



# Module 1 Summary

## Welcome to d21

*Jim Carroll – CEO, diaTribe Foundation*

Jim Carroll kicked off d21 by welcoming all of the participants to diaTribe's stigma-busting efforts. He thanked diaTribe's sponsors for their generous contributions, including One Drop (Presenting Sponsor), Abbott (Silver Sponsor), and AstraZeneca, Dexcom, and Sanofi (Bronze Sponsors), before passing the mic off to Brooking Gatewood of the Emergence Collective.

*Brooking Gatewood – Co-Founder, Emergence Collective*

Brooking Gatewood began Module 1 by orienting the participants to the work ahead and reflecting on the work that has been done at the previous dSeries events.

- The dNetwork aims to be the hub for high impact, aligned action to address type 2 diabetes in the US. This won't be easy; diabetes is a "wicked problem" and smart action takes time and resources.
- To help us address the diabetes epidemic, diaTribe is using a framework called Theory U: a model for group action and learning amidst complexity that flows from "sensing" the system together to "reflecting" to discover areas of strategic action to "acting" iteratively toward a new vision. In previous dSeries events, we have focused on *sensing* and partially on *reflecting*. As we move forward at d21, we have shifted into *reflecting* with the hope that we can begin *acting* in the near future.
- Stigma has been identified as the first lever for collective action. Diabetes stigma has been a core topic at the dSeries events over time and at d19, stigma showed up in many places on the [diabetes systems map](#). If we can address diabetes stigma, it will have ripple effects across many areas of the diabetes ecosystem.

## Networking and Check-Ins

Before getting into the bulk of the program, Gatewood invited all of the participants into small breakout rooms to introduce themselves and reflect on several important questions including:

- What progress has been made on each person's [Personal Action Plans](#) since November? Did they make any adjustments or were any lessons learned?



- What new opportunities for influencing diabetes framing have they noticed since last fall?
- Have they been thinking about their work differently as a result of our exploration of stigma at or after d20?

The participants were then brought back into the main room for a quick share-out before the program shifted to Chris Barnes of Emphatic Communications.

## A New Year of Learning

*Chris Barnes – Principal, Emphatic Communications*

Chris Barnes delivered an insightful presentation on the work done behind the scenes leading up to d21, including takeaways from key interviews conducted with members of the Stigma Strategy Group and where we are on the path to developing stigma projects.

- Barnes started by outlining that the group is starting to converge and make real decisions around stigma projects. These decisions are informed by landscape research, expert interviews, and the resources and capabilities of diaTribe.
- Landscape research of over 240 stigma-busting ideas in a variety of movements showed that there are some diabetes stigma resources but they are scattered and not exhaustive and evidence and evaluation are key as we aim to connect all the dots. [Shatterproof](#), an organization tackling the stigma around opioid addiction, was identified as a positive model to emulate.
- Interviews with experts in the Stigma Strategy Group helped identify that: stigma is complex, intersectional, and individual; more research is needed but other efforts can be pursued in parallel; diabetes organizations can amplify impact by working together; and we're still early in the process of addressing stigma around diabetes. These interviews also explored the question: "What do you want people to know about diabetes and diabetes stigma?" Summarizing results, Barnes shared that stigma:
  - Directly and negatively affects a person's ability to manage their diabetes.
  - Directly and negatively affects people's thoughts about themselves, which then indirectly affects people's motivation and their behaviors.
  - Directly affects how providers interact with patients.
  - Is directly connected to how we talk about people with diabetes. (We cannot separate words from the context of people's experience; when words are so often negative and judgmental, they impact stigma.)
  - Is also communicated through actions and choices, implicit and explicit biases.



- Barnes explained how, through many iterations, five project areas were identified as having potential for significant impact and potential success. The participants would later move into project-specific breakout groups to develop these ideas further.
  - [Stigma Information Hub](#) – An expertly curated, easily-accessible, easily-shared web resource about diabetes stigma including what stigma and bias look like, why it matters, how to challenge it, and how to avoid stigmatizing people with diabetes.
  - [Healthcare Provider Education](#) – Aimed at raising awareness of diabetes (and weight) stigma among healthcare providers by providing medical education (at multiple points in training), contact-based learning experiences, CME courses, and conversation guides or language aids.
  - [Industry-Driven Stigma Initiative](#) – Aimed at tapping pharma, device, and diagnostic companies and other diabetes-related orgs to raise awareness of diabetes stigma and how intentional communication in the industry can help.
  - [Market/Ethnographic Research](#) – Research to learn about and document (a) the lived experiences, attitudes, and perceptions of stigma and bias among people with diabetes, and (b) identifying and describing key target audiences.
  - [Academic Research Agenda](#) – The goal is to 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.

*Matthew Garza – Associate, diaTribe Foundation*

Matthew Garza delivered a short presentation on stigma-related research and a potential research agenda outline, highlighting the diaTribe Foundation's draft agenda and ideas proposed by several key leaders in the field.

- We know that academic research is needed to lay a groundwork for prioritization, funding, and attention. We also know that we can't wait for exhaustive research results before we act; there are other project areas that can work in parallel.
- A draft agenda might include:
  - A prevalence study that also establishes clinical significance.
  - Expanded research to ask more nuanced questions that further our understanding of diabetes stigma.
  - Research that surveys public attitudes, healthcare professionals, partners and families, and also intervention and message testing.



- A plan to disseminate results in media, mobilize the medical and diabetes community, and inform policy initiatives.

## Advancing Top Stigma-Busting Project Ideas

Gatewood then invited all of the participants into project-specific breakout rooms, where participants were led by a facilitator to discuss a number of important questions including:

- What are the most important strategic questions to be asking right now as we progress within the project idea?
- How should these questions be prioritized?
- What next steps are important for advancing these project ideas forward?
- And a number of project idea-specific questions.

Summaries of the breakout groups can be found below:

- [Stigma Information Hub](#)
- [Industry Driven Stigma Initiative](#)
- [Healthcare Provider Education](#)
- [Academic Research Agenda](#)
- [Market/Ethnographic Research](#)

The diaTribe team will work with the Stigma Strategy Group to select which of the ideas developed during these sessions to move forward with, within the d21 timeframe.

## Spotlight on New Diabetes Stigma Research

*Dr. Rebecca Pearl – Assistant Professor, University of Florida*

Dr. Rebecca Pearl delivered a presentation on a current research proposal that she is submitting to the APA for a \$20,000 research grant. In a study of 800 adults with type 2 diabetes, participants will complete a 15-minute self-report survey online. Her proposed study has three specific aims:

- Aim 1: To establish the prevalence of type 2 diabetes stigma in a diverse sample of 800 adults.
- Aim 2: To identify participant characteristics associated with type 2 diabetes stigma.
- Aim 3: To determine the clinical significance of type 2 diabetes stigma for depression, anxiety, health-related quality of life, and diabetes management.



## Looking Ahead

### *Brooking Gatewood*

Gatewood concluded Module 1 with a brief look ahead at what is to come:

- Module 2 (May 25, 2021) will look at developing a shared core stigma-busting narrative and potential project idea updates and input opportunities.
- Lighting Talks (July 20, 2021) will be a night of learning, open to the public, as several exciting speakers deliver TED-style talks .
- Module 3 (July 21, 2021) will allow for continued narrative development with the potential for some communications training and a potential project launch.

Stay tuned as this work will evolve over the next few months as we continue our research and ideation process! As always, we welcome input at any time at [stigma@diatribe.org](mailto:stigma@diatribe.org).

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