their language is a big challenge.
 - How do we get people to care about diabetes? (Barnes shared that this is explicitly *not* a design goal for the initial phase of the stigma hub because it will be focused on content for people who do already care about diabetes.)
 - Be open to learning from who is communicating well already.
 - Making change requires a slow and steady march.
 - **Who are the people communicating about diabetes? How do we reach them?**
- **What will motivate you to use this site or tell other people about it?**
 - **Ready-made resources that people can download and use.**
 - Communication training that focuses on improving skills rather correcting "wrong" choices
 - Stories are always powerful. Recordings that showcase what stigma means personally for people.

- A Grammarly-style tool that automatically checks language.
- **What tools will help you address stigma in your sphere of influence?**
 - **Consensus around the key messages to communicate about stigma, and practical tools**
- **What does success look like and how might we evaluate and measure our effort?**
 - **Adoption of non-stigmatizing communications and language as an element of policy at major organizations and inclusion in standards of care.**
 - By a certain date we want a certain number of medical (and/or diabetes educator) training programs to use our hub content or have incorporated our content as part of their curriculum
 - Re-education is a bigger challenge than education, so find ways to focus on initial training
 - Identify journalists with a history of writing about diabetes, introduce them to the hub and content, then after a period of time, evaluate how their work has changed
 - Widespread website utilization.

Barnes finished with a look ahead, engaging participants to be involved moving forward

- Participants agreed that a brief update of the website progress as well as how work from the other project groups integrates with the website development would be valuable to share with the whole group at Module 3.
- Participants spent time sharing the ways in which they wish to be involved in the website development moving forward – as reviewers, editors, content creators, and more.

dNetwork Development: *Shaping a strategy for growth*

Facilitator: Brooking Gatewood

Participants: Angie Bricco, Larry Soler, Kyle Jacques Rose, James Corbett, Deana Zabaldo

Gatewood presented a draft membership outline for a network to fight diabetes stigma, and the group explored key strategic questions and suggestions for successful growth of our efforts:



	Supporter	Member	Influencer	Visionary	All-Star
Sign up for newsletter / Stay informed	✓	✓	✓	✓	✓
Share your stigma stories / Why you care		✓	✓	✓	✓
'Coming Out' Action / For those who are impacted by diabetes to join the community	✓	✓			
Take the Influencer Pledge / Lead change!			✓	✓	✓
Attend dNetwork events				✓	✓
Engage in research & education					✓
Join or lead coordinated action campaigns					✓
Sponsor or Donate	✓	✓	✓	✓	✓

- Participants expressed interest in thinking big to help us achieve our goals. They explored options for an initial 'big splash' campaign such as a Coming Out event and/or an Influencer pledge to invite a broader audience into this effort, and ways to use existing dNetwork influencer connections to launch such a campaign and build the visibility and funding needed for wider-reaching impact.
- What kind of network and which groups do we want to mobilize? What does success look like? What are the messages that motivate people?
 - We want to develop a healthy community that feels supported for their diabetes and has a sense of pride in belonging to a supportive community – how can we ALL get access to affordable medicine, care, dignity, etc.?
 - Both grassroots and grasstops may be needed (as evidenced by Shatterproof)
 - What are we fighting FOR? Acceptance.
 - What are we fighting AGAINST? Discrimination, the mental and emotional burden of the disease, the pressure to be perfect.
- Which kinds of efforts should we focus on first? Where might we partner for greater impact?
 - Make a big splash first with an initial, attention-grabbing campaign (social media, influencers, celebrities)
 - Then develop a smart partnership strategy – partnership with other groups already deeply invested in community activism might be wise. Think about intersectional partnerships with existing efforts to address related issues such as social determinants of health, obesity, equity in access to care, employee healthcare, or food access. These could also be corporate commitments.

- There may be a role for institutional guidelines or pledges from corporate and health care provider partners to support stigma-reducing policies and practices in their organizations.
- What successful campaigns can we learn from?
 - Disability rights movement, Got Milk, Autism awareness, Anti-smoking movement, HIV / AIDS (Discrimination + Anger → Action), Petroleum Industry (managed to recruit 10k+ volunteers to be volunteer lobbyists for their industry. How? Because people hate gas tax. Powerful example that we can find such a hook to mobilize change.), Avon health educators.
- Other questions:
 - How do we break through the traditional channels?
 - How do we engage research and community together?
 - How do we work with the personal responsibility frame that is so common in this country?

Healthcare Provider Engagement: Identifying actionable strategies

Facilitator: Caroline Pappajohn

Participants: Stephen Brunton, Bob Gabbay, Nick Cuttriss, Orville Kolterman, Luigi Meneghini, Henry Rodrique, Elaine Chiquette

For both the HCP engagement and media advocacy projects, the groups followed a similar discussion outline. Participants spent the first thirty minutes of the breakout session discussing “small but doable actions” that will produce “high-value wins.” These actions are those which can be achieved by voluntary action with limited staffing within six to twelve months but which also help foster understanding of diabetes, eliminate misplaced blame, ensure access to care, and/or build momentum for the dNetwork as a home for more ongoing actions in service of these goals.

Small but doable actions that arose included surveys around bias, campaigns, raising awareness at conferences and scientific sessions, and targeting residency programs, medical students, and premedical students

- **Conduct surveys that can help identify bias among HCPs** as it relates to chronic illnesses such as diabetes.
- Creating t-shirts as a quick way to raise awareness around diabetes stigma. They are also a way to “manage up” by encouraging patients to bring issues and concerns up to their healthcare teams – patient empowerment.
- Identify ways to use storytelling (in addition to data) to influence HCPs.
- **Raise awareness in annual scientific sessions and conferences with established networks.**

- Identify digital opinion leaders who speak about diabetes in the social media space and who have a large following. Work with them to educate and provide awareness around stigma
- Identify ways to add stigma education to residency programs across the country.
- Annual meeting with chief primary care physician residents from across the US which includes short workshops. This could be an electrifying topic for residents to share their thoughts on and raise awareness around. Is it possible to bring someone from diaTribe to facilitate discussions around stigma
- Target medical student associations like AMSA and SOMA to educate the next generation of doctors on diabetes stigma

The group then shifted for the second half of the breakout session to “thinking big.” For this activity, participants were tasked with exploring one or two larger, long-term, high value and high impact projects that the group could prioritize developing alongside the small wins discussed previously.

THE BIG IDEA: Consensus Statement on bias towards diabetes & obesity (or all chronic conditions) to be published in an academic journal

- What does success look like?
 - Holding consensus meetings with various professional societies and organizations → statement + endorsements + publication. Publication should be in print (such as in journals like Clinical Diabetes), and could also be included in medical guidelines.
 - Those working on the statement participate in d22, and the project gains enough engagement from others that the project is owned outside of diaTribe, with diaTribe in a facilitative supporting role.
- What are the essential early action steps to move this idea forward?
 - Reach out to a small number of primary care associations, obesity associations, the ADA, dietician groups, the AMA, bariatric surgery associations, mental and behavioral health organizations, ADCES, etc, and coordinate initial meetings.
- What additional support and resources are needed to be mobilized for success?
 - We will need to secure funding to pay for travel, accommodation, program funding, etc. for these consensus meetings.

Media Advocacy: Identifying actionable strategies

Facilitator: Matthew Garza

Participants: Cherise Shockley, Ansley Dalbo, Eileen Opatut, David Lee Strasberg, Anna Norton, Lee Kaplan, Thom Scher, Andrew Vilcinskis, Tom Cirillo

The media advocacy followed an identical format to the HCP engagement group (above).

Small but doable actions that arose included analysis of the media and social media landscapes, holding social media events to engage the community, and creating shared media lists of the people writing and talking about diabetes

- **An analysis of the social media landscape and social media user networks.** Look at specific platforms, social media influencers, keywords, hashtags, interactions, and trending topics to understand where diabetes and diabetes stigma surface and what the conversations around these topics look like.
- **Host a Facebook Live to engage with people with diabetes** on the question of “stigma” versus “bias” and which of these topics lands and connects with people more.
- **Conduct landscape research on current media coverage of diabetes**
 - Observe reporting mediums (podcasts, TV, morning shows, etc.) and, instead of tracking if they talk about diabetes “correctly,” track whether they are talking about diabetes at all.
 - Identify 30-50 influential editors and learn what they plan on covering around the topic of diabetes.
 - Track articles and stories on “All-Star” people with diabetes and their exceptional accomplishments. How do these stories (and their messaging) differ from stories about “normal” people with diabetes doing “normal” things?
- **Create a shared media list** for the dNetwork that identifies authors and publications that write about diabetes.
- **Revisit the Language Matters resources.** Find a way to convert the current resources and build a one-pager that is more media-centric (as opposed to patient or provider-centric).

THE BIG IDEA: Create a media kit (or set of media kits) that focus on a core story of diabetes.

- **We need to first define a series of big, overarching messages that we want our “core story” to portray.**
 - **Identify the ways in which audiences will differ.** How will a toolkit for a television producer differ from a toolkit for a healthcare provider who has a podcast?
- **Create messaging for people with diabetes about their own self-worth.**
 - Identify the conflicting messages surrounding diabetes in the media (an idea also on the small but doable action list above).
 - **Create a repository of anecdotes and stories about people with diabetes.**
- **What additional support and resources are needed to be mobilized for success?**
 - **Grassroots engagement in creating the message.** How can this work help people living with diabetes feel valued?
 - Specialists on the team that is creating toolkits who can help ensure we avoid doing more harm than good with our messaging. **This should also include experts in different areas of media who can help guide the messaging** (social media, networks, TV, general public, people with diabetes, etc.)

- Other thoughts to consider:
 - Though seeing images of people with diabetes in the media won't fix everything, it is a start. There is a need for media kits that teach people *how* to portray diabetes.
 - Changing the general public's hearts and minds is important, *however* another important consideration is changing the experiences of people with diabetes who are impacted by stigma and making sure that their lives are improved by the work.
 - We should explore whether a campaign like the coming out process, which was successful in the LGBTQ movement, would be beneficial in this movement as well.

Closing Reflections

Brooking Gatewood, Jim Carroll

Gatewood asked work group facilitators to share highlights from each session, and let the group know that this work would be continuing over the coming months and into Module 3. Gatewood and Carroll closed with appreciation for event participants, the design team, the diaTribe staff, and our generous sponsors, without whom none of this stigma-busting work would be possible!

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EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

POWERED BY

THE **diaTribe**
FOUNDATION

WRITTEN BY

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