



EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

PARTICIPANT PRE-READER

MODULE 1

MARCH 30, 2021



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TABLE OF CONTENTS

Agenda	2
STIGMA STRATEGY GROUP UPDATE	
About the group	3
Stakeholder interviews	
Summary of key ideas	4
What do you want people to know?	7
Where might we focus?.....	9
Project ideas	10
Landscape research: select examples	14
STIGMA IN THE MEDIA	
What does diabetes stigma look like in the media?	16



AGENDA

MODULE 1: RECONNECTING AS STIGMA BUSTERS

Tuesday, March 30, 9:30–12 PDT/12:30–3:30 EDT – Zoom

-
- 9:30 AM** OPENING REMARKS
Welcome to d21!
Re-orienting to dSeries history and the vision for d21 and beyond
-
- 9:45 AM** BREAKOUTS AND SHARE-BACKS
Networking and Check-ins
How has our thinking and learning evolved since d20?
-
- 10:10 AM** PRESENTATION/Q&A
A New Year of Learning featuring Chris Barnes of Emphatic Communications
A download on post-d20 research insights and emerging strategies for dNetwork stigma-busting
-
- 10:30 AM** Break
-
- 10:45 AM** BREAKOUTS AND SHARE-BACKS
Advancing Top Stigma-Busting Project Ideas
Strategic input sessions
-
- 11:30 AM** PRESENTATION/Q&A
Spotlight on New Diabetes Stigma Research featuring Dr. Rebecca Pearl of the University of Florida
New directions for diabetes stigma research
-
- 11:45 AM** CLOSING REMARKS
Looking Ahead
Action steps & reflections on the day
-

STIGMA STRATEGY GROUP UPDATE

At d20, The diaTribe Foundation asked for volunteers to become part of a Stigma Strategy Group — an ad hoc advisory team of experts from a variety of domains: diabetes, obesity, stigma, healthcare, industry, and social change — to assess opportunities, prioritize questions and potential actions, and create a playlist for steps that can be taken to address stigma in diabetes.

Initial goals:

- inform our understanding of stigma experienced by people with diabetes and of existing approaches to tackle stigma in diabetes and other domains
- assess stigma-busting ideas discussed at the d20 Executive Innovation Lab and generate and refine new project ideas
- identify/prioritize questions for research

Strategy Group d20 volunteers

Angie Bricco

Sanofi | Head, US Public Affairs and Patient Advocacy, Primary Care

Dr. Kelly Brownell

World Food Policy Center, Duke University | Director

Dr. Stephen Brunton

Primary Care Education Consortium | Executive Vice President

Noelle Bush

Boehringer-Ingelheim | Director of Marketing—Jardiance

Ansley Dalbo

Diabetes—What To Know | CEO

Dr. Phyllisa Deroze

Black Diabetic Info | Founder

Jennifer Hahamian

Jennifer Hahamian Consulting | Marketing and Business Development Consultant

Carl Rashad Jaeger

Scott Street Films | Creative Director

Scott Johnson

mySugr North America | Patient Success; Scott's Diabetes | Blogger

Dr. Lee Kaplan

Obesity, Metabolism and Nutrition Institute, Massachusetts General Hospital | Director; The Obesity Society | President

Karmeen Kulkarni

Abbott Diabetes Care | Director of Global Scientific Affairs

Dr. Alan Moses

The diaTribe Foundation | Board of Directors; BiomX | Board of Director; Novo Nordisk A/S | Former Global Chief Medical Officer

Marla Oringer

Diabetes Advocate, Awareness Builder, Strategic Advisor

Thom Scher

Beyond Type 1 | President/CEO

David Lee Strasberg

Lee Strasberg Institute | Creative Director and CEO

Dr. Karen Talmadge

Nabu Strategic Advisors | President

Virginia Valentine

Advanced Practice Nurse-Clinical Nurse Specialist

Additional input from...

Dr. Bob Gabbay

American Diabetes Association | Chief Scientific and Medical Officer

Dr. Jane K. Dickinson

Teachers College Columbia University | Program Director/ Lecturer, Diabetes Education and Management

Dr. Susan Guzman

Behavioral Diabetes Institute | Co-Founder, Clinical Psychologist; Diabetes Psychology Associates | Director

Kate Cockrill

Kate Cockrill Coaching and Consulting | Coach, Trainer, and Consultant | former Executive Director of The Sea Change Program

Preliminary research brief: stakeholder interviews

METHOD

Qualitative research was conducted by Chris Barnes of Emphatic Communications in February and March 2021. Semi-structured interviews were conducted as one-on-one conversations with Stigma Strategy Group volunteers and included a mix of standardized questions and questions tailored to mine individuals' domain expertise. Questions evolved with each interview to reflect learning and to gather feedback on ideas raised in earlier interviews. Additional interviews were conducted with independent experts working on stigma.

Note: Interview comments have been summarized and arranged to tell a story. Because it's a reflection of I heard and what I judged as important when identifying common themes, SSG members were invited to review the summary and note any concerns about distortions or omissions.

– Chris Barnes, Emphatic Communications

Summary of key ideas

Stigma is real, complex, intersectional, and individual

- PWD and public don't know what "stigma" is, but they do feel bias and blame
- Stigma is different for people with T1 (disability) and T2 (responsibility); *an oversimplified but useful way to understand a typical difference*
- The reality of experienced- and self-stigma is nuanced, complex, and individual
- Seeing examples can help people learn to recognize/label stigmatizing situations
- Weight stigma is a significant intersectional part of T2 diabetes stigma, as is racism

People with diabetes sometimes contribute to stigma

- Self-stigma is common, harmful, lasting, and challenging to address
- PWD are a microcosm of broader society
- It would be helpful (and possibly challenging) to find a narrative that speaks to common experiences of people with diabetes, rather than differences between T1 and T2

Research on diabetes stigma is needed

- Most see value of academic research as
 - advancing our understanding of stigma
 - laying a foundation for prioritization and funding
 - a tool to help address objections (to behavior change) among physicians
 - opportunity to study the degree to which addressing weight stigma alone would improve lives of PWD
- Most endorse developing/publishing a research agenda to shape academic studies
- Most say it's important to pursue survey data now to learn directly from people with diabetes (do this in parallel, distinct from academic studies)
- Some say it's important to pursue market testing of messages regarding stigma as early as possible

We can't wait for research before we act

- Stigma has been discussed for some time already in diabetes arena
- Not enough people in the diabetes arena recognize stigma as a problem
- Concern about lack of “real action” on stigma despite years of trying to make progress
- A number of people pointed out that you don't need research to know...
 - that racism exists in the US... that people in the 80's with HIV faced bias... that some PWD suffer stress about the cost of insulin
 - point was not to discount value of research, but to urge against prioritizing research at the expense of more immediate steps

Stigma is a barrier to other efforts

- Not everyone is convinced that working on stigma is the best high-value action for the dNetwork to focus on, but all see stigma:
 - as a barrier or impediment to progress in other areas of the diabetes ecosystem
 - as undermining our ability to get public attention and research funding in particular
 - as causing ongoing harm to PWD in healthcare settings
 - as exacerbating health inequities
 - as a barrier to PWD being visible (reluctance to disclose, and/or to use visible technology or treatment)
 - as a barrier to PWD taking their disease seriously/managing their disease

We're not ready to launch a large-scale messaging campaign at general public...

- Most people say we're not ready, others felt that we can be, and some felt that regardless: it still needs to be our highest priority because it's necessary for the impact we want
- Many questions need addressing:
 - Which audiences?
 - What do we want to make happen (in those audiences)?
 - What are our intended message(s)?
 - What language and framing will make our message(s) effective?
 - What can be sustained and for how long?
 - How much time and money would it take to do the work to “get ready”?

We can make progress by working on stigma inside the “world of diabetes”

- Pick the “low-hanging fruit”
- Learn lessons that will help make a big media blitz smarter and more effective
- Broad agreement on need to improve HCP interactions with PWD
 - Some point out: a campaign that drives people to HCP interactions will contribute to stigma unless you deal with HCPs first
- Thoughts about where to start include:
 - healthcare providers, media monitoring, professional diabetes communicators (industry, advocacy, professional orgs), and congress (Congressional Diabetes Caucus)

Diabetes organizations can amplify their impact by working together

- Trying to launch a joint effort that includes multiple organizations (e.g., ADA, ADCES, JDRF, BeyondT1) might best be pursued outside of dSeries context
- Partnership with industry coalitions may have benefits over partnerships with single entities

diaTribe can play a valuable role but can’t tackle stigma alone

- diaTribe has proven core expertise in publishing information and convening leaders
- diaTribe has influential connections but limited resources, may not be able to drive sustained action alone

A new, separate organization may be needed (but that’s a big challenge)

- Some voice strong support for this idea; GLAAD was mentioned as a model for focusing on messaging and media representation
- Others voice strong concerns about the difficulty of creating a new organization
 - mixed view of whether this is practical (GLAAD was initially a volunteer org)
 - uncertainty about whether there’s enough urgency to drive volunteers, funding, and the work needed to launch a new org
- Who would take responsibility for launching this effort?

A useful target for the Stigma Strategy Group (over next several months) is a prioritized list of potential projects.

- people share an interest (some say passion) for working on stigma, but contributions to the SSG will have to fit in individual’s existing schedules
- diaTribe’s contribution in advancing this topic is appreciated
- everyone understands that addressing stigma is a long-term project (decades)

What do you want people to know? Gathering the seeds of a “core story.”

SOG interviewees were asked to identify the “three things you want people to know” for diabetes and diabetes stigma. (In some early interviews, people were instead asked to share their thoughts about a “core story” for diabetes and diabetes stigma.)

The following statements are a summary of those results based on an aggregate review and analysis and interviewee feedback; answers have been placed in categories by audience and edited lightly for clarity, but the language comes directly from interviewee comments.

The ideas collected in stakeholder interviews are an early step toward crafting a narrative around diabetes and stigma. *The initial focus here is on what we think is important to say.* (The wording below is *not* a suggestion for campaign language or for *how* we convey messages to different audiences for optimal impact and inspiration.)

What 3 things do you want **people with diabetes** to know about diabetes?

- **It’s not your fault**
 - you are responsible for managing the disease, but you are not to blame for it
- **Diabetes is doable**
 - there’s a lot you can do to live a long, healthy, happy life with diabetes
- **Your story is unique but you are not alone**
 - we see you, and you matter

What 3 things do you want **the public** to know about diabetes?

- **Diabetes is not someone’s fault**
 - no one “chooses” diabetes; it is a chronic, progressive, disease
 - it’s product of complex factors: people aren’t just lazy and eating wrong foods
 - people are responsible for managing their disease but are not to blame for it
- **Diabetes is a serious, complicated disease**
 - challenging to manage (though improving)
 - an enormous burden; it’s tiring! (for T1 & T2)
- **Diabetes is doable**
 - there’s a lot people can do to live a long, healthy, happy life with diabetes
- **Most people are trying their best**
 - people’s “best” reflects context, capability
- **Blame and shame cause harm**
 - does not encourage people to be healthy
 - shame undermines positive change

What 3 things do you want **healthcare providers** to know about diabetes?

- **Diabetes is not someone’s fault**
 - no one “chooses” diabetes
 - people have responsibility for managing their disease but are not to blame for it
- **Blame and shame cause harm and are not effective clinical tools**
 - blame is not an effective strategy for encouraging management skills
 - shame undermines positive change
- **Most people are trying their best**
 - what “best” looks like reflects circumstance, capability, and full context of their life
 - obstacles take many forms: financial, emotional, access (healthcare, food, safety)

What 3 things do you want people to know about diabetes stigma?

Because they ladder well conceptually, here are the five ideas that Jane K. Dickinson articulated:

- Stigma directly and negatively **affects a person's ability to manage** their diabetes.
- Stigma directly and negatively **affects people's thoughts about themselves**, which then indirectly affects people's motivation and their behaviors.
- Stigma directly **affects how providers interact** with patients.
- Stigma is **directly connected to how we talk** about people w diabetes.
 - we cannot separate words from the context of people's experience, and because the words are so often negative and judgmental, they impact stigma.
- **Stigma is also communicated through actions and choices, implicit/explicit biases**

“People hear all the little conversations that we have in our heads about them; that comes through in our interactions.”

– Virginia Valentine

Other comments SSG members made when asked about stigma:

- Even though diabetes is preventable, starting with the idea of preventing diabetes may not be the best option; **prevention messages can lead to stigma.**
- **Diabetes is complex and different for everyone**, and stigma comes in many flavors. One **common diabetes experience: loneliness, alienation, powerlessness.**
- Lot's of **people don't know that they've been a victim of stigma...** any time people feel reluctant to ask questions of their doctor, feel devalued... [that's] stigma.
- [specifically for T2 folks] you shouldn't feel any shame about management; **whatever you have to for do management is okay**, the focus should be on doing what you can, not feeling like you're a failure because you ended up on insulin.
- People are doing the best they can: **Don't make assumptions.** Everyone is interested in being healthy, but [vary] in capacity.
- There are so many people who experience stigma in awful ways because of obesity, and this **can lead people to the mindset of: “don't talk about healthy at all.”**
- **People don't know what “stigma” means** – show people experiences, demonstrate the scenarios in which stigma occurs, let people identify with the experience, then help them understand ways to talk about it.
- **We already know enough to craft a core story** over the course of a couple days [e.g., in a workshop, with right group of people]; *a minority view*
- Diabetes is a **disease state and not a behavioral state.**
- [Clinicians need to] **motivate people with a carrot, not a stick.** The medical community too often talks about all the things that will go wrong. Then people feel like, “Why should I bother?” instead of [being engaged by positives messages and actions].



Where might we focus?

This graphic visualizes the tension between reducing stigma in the lives of individuals with diabetes and raising public awareness as a strategy for trying to bend the curve on diabetes. Interviewees acknowledged the challenge of figuring out where to start.

	Diabetes World People who think or talk about diabetes	Non-Diabetes World People who don't think or talk (much) about diabetes
<i>What challenge should we focus on?</i>	<p>Diabetes? Blame & Shame</p> <p>STIGMA</p> <p>Obesity? Race/ethnicity?</p> <p>Stigma can be a barrier to awareness because it makes PWD not want to be exposed</p>	<p>Understanding? Concern?</p> <p>AWARENESS</p> <p>Empathy? Alarm?</p> <p>Lack of diabetes visibility and context (in media, at work, in community) allows stigma to go unaddressed</p>
<i>Helps how?</i>	Improve things for individuals	Improve things for population
<i>Who is involved?</i>	<p>Who is doing the talking?</p> <ul style="list-style-type: none"> • HCPs • PWD • Industry • Advocates • Friends and family • Media (only a little, what does portrayal look like?) 	<p>Who is doing the not-talking?</p> <ul style="list-style-type: none"> • General public (mostly non-diagnosed, but also diagnosed) • Media • PWD and friends and family • HCPs (primary care) • Research funders (Congress)
<i>Strategies?</i>	Reduce stigmatizing messages (in language and behavior), and give people permission to let go of self-stigma	Develop a cohesive, consistent, intentionally framed core story about diabetes (and PWD) for delivery to varied audiences through multiple channels.
<i>Project ideas?</i>	<p>Help professional communicators do better</p> <p>Improve HCP stigma awareness and tools</p> <p>Curate stigma resource hub</p>	<p>Ladder precursor steps:</p> <ul style="list-style-type: none"> • research • core story • message testing • spokespeople <p>Media tracking and analysis</p>
<i>Considerations?</i>	<p>Industry easier (low-impact)</p> <p>HCPs hard, critical (high impact)</p>	<p>Hard, but bigger impact?</p> <p>Scale needed to tackle epidemic</p>

Most interviewees (but not all) suggested that starting with pilot projects in “diabetes” world” would be an advantage, both to provide some easier “wins” and to learn valuable lessons that can inform a large-scale media campaign for the general public.

Project ideas

A number of specific stigma-related project ideas arose in stakeholder interviews. In some cases, experts were asked to comment on ideas that had been suggested as part of the brainstorming work d19 and d20 events. In other cases, interviewees suggested project ideas.

Stigma information and resource hub

WHAT is it? A website (or set of web pages) that consolidates information about diabetes stigma (and weight stigma) into an expertly curated, easily-accessible, easily-shareable resource. Envisioned as “one-stop shopping:” a single place people can visit to learn about the kinds of stigma that affect people with diabetes:

- what stigma is and why it matters
- what stigma can look like (show variations)
- how to challenge it
- how to avoid stigmatizing people with diabetes
 - messages you send
 - language you use
 - context you create

WHO is it for? People who write and talk about diabetes (industry, advocacy groups, professional orgs, public health professionals, healthcare organizations, insurers, journalists, media/entertainment).

A secondary/distinct audience might be people with diabetes, though some experts caution against focusing on language used by PWD in the current cultural climate (risk being perceived as “word police”).

WHY do this? Stigma is not well understood, resources for media and journalists are scant, and information available about diabetes stigma is scattered across multiple stakeholder sites (ADA, ADCES, diaTribe, and others).

Considerations / ideas / comments:

- start with compilation, curation, and presentation; then consider content creation
- simple, not academic or formal, easily usable and accessible
- scenarios guide that gives example situations of diabetes stigma in action, and potential responses and actions to mitigate stigma
- videos might show different flavors of stigma in different settings (like healthcare interactions, workplace, family gatherings, etc.)
- style guide for newspapers/journalists is key
- a social media toolkit with customizable tweets and Facebook/Instagram/LinkedIn posts about diabetes stigma and framing
- might diaTribe be a good host for this as an independent well-respected voice?
- who might help fund this?
- might it be endorsed/promoted by multiple diabetes organizations?

Industry-driven stigma initiative

WHAT is it? Encourage pharma, device, and diagnostic companies and other diabetes-related businesses, to raise awareness of diabetes-related stigma and how intentional communication from “industry” can help.

WHO is it for? Communications professionals in Public Relations, Marketing, Sales, Learning & Development, and other functional groups.

WHY do this? Diabetes-related business, as well as advocacy groups and non-profits, communicate about diabetes every day to people with diabetes, healthcare providers, payers, investors, and policy makers. The diabetes industry is relatively small, communications professionals care about their craft and are motivated to learn. In addition, as employers, diabetes-related businesses can also

play a role in educating the people they employ about diabetes stigma through employee-focused education, wellness programs, and other internal communications.

Considerations / ideas:

- preferable to work with an industry coalition
- resources suggested include:
 - white paper or guide summarizing language and imagery suggestions
 - framing fact sheet that expands on the five basic frames
 - tip sheet for effective communication strategies to educate others about diabetes stigma
 - a language guide that gives examples of “instead of this, say that”
 - communications audit protocol/ suggestions
 - content for sales module that can educate sales force about stigma and language

Framing / Language trainings

WHAT is it? Small-group workshops that focus on practical application of framing technique and non-stigmatizing language and provide an opportunity to practice skills in a supporting environment.

WHO is it for? Communications professionals (industry, healthcare, advocacy, political, journalists, media/entertainment).

WHY do this? Learning about framing content from d20 was valued, but some participants asked for more opportunities to practice and for more resources to help with putting the techniques into practice.

Considerations / ideas:

- how might this be funded?

Academic 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 on health systems and populations.

Considerations:

- might there be a benefit if created/announced as a joint effort from multiple diabetes organizations?
- need to establish research priorities and key topics of interest
- what does a research agenda need to look like to be credible? (what process? how formal?)

Audience / Ethnographic research

WHAT is it? Use market research and ethnographic methods (e.g., personal stories) to learn about and document the experiences, attitudes, and perceptions of stigma and bias among people with diabetes.

A separate project could use market research to identify and describe audiences for stigma messaging.

WHO is it for? Advocates, messaging/campaign strategists, researchers, healthcare providers, people with diabetes.

WHY do this? As a compliment to academic research, this project (or projects) can help us focus resources, improve efficacy of stigma-busting efforts, and enhance credibility for proposed solutions among people with diabetes.

Directly engaging people with diabetes can help us better understand both the diversity and commonality of experiences, and the ways people interpret those personal experiences.

Personal stories are a common tool in stigma-busting efforts and are widely used in other domains (mental health, abortion, HIV/AIDS, etc.) as a proxy for contact, to create empathy, and to build community.

Considerations / ideas:

- what can we learn and use quickly while waiting for completion of needed academic research?
- how might “softer” research add value beyond what academic research will contribute?
- storytelling is relatively common in the diabetes ecosystem (online communities, patient story walls, etc.); how might we help add a stigma focus to what currently exists?

National media campaign to raise awareness of diabetes stigma

WHAT is it? Coordinated messaging campaign aimed at national audience that will raise awareness of diabetes stigma

WHO is it for? General public, PWD, policy makers.

WHY do this? To create a serious national conversation about the impact of diabetes on peoples lives, and the impact of our attitudes and words on people with diabetes

Considerations / ideas:

- would want to do small pilot projects first
- what is lost/gained by focusing on specific regions as opposed to a national campaign?
- a media campaign that raises awareness about diabetes stigma
 - videos of people with diabetes that showcase diversity (backgrounds/lifestyles)
 - videos to humanize people through phrases like “I am a mom of three, a software engineer, a soup kitchen volunteer, and a person with diabetes.”
- identify diabetes “docents” (people on the ground) and create a diabetes stigma / implicit bias education training program for them to disseminate through their work.
- partner with ADA, NMQF, other orgs with existing diabetes efforts (e.g., 100 years of insulin), add elements of stigma education.
- visual public health campaign (posters, stickers, etc.) to draw attention to diabetes stigma.
- pledge cards: small, customizable, and visually appealing templates that can be distributed to individuals or organizations to post on their websites/social media channels.

Media campaign aimed at congress

WHAT is it ? Coordinated messaging and advertising campaign that raises diabetes as an issue of national concern.

WHO is it for? Members of congress and their staff, general public, PWD.

WHY do this? Congress holds the key to funding (NIH); the issue of diabetes is (we assume) not well understood.

Considerations / ideas:

- need to drive constituent interest first?

Tracking/Reporting: Diabetes in media and culture

WHAT is it? Collect, analyze, and share data on the portrayal of people with diabetes in media (broadcast news, entertainment, print, sports, social media, etc.).

WHO is it for? Content creators and publishers including journalists, editors, publishers, entertainment industry professionals (writers, producers, executives, talent, etc.), and social media influencers.

WHY do this? Data is foundational for establishing the problem, establishes credibility for media advocates, and is critical information for directing strategy and tactics.

Considerations / ideas:

- like GLAAD... see ADD idea that emerged from d19 brainstorming
- connect with journalists, editors, publishers to better understand how to raise the profile of diabetes and stigma; what interests/doesn't interest them? Barriers?
- fund a 3-month effort fueled by interns to look at print journalism, streaming media, network television, film, etc.
- create [1-week] curriculum for media portrayal research that can be used in college classes; purpose is to leverage students to do collection work.
- might start with the other social media diabetes communications: Healthline for instance, writes about diabetes constantly

Healthcare provider education and tools

WHAT is it? One or more projects aimed at raising awareness of diabetes (and weight) stigma among healthcare providers by providing education, resources, experiences, and tools.

WHO is it for? Healthcare providers and/or providers in training.

WHY do this? The impact of experiencing stigmatizing language and behavior in care settings can be significant and lasting for people with diabetes. In addition: successful efforts to raise awareness of diabetes and prediabetes in the general public are likely to encourage people to seek care and guidance from healthcare providers; addressing stigma in healthcare settings is therefore a key element of a systemic approach to addressing the diabetes epidemic.

Considerations / ideas:

- medical education curriculum for tomorrow's care providers (academic medical centers, nursing programs, DE education, etc.)
- where might we create a pilot program?
- what models exist that we might follow?
- need to raise awareness of diabetes/weight stigma in clinical settings
- research/data necessary but not sufficient to change provider attitudes behavior
- experiences (like having to track glucose, food, and exercise for a week) and contact-based learning opportunities help create understanding and empathy
- partner with a large healthcare organization?
- providers (like most people) don't see their own bias; an interactive "implicit bias tool" might help and could report out recommendations for learning
- CME is an opportunity for practicing clinicians to learn about stigma

Landscape research

Landscape research is an essential part of an initial discovery process and is intended to help answer the questions: What already exists? What other stigma-busting efforts might we learn from? What content and materials might we model our deliverables after?

METHOD

Initial Internet research was conducted by Emphatic Communications in January – March 2021, primarily using Google and DuckDuckGo search engines. Searches were also conducted within specific diabetes organization websites (e.g., ADA, Diabetes.UK), research archives (e.g., PubMed, ResearchGate), and on YouTube. Links were captured and labeled; when deemed relevant, documents or other types of resources were downloaded, screen shots of high-value stigma-related websites were captured.

OBJECTIVE

The primary objective was to learn from any existing diabetes-related, stigma-specific efforts, identify coalitions and collaborations working on stigma in other areas, and find practical resources created to address stigma and bias. Academic research was not the focus of this effort. Example target resources:

- consensus reports, white papers, strategic plans
- communication hubs
- conversation guides and fact sheets
- videos
- tool kits
- trainings
- social media campaigns
- media analysis and guidelines

Findings

Over 240+ resources have been identified as related to stigma and potentially informative. Analysis and extraction of key lessons is underway. Meanwhile, the select resources below illustrate a variety of approaches, budgets, funders, areas of focus, target audiences, polish, type of resources, and degree of thoroughness.

A few highlights

Strategic guidance

- **Shatterproof.** Working on addiction stigma with assistance from McKinsey and the [Public Good Projects](#).
 - 2020 White paper/ strategic stigma plan: [A Movement to End Addiction Stigma](#); *highly recommended*.
 - web pages of note: [Learnings from successful change movements](#) and [Plan to Combat Stigma](#).
- **Sea Change Program.** Now sunsetted; was dedicated to transforming the culture of stigma around abortion and other stigmatized reproductive experiences.
 - [The Stigma Toolkit](#). Provides tools for communities and organizers to use.
- **NASEM:** [Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change \(2016\)](#);
 - National Academies (of Sciences, Engineering, and Medicine consensus report on stigma and what has worked to change negative norms concerning mental and substance use disorders.

Media analysis and guidelines

- **Mindframe.** Mindframe supports safe media reporting, portrayal and communication about suicide, mental ill-health, alcohol and other drugs and provides comprehensive national guidance, training and education. Well-funded, and nicely produced content and presentation.
 - [Mental ill-health and suicide: A Mindframe resource for stage and screen](#)
 - [SANE Australia StigmaWatch](#); an online resource and stigma reporting site
- **Guidelines for Media Portrayals of Individuals Affected by Obesity**, a joint effort of The Rudd Center for Food Policy and Obesity, The Obesity Society, Obesity Action Coalition, Obesity Medicine Association, and American Society for Metabolic and Bariatric Surgery.
- **Rethink Obesity: A media guide on how to report on obesity** from Obesity Australia; good examples of imagery but uses problematic myth/fact construction.
- **HIV & AIDS in the News: A Guide for Reporting in a New Era of Prevention & Treatment** 2015 joint effort of GLAAD, Elizabeth Taylor AIDS Foundation, and AIDS United; robust content.

Stigma information hubs and resources

- **Stigma-Free Society**; based in BC Canada; expanded from mental health focus to all kinds of stigma and offers a variety of resources.
 - example of youth/educator tool: [Stigma-Free COVID-19 Youth Wellness Toolkit](#)
- **Obesity Action Coalition**; The OAC is a leading voice on obesity stigma working on awareness, education, advocacy, and support for people and their health. Links to a variety of programs, resources, and donation opportunities.

- **StigmaFreeWV.** Example of a state resource focused on mental health. Links to a variety of videos and tools; less polished than some sites and more robust than many state hubs.
- The **Anti-Stigma Project.** Formed in 1993, focused on mental health, appears to be one of the longest running stigma efforts.
 - [Anti-stigma trainings](#)
 - [Distorted Perceptions Campaign](#)
- **Make It Ok.org**; focused on mental health, examples of what stigma looks like, quizzes, read/share stories, take a pledge, etc.
- **Time to change.org** [Global anti-stigma toolkit](#), focused on mental health, with a specific focus on global audiences and lived experiences in specific countries.
- **BringChangeToMind**, high-profile, 10 years of advocacy on stigma and mental health.

Language

- **NHS England – Language Matters:** [Language and Diabetes](#); 2018 booklet is a brief practical resource; many other similar resources exist.
- **International Planned Parenthood Federation:** [How to talk about abortion: a guide to rights-based messaging](#); a robust resource, includes language guidance, checklists, image guides, background on stigma; strong advocacy perspective.

Imagined contact: personal stories

- **Greaterthan.org**, focused on HIV, includes personal stories, fact sheets, other support information.
- **Mental Health Coalition** [How Are You Really?](#) Uplifting, honest stories focused on mental health experiences.

What does diabetes stigma look like in the media?

Over the past few months, diaTribe has been collecting articles, stories, videos, and other forms of media which show examples of how diabetes, overweight, and obesity are portrayed in the media and how the stigmas surrounding these issues are being talked about. We have curated a short list of some of the most notable articles here.

“A Thank You to Diabetes”

Written for Beyond Type 1, the author of this article does a great job framing diabetes stigma in the introduction by relating it to our tendency to blame people for unfortunate circumstances. In doing so, it set up the article to tackle a difficult topic with a sense of optimism.

“Misrepresentation of Type 1 Diabetes in the Media”

This author highlights some notably-inaccurate representations of people with type 1 diabetes in popular media. From sitcom episodes, to children’s shows, to movies, stigma and over-exaggerated symptoms and treatments come to the forefront and lead to negative consequences.

“Living the Dream: Becoming a UK Soccer Star with Type 1 Diabetes”

This is an interesting article about a professional athlete with type 1 diabetes and his experiences confronting stigma in a hyper-masculine, show-no-weakness sports culture.

“Expert Perspectives: How does stigma affect people with type 2 diabetes?”

This article includes valuable expert opinions to explain what diabetes stigma is, including why it exists and the harm it can cause to people living with diabetes.

“Everything You Know About Obesity is Wrong”

The hook for this article is particularly powerful: “For decades, the medical community has ignored mountains of evidence to wage a cruel and futile war on fat people, poisoning public perception and ruining millions of lives. It’s time for a new paradigm.” The rest of the article is equally as powerful, bringing in individual stories and research on how we got it wrong when it comes to overweight and obesity.

“The Harmful and Insidious Effects of Fatphobia”

The author of this article tackles weight stigma, labeling it “fatphobia.” In particular, the author does a good job leading with the facts (instead of the myths) and showcasing the large scope of this problem.

“Leave Fat Kids Alone” and the associated reader responses “Ending Obesity, and Its Stigma”

In the primary article, the author argues that the “war on childhood obesity” hasn’t solved much, but it has led to a lot of shame. Unfortunately, the reader responses to this article, which vary from people using stigmatizing language themselves to people sharing their own stories of the shame they felt, show that a lot of work still needs to be done.

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WRITTEN BY

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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.

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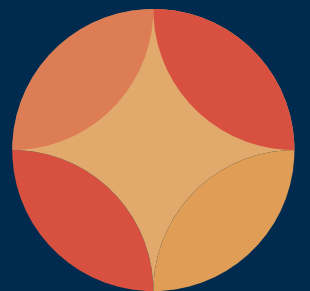


EXECUTIVE INNOVATION LAB IN
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PARTICIPANT PRE-READER

MODULE 2

MAY 25, 2021



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TABLE OF CONTENTS

Agenda	2
dNetwork Stigma Busting Priorities	3
Shifting Stigma – What Do We Know?	7
Citations	13



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
-



dNetwork Stigma-Busting Priorities

What is our goal?

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.



How will we get there?

1. **Getting Smarter Together.** Bringing leaders together to better understand the world of diabetes and how we can work together to reduce its impact. Sharing best practices for change, and commissioning research and training to fill gaps in our knowledge & skills.
2. **Educating & Influencing.** Working to reduce misplaced blame by shifting messaging in our individual and collective spheres of influence with evidence-based, stigma-busting language and frames. (See [part 2](#) of this pre-reader for a review of resources).
3. **Activating Ourselves and Others.** Building a movement and leveraging our influence to engage more and more leaders across levels to change behavior, culture, policies, and systems. Together we can pool resources and mobilize power to reach our goal!

diaTribe	dNetwork leadership
<p>As the CONVENOR & COORDINATOR for the dNetwork, diaTribe has committed to delivering the following:</p> <ul style="list-style-type: none"> • A systems map of the diabetes ecosystem and collective identification of key levers for change • A strategic roadmap for one key lever – reducing diabetes stigma • A stigma research agenda and support of essential research funding 	<p>With additional resources, partnership, and member leadership, together we could also deliver:</p> <ul style="list-style-type: none"> • High impact media and culture change strategy & campaigns • Stigma-reducing training for health care providers • Legislative and health care policy campaigns to reduce the impact of diabetes • And more – where your interests + dNetwork goals align

- A centralized diabetes **stigma resource hub**
- **Convenings** of the dNetwork + regular spaces to drive forward shared learning and action (dSeries+)
- **Strategic engagement** of policy makers, business leaders, and influencers to support ongoing systemic change efforts

How can you contribute?

We know you are all busy leaders with many commitments. So in **Module 2** we want to explore where this effort and your commitments and interests align to help us develop an actionable strategic roadmap for this effort.

In preparation for our time together, we ask you to reflect on the following questions:

Where does stigma-busting intersect with your work / passion projects? How would eliminating diabetes stigma make your work / passion projects easier?	Where might you be able to contribute leadership to this effort with the most ease? <i>(see table below for some ideas!)</i>	What kind of support do you need from diaTribe & the dNetwork in the years ahead to support your easeful participation in this effort?
--	--	--

As noted above, diaTribe has committed time and resources to develop some key catalyzing resources for this long-game effort. With your input and support, we are building a research agenda and a strategic stigma-busting roadmap for launch after **Module 3**. We are also developing a website home for our work – this website will start as an information and education hub and can evolve to support future campaigns co-created with, and by, dNetwork members. As a small nonprofit, diaTribe can only take on so much toward our ambitious goals. But as a diverse network of powerful influencers and organizations from across the diabetes ecosystem, we can move mountains – *if* we align incentives and resources wisely.

To go further and faster in this long-game effort, we will need your leadership.

Based on input from Module 1 and some recent interviews with dNetwork members, we are proposing five areas of engagement for the next year that we work on developing and advancing through d21 and beyond. **At Module 2 we will break out into action planning work groups in each of these 5+ areas – please review them in advance and consider which area you would most like to participate in moving forward.**

Research	<ul style="list-style-type: none"> ● Answer: What theory of stigma is most resonant for our work in diabetes? ● Answer: What baselines and metrics would best help us measure the efficacy of our efforts to reduce stigma? ● Conduct a literature review ● Input into research agenda development ● Design, conduct, and/or fund research projects
Website Launch	<ul style="list-style-type: none"> ● Provide reactions and input to web design team as needed ● Share or help develop content and resources with web team for inclusion in the stigma information hub ● Help develop and launch a brand and marketing plan
Network Development	<ul style="list-style-type: none"> ● Help us define levels of membership and engagement ● Help us develop our Influencer Pledge to enhance commitment to contact-based education strategies (<i>see part 2 of pre-reader</i>) ● Support recruitment strategy and actions for future dNetwork growth ● Support pooled fund development for future dNetwork projects
Health-Care Provider Engagement	<ul style="list-style-type: none"> ● Lead process to research and evaluate the effectiveness of current stigma reduction programs in healthcare ● Design CME curriculum or partner with existing programs we might draw on ● Design medical school curriculum or partner with existing programs we might draw on ● Other methods based on research TBD
Media Advocacy	<ul style="list-style-type: none"> ● Track news, TV, movies, etc. for stigma related content ● Seek targeted stigma-busting wins in mainstream media depiction of characters with diabetes ● Develop targeted campaigns and toolkits to change diabetes representation in media ● Develop style guide
Other?	<ul style="list-style-type: none"> ● Do you have a passion project idea that you are willing to lead with support from other dNetwork members? Bring your proposals to Module 2!



We look forward to exploring these areas of action together with you in the coming months!

The next section of this pre-reader offers an updated compilation of what we know about shifting stigma. We all want to continually revisit this evidence-based information and consider how we can use it to inform our collective strategies and create change one conversation at a time, every day, in our myriad spheres of influence.

Shifting Stigma – What Do We Know?

Diabetes stigma: the experiences of exclusion, rejection, prejudice, or blame that patients unfairly experience due to their condition

Evidence shows that stigma (the negative attitudes or discrimination against someone based on a distinguishing characteristic) is a significant source of stress and social disadvantage for affected individuals, and it is a driver of morbidity and mortality at the population level.^{1,2}

Diabetes stigma stems largely from the belief that individual behavior and poor choices result in developing diabetes. People with diabetes have reported feelings of fear of social embarrassment, rejection, being treated differently, and guilt associated with behaviors such as injecting insulin or refusing unhealthy food options at social events.² Moreover, adults with diabetes have reported that stigma and discrimination exist in the workplace, in travel, in maintaining friendships, and even in adopting children.¹ The experience of diabetes stigma also disproportionately affects those with a higher BMI, higher A1C (and less Time in Range), and poorer self-reported blood glucose control.³

Combatting and eliminating stigma is crucial to being able to make significant progress in the diabetes epidemic and affect the other levers for change that were identified at d19. We need to synthesize the work done in other social movements to understand how to shift stigma. This allows us to identify areas where we can incorporate strategies into our individual work and life to influence change within our personal networks and spheres of influence.

There is much to learn from other stigma efforts

A variety of evidence-based approaches have been used to address stigma – from education to media campaigns to legislative actions

Prior social movements have done significant work identifying strategies for shifting stigma and interventions that can be leveraged to change people's attitudes and prejudices. Interventions are organized efforts aimed at promoting specific behaviors and habits that can improve physical, mental and emotional health. Intervention strategies can often be separated into two main categories:^{4,5}

	Aim	Examples
Interpersonal and/or intrapersonal level	Combat self-stigma and stigma purported by an individual's beliefs or behaviors.	Counseling and peer-based approaches, information-based education, skills-based education, and contact with affected groups. ⁴⁻⁸
Structural level	Combat stigma that is purported by institutions, laws and policies, and the media – this requires collective action and widespread social pressure. ⁴	Protest and advocacy, legislative and policy change, social marketing and media campaigns, and involving community members (“from self-help to social reform”). ⁴⁻⁸

Focal area: Education is key to affecting change

Education is consistently used across social movements and is one of the core methods for affecting change.

- These interventions can present factual information to combat misinformation and harmful myths or beliefs about the stigmatized group (information-based).⁵
- They can also provide practical skills for working with stigmatized groups or addressing stigma when it is encountered (skills-based).⁴
- Educational interventions can take the form of educational programs, modules, trainings, videos, conversation guides, multi-day workshops, free tool kits, web-based learning tools, or contact with affected groups.
- Education must always be thought of in the context of audience and framing. How information is presented to one group may need to be very different from how it is presented to another group.
- One of the best ways to educate in practice is to utilize personal interaction with people who have diabetes and the groups that are perpetuating stigma. This contact-based approach is discussed in more detail below.

The research shows that educational interventions have varying results.⁴⁻⁸ It's important to note that information-only campaigns have been shown to be less effective than those which also include some skills-building⁴ and that educational interventions are much more effective at reducing stigma in youth and adolescent groups than in adults.^{4,5}



We can draw on existing work on addressing diabetes stigma with educational interventions

- Leading experts have identified the language we use to talk about diabetes as a key target for education. Dickinson, et. al. identified several guidelines and recommendations for talking about diabetes.⁹ You can learn more about language recommendations from “[The Use of Language in Diabetes Care and Education](#)” from Dickinson, et. al. or “[Language Matters](#)” from the NHS England.

Guiding principles for communication with and about people living with diabetes	Diabetes is a complex and challenging disease involving many factors and variables.
	Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment.
	Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach.
	Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes.
Use language that:	Is neutral, nonjudgmental, and based on facts, actions, or physiology/biology.
	Is free from stigma.
	Is strengths-based, respectful, inclusive, and imparts hope.
	Fosters collaboration between patients and providers.
	Is person-centered.

(Adapted from “[The Use of Language in Diabetes Care and Education](#)”)

- Another key target is framing diabetes to others. Framing means making choices about how we explain an issue or problem, what we emphasize, what we say – and what we don’t say.¹⁰ By carefully framing educational materials (and by extension other interventional strategies such as large-scale media campaigns), we can create messages that avoid othering and instead recognize our universal experience. The FrameWorks Institute made recommendations to addressing diabetes stigma at d20 which include:

<p>Show – don't tell – what stigma is and explain implicit bias.</p>	<ul style="list-style-type: none"> • Simply saying that certain groups are stigmatized does little to help combat stigma and can even backfire. Show people what stigma looks like. • Explaining what implicit bias is (the unconscious ways of thinking about groups of people) and how it is harmful helps people understand that diabetes and the stigma around it are challenges we need to address together.
<p>Start with what you want people to know about diabetes instead of repeating damaging myths.</p>	<ul style="list-style-type: none"> • The myth-fact structure common in communications about health often backfires – we tend to remember the thing we hear or read first, so we are more likely to remember the myth as true. • The backfire effect can get worse over time as people's memories begin to fade, and even lead people to attribute the myth to the people trying to refute it. • Always try to avoid repeating false information about diabetes, and if you have to refute false information, start with the facts.
<p>Explain equity and always link it to clear solutions.</p>	<ul style="list-style-type: none"> • Racial inequities affect every aspect of our lives, including our health outcomes. Diabetes is no exception. • Most people don't understand what inequity means, or how inequities work. Communications should clearly explain what inequity is and why it is important to address.
<p>Avoid crisis: instead talk about how we can tackle diabetes, together.</p>	<ul style="list-style-type: none"> • Talking about diabetes as a public health crisis makes sense, but crisis messaging often presents problems as too big and overwhelming to solve. • When everything appears to be a crisis, crisis fatigue begins to set in. Rather than engage, people tune out. • If we want sustained attention and support for treating the diabetes epidemic, we need to keep people engaged over the long term – not just short term for the crisis.
<p>Talk about what we all need to be healthy, while still discussing people's specific needs.</p>	<ul style="list-style-type: none"> • In our society, people are thought to be solely responsible for our own health. • When we use messages that begin by emphasizing what we all need to have good health – like high quality preventative healthcare, access to safe and exercise-friendly outdoor spaces, and healthy affordable food choices – we divert thinking away from individual blame and toward our common experiences.

(Adapted from "[Changing the Narrative around Diabetes: A FrameWorks Framing Brief](#)")

Education can be bolstered through contact with affected groups

People without stigmatized conditions often have little meaningful contact with those who do, fostering discomfort and prejudice toward stigmatized groups.¹¹ One of the most vital ways for a person to reduce stigma is directly interacting with groups that are experiencing it.⁴⁻⁸

- Contact interventions aim to create in-person interactions between majority and minority individuals which can lead to reductions in prejudice between the groups.⁴
- This could include actual one on one connections, or facilitating spokespeople to educate groups and present an actual face for the stigmatized condition.⁵
- Contact interventions, especially when combined with education, have been shown to have sustained improvements over time, and they have been shown to be generalizable outside the intervention group.⁴

Looking forward: Larger structural interventions could be right on the horizon, as well as more targeted, interpersonal interventions, like counseling and peer-support

1. Counseling and peer-based approaches
 - The research on these intervention strategies is promising. Counseling and peer-support services have been shown to reduce anxiety and internalized stigma, provide emotional support and coping mechanisms for dealing with stigma, provide healthcare information, and help build community.⁴⁻⁸
2. Social marketing and media campaigns
 - This is a huge target that requires careful thinking around audiences, framing, education, and visibility.
 - Research has shown that these campaigns generally have positive effects.^{4,6} In these campaigns, it will be key to alter the current media narrative around the stigmatized group using framing techniques.
 - The outcomes of these campaigns are difficult to measure given the very large target population; the impacts on the target audience's behavior, attitudes, and emotions and whether the campaign's messages penetrated into the culture of the target audience are not easily quantified.⁴
3. Legislative and policy interventions
 - Though enacting these changes takes significant resources and mobilizing, their impact is often widespread and positive, especially in addressing the larger, structural issues that lead to stigma.⁵
 - These interventions have proven to be particularly successful in the LGBTQ and Civil Rights movements and in reducing HIV stigma.^{5,6}

4. Advocacy

- Often the catalyst that leads to the legislative and policy changes addressed above, protest is generally defined as an action that calls public attention to the stigmatizing attitudes and the behaviors that promote these attitudes and often starts with advocacy efforts at the grassroots level.^{4,5}
- Again we can look to the LGBTQ and Civil Rights Movements as evidence of the effectiveness of this intervention.
- Though the research shows that protest can generally lead to positive outcomes, there is also evidence that this type of inflammatory action can lead to retaliation from opposing groups.⁵

A final note on defining and measuring successful stigma reduction

To be able to align around shared measures of success, we must first align around which evidence-based models of stigma interventions make the most sense for applying to diabetes. We hope to engage our research group on this task at Module 2

It's also worth noting that though we know that evidence-based approaches are essential to measuring efficacy – prior efforts also show us why and where measurement can be especially tricky in practice when it comes to a stigma-reduction interventions:

- Interventions to shift stigma often use multiple strategies simultaneously. Additionally, there is often overlap between types of interventions. These factors make it difficult to identify which strategies actually work.
- There is a lack of valid, reliable, or consistent measures of stigma interventions.
- There are discrepancies in research methods (such as a lack of control groups) between studies.
- There is often no data on the long-term effects of an intervention strategy.

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DIABETES AND PREDIABETES

MODULE 2 SUMMARY
& HIGHLIGHTS





TABLE OF CONTENTS

Agenda	2
Welcome Back to d21	3
Grounding in the Why	3
Flash Visioning	5
Mapping Our Interests in the Stigma Fight	6
Collective Action Strategy and Updates	7
Action Planning Working Groups	8
Research	8
Stigma Information Hub	10
dNetwork Development	11
Healthcare Provider Engagement	13
Media Advocacy	14
Closing Reflections	16



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

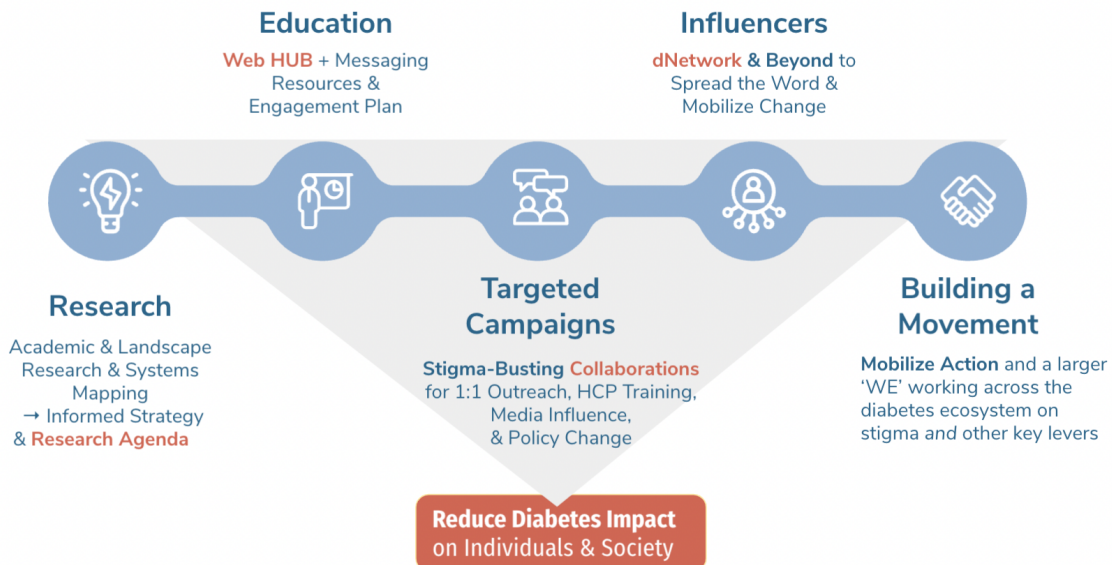
Reducing the impact of diabetes on society and improving the lives of people with diabetes by fostering understanding of the disease, eliminating misplaced blame, and ensuring access to care.



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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BROOKING GATEWOOD, AND JIM CARROLL

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EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

PARTICIPANT PRE-READER

MODULE 3

JULY 20-21, 2021



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TABLE OF CONTENTS

Agenda	2
Refresher: dNetwork Stigma-Busting Priorities	3
Diabetes Stigma Story Building Blocks	4
Other Stigma Concepts and Messages	6
Types of Stories	7
More on the Public Narrative	8



d21 EXECUTIVE INNOVATION LAB ON DIABETES AND PREDIABETES

AGENDA

MODULE 3: SHAPING STORIES FOR CHANGE

Wednesday, July 21, 9:00–1:00 PDT/12:00–4:00 EDT – Zoom

-
- 9:00 AM** OPENING REMARKS
Welcome Back for Module 3!
Collecting insights from the Lightning Talks
-
- 9:15 AM** BREAKOUTS AND SHARE-BACKS
Core Project Ideation Sessions
Furthering core messaging
-
- 10:15 AM** Break
-
- 10:30 AM** FULL GROUP WORKSHOP
Delivering the Message: Stigma-Busting Storytelling Workshop
Understanding the core messages, identifying audiences, and individual story development
-
- 12:00 PM** BREAKOUTS AND SHARE-BACKS
Looking Ahead
Updates and next steps for our stigma-busting action areas, integrating story-telling into our individual and collective actions, and what's beyond d21
-
- 12:40 PM** CLOSING REMARKS
Next Steps
-

Refresher: dNetwork Stigma-Busting Priorities

What is our goal?

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 will we get there?

1. **Getting Smarter Together.** Bringing leaders together to better understand the world of diabetes and how we can work together to reduce its impact. Sharing best practices for change, and commissioning research and training to fill gaps in our knowledge & skills.
2. **Educating & Influencing.** 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 Ourselves and Others.** Building a movement and leveraging our influence to engage more and more leaders across levels to change behavior, culture, policies, and systems. Together we can pool resources and mobilize power to reach our goal!

What is our focus for Module 3?

Practicing stigma-shifting messaging through powerful storytelling

Over the last year working together on this topic, we've been collecting core messages - from you and from landscape research - which we have compiled as a reference in the coming pages. As we shared in the [Module 2 pre-reader](#), research shows that 1-on-1 contact-based education strategies are some of the most effective ways to shift stigma. So our work in Module 3 will involve crafting customized stories for the audiences we can influence that help change the narrative on diabetes in America. This pre-reader offers some resources to help you think about the kinds of stories you might tell to help others think differently about diabetes.



Quick-reference guide: Diabetes stigma story building blocks

WHAT we want to say reflects our knowledge and values

Key ideas

Essential concepts written as impersonal statements, usually focused on a single issue; ideally these ideas are facts, but they may also be assumptions (to be validated when possible) or consensus opinions.

HOW we say things reflects our target audience(s) and context

See *Message, Narrative, Story* on next page.

Diabetes	Stigma	Diabetes Stigma
Diabetes is a serious complicated disease.	Stigma is real, complex, intersectional, and individual.	Stigma is a barrier to efforts that seek to address diabetes care in the US.
Diabetes is the product of complex factors.	Stigma comes in many flavors.	Stigma is directly connected to how we talk about people with diabetes.
People are responsible for managing their disease but are not to blame for it.	Blame and shame cause harm.	Stigma can be experienced differently for people with T1 (disability) and T2 (responsibility).
Diabetes is individual — it is different for each person	Shame undermines positive behavior change.	More research on diabetes stigma is needed.
Common diabetes experiences include feelings of loneliness, alienation, and powerlessness.	Stigma directly and negatively affects a person's ability to manage their diabetes.	Some people intentionally blame people with diabetes because they think it will spur action.
Diabetes is doable — it can be managed, but it is hard and tiring.	Stigma directly and negatively affects people's thoughts about themselves, which then indirectly affects people's motivation and their behaviors.	Shaming people with diabetes is not an effective way to help them more effectively manage their disease.
Diabetes management is getting better.	Stigma is also communicated through actions and choices, implicit/explicit biases.	Genuine compassion and person-centered, empowering language help reduce diabetes stigma.
The impact goes beyond individuals — diabetes is a public health and equity issue.	People may not realize that they've experienced stigma.	
Diabetes disproportionately affects communities of color and lower income communities.	Stigma directly affects how providers interact with patients.	
We need systemic solutions that include community support, culture change, and equitable access to quality foods, healthcare, exercise and information.		

The ideas listed above have been distilled from research, participant ideation at dSeries events, and stakeholder interviews. In each column, ideas are arranged from top to bottom in a logical sequence to help identify whether any key ideas are missing.

Quick-reference guide: Diabetes stigma story building blocks (*continued*)**HOW** we say things to communicate ideas for a specific audience and context**Message**

Statements, similar to a key idea, but written to a person or audience and tailored to have a specific emotional effect. Often crafted to feel like they are being spoken aloud; examples include tag lines, campaign slogans, and value propositions.

Diabetes is not a joke.

Diabetes is not your fault.

No one chooses to have diabetes.

Diet and exercise are part of the story — but not all of it.

Diabetes is a medical condition and is nothing to be ashamed of.

Your story is unique but you are not alone.

There's a lot of people who can do to live a long, healthy, happy life with diabetes.

People with diabetes deserve our respect, support, and compassion.

Narrative

Narratives convey multiple ideas in an intentional flow for a specific audience. They differ from stories in that they do not need to be personal, although they can be. Advertisements and marketing materials often contain a form of narrative. Narratives can be more or less compact. The **bold** statements below show a “tighter version” that delivers essential ideas.

Diabetes is a serious personal and public health challenge that affects someone you know.

People with diabetes are sometimes blamed for their disease and made to feel shame or embarrassment.

Diabetes is sometimes even treated as a joke in our culture.

When we hold negative opinions about people with diabetes, we cause them harm.

Viewing someone (or even yourself) in a negative way just because they have a health condition is a form of stigma.

Addressing stigma is an essential missing element of effective diabetes care.

Together, we can eliminate misplaced blame, build understanding and compassion, and help people live well with a serious — but doable — disease.

You can make a difference. Here's how...

Story

Stories convey ideas and create human connection by weaving ideas that we want to communicate into an emotional experience that is personal, relatable, and inspires reflection or change.

Last year my father was diagnosed with diabetes. Not even twenty-five years ago he was a 140 pound, collegiate cross country runner, and now he wears a continuous glucose monitor and has to deliver multiple injections of insulin each day to stay alive.

He works hard every day to make sure that he stays healthy and will be able to be around to see all of his kids grow up and grow old. So many people in the world are just like my dad, doing their best with a complex disease, and every single one of them deserves compassion, respect, and support — not stigma.

Other Stigma Concepts and Messages

What follows are representative messages from other stigma efforts, with the specific conditions omitted — review these examples for ideas about how you might deliver messages around diabetes stigma to help get your creative juices flowing for Module 3!

Stigma is when someone, or even you yourself, views a person in a negative way just because they have _____. Some people describe stigma as a feeling of shame or judgement from someone else. Stigma can even come from an internal place, confusing feeling bad with being bad.

We're creating a culture of dignity and respect for all people's _____ and _____ lives.

"_____" stigma is the shared understanding that _____ is socially and morally unacceptable.

_____ stigma is negative attitudes and beliefs about people with _____. When we support people with _____, we make it easier for them to lead healthy lives.

Stand up to stigma: • Talk openly about [living with diabetes] and stigma. • Choose supportive language that is not stigmatizing. • Speak out to correct myths and stereotypes. • Educate yourself and others.

Join the movement to stop _____ bias... in the media, at work, in healthcare, in education.

What can I do to #stop_____bias? 1. Ask yourself if you hold negative opinions about people with _____. If so, remember _____ is a complex disease with multiple causes including genetic, biological, and other uncontrollable factors. 2. Challenge people who express negative opinions about people with _____. 3. Be Part of the Solution. With your help, we can build a better world, free of _____ bias. We deserve a world where everyone is treated with dignity and respect.

Are you seeing clearly? Would knowing someone has _____ change the way you see them?

The need to eliminate stigma is nothing new.

Let others know there is hope and understanding. You can change the way the world sees _____.

The biggest killer out there is stigma. Stigma keeps people in the shadows. Stigma keeps people from coming forward and asking for help. Stigma keeps families from admitting that there is a problem.

"Thanks to stigma, people living with _____ are:

- Alienated and seen as "others."
- Perceived as _____.
- Seen as irresponsible or unable to make their own decisions.
- Less likely to be hired.
- Less likely to get safe housing.
- More likely to be _____ than offered health care.
- Afraid of rejection to the point they don't always pursue _____."

With COVID-19 making the _____ epidemic worse, ending the stigma surrounding _____ is more important than ever.

_____ bias is holding negative attitudes about people's _____ or harming and shaming someone because of their _____. Additionally, _____ bias looks different to everyone and unfortunately, gender and ethnicity play a role in it. Oftentimes, people internalize _____ bias and blame themselves for _____ which can be incredibly damaging.

Non-compliant, lazy, dishonest, lacking self-control, sloppy, unsuccessful, unintelligent. Let's call these attitudes and perceptions what they really are – _____ bias.

We are the old and the young fighting as one to end the stigma around _____. The generational divide can't stop us from talking it out and taking action on _____. Together, we are Generation #_____

Individuals living with _____ often internalize the stigma that exists in our culture, damaging hopes for _____. Some don't seek treatment from a [health professional]. Their conditions worsen because they aren't receiving the support and care they need to recover.

Stigma harms the 1 in 5 Americans affected by _____. It shames them into silence and prevents them from seeking help. Take the StigmaFree quiz to see if you might be affected.

Through powerful words and actions, we can shift the social and systemic barriers for those living with _____.

Types of Stories

For the purposes of our diabetes stigma storytelling, we've selected a few approaches that you might find helpful when thinking about how to tell effective stories:

Shaping a Public Narrative (see the next section for more on this technique):

- Story of SELF (why I care)
 - “I saw this thing / had this experience...”
- Story of US (why this issue is important)
 - “Clearly we need to do something, because...”
- Story of NOW (what action is needed)
 - “So let's ____”

Telling a Personal Journey Story

This can take many forms – but for our purposes, it usually involves sharing an experience of adversity → how that experience shaped you (or the character in the story you are telling) → why it's motivating you to call for action. Here's an [overview of many of the classic personal story structures](#) to draw from and consider.

Amplifying Others' Stories

There are good reasons why we tend to avoid telling others' stories. But there are also ways to amplify others' stories in a respectful and consensual way in order to help change the current narrative and spread compassion and understanding of the truth of living with diabetes. Some key points to consider:

- When someone's story affects you, it effectively becomes a shared story
- Know WHY you are telling this particular story
- (*Where you have permission*), sharing parts of others' stories that counter common stigma-perpetuating narratives can be an impactful way to change hearts and minds!

Highlighting Intersectional Stories

Drawing on any of the above stylistic methods, consider starting with an issue you know your audience already cares about. Then showing them how the issue of diabetes stigma is similar or related, you can make the link as to why they should care and act to address diabetes as well. This is also a good way to highlight complexities; real stories aren't always as simple as they at first seem. [See Chimamanda Ngozi Adichie: The danger of a single story.](#)

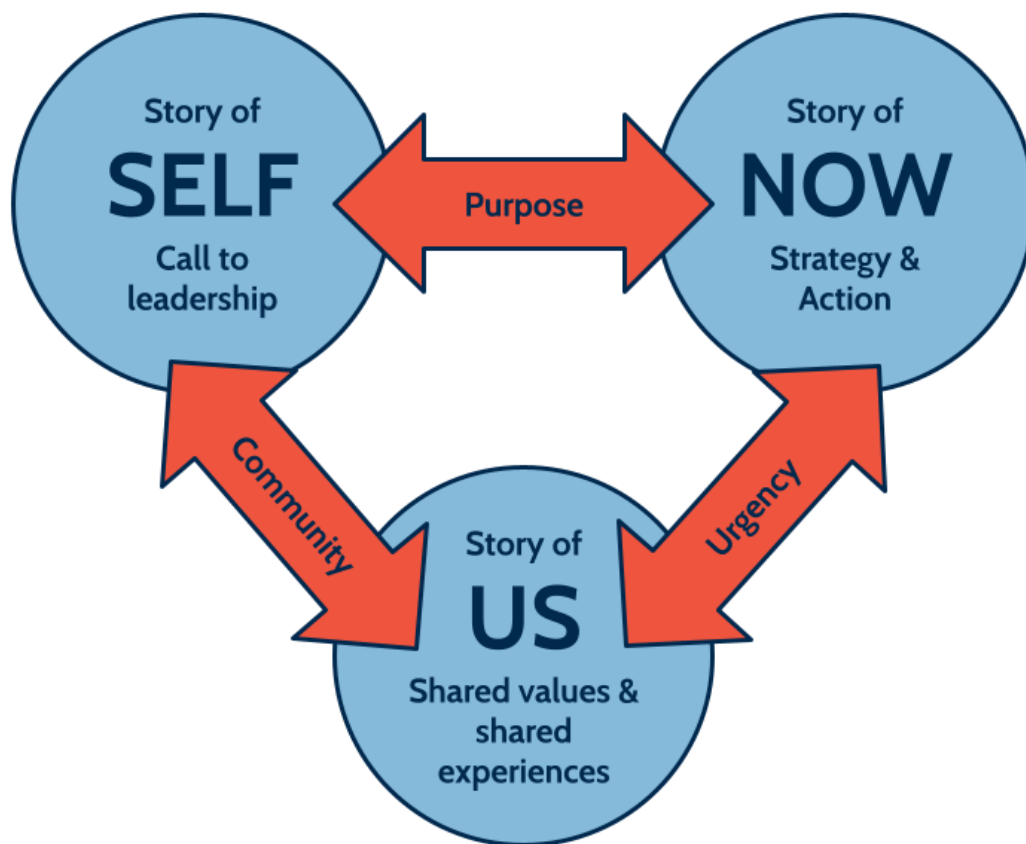
Telling the Story Without Storytelling

Some of you may be able to draw on other ways to convey messages – with images, cartoons, events, advertisements, music, poetry, and more – and these other modalities can be powerful complements to consider in getting your message across to your core audiences!

More on Public Narrative

The content below has been adapted from the work of Marshall Ganz at Harvard on the role of leadership in shaping and shifting public narrative (text adaptation by Serena Zhang & Voop de Vulpillieres). We will be drawing on this approach to storytelling during Module 3 so we recommend familiarizing yourself with this framework, and start thinking about what key audiences you want to target, and what your public narrative might look like with regard to addressing diabetes stigma.

Public narrative combines a story of self, a story of us, and a story of now.



A “story of self” tells why you have been called to serve.

Every one of us has a compelling story to tell. We have all made choices that shaped our life’s path – how to respond to challenges we faced as children, whether or not to take leadership in our places of worship, our schools, where we found the hope to take risks, etc. The key focus is on choice points, moments in our lives when our values become real and when we have to make choices in the face of uncertainty.

When did you first care about being heard, about concern with others, about abuses of power, about poverty? Why? When did you feel you had to do something? Why did you feel you could? What were the circumstances?

The power in your story of self is to reveal something of yourself and your values – not your deepest secrets, but the key shaping moments in your life. We all have stories of pain, or we wouldn't think the world needs changing. We all have stories of hope, or we wouldn't think we could change it.

A “story of us” communicates why our community in particular is called to act, and why we in particular have the capacity to lead.

Just as with your story of self, the key choice points in the life of the community are those moments that express the values underlying the work your organization does. The key is to focus on telling a story about specific people and specific moments of choice or action that shaped your community.

Tell a story that invites others to join you in this community.

A “story of now” communicates the urgent challenge we are called upon to face now.

The story of now focuses on the challenge that requires action, the hope for that action, and the choice we are calling upon others to make.

In a story of now you call on others to join you in action.

Incorporating Challenge, Choice, and Outcome in Your Own Story

There are some key questions you need to answer as you consider the choices you have made in your life and the path you have taken that brought you to this point in time as a leader. Once you identify a specific choice point, perhaps your first true experience of challenge, own your choice to do something about it, dig deeper by answering the following questions.

Challenge: Why did you feel it was a challenge? What was so challenging about it? Why was it your challenge?

Choice: Why did you make the choice you did? Where did you get the courage (or not)? Where did you get the hope (or not)? Did your parents or grandparents' life stories teach you in any way how to act in that moment? How did it feel?

Outcome: How did the outcome feel? Why did it feel that way? What did it teach you? What do you want to teach us? How do you want us to feel?

A word about challenge: sometimes people see the word challenge and think that they need to describe the misfortunes of their lives. Keep in mind that a struggle might be one of your own choosing – a high mountain you decided to climb as much as a valley you managed to climb out of. Any number of things may have been a challenge to you and be the source of a good story to inspire others.

Consider Action Motivators →

Action Inhibiting Emotions	Action Motivation Emotions
Inertia	Urgency
Apathy	Anger/Anxiety
Fear	Hope
Isolation	Solidarity
Contentment	Awe
Sadness	Excitement
Shame	Amusement/Humor
Overwhelm / Crisis	"You can make a difference!"

This table draws on three sources on emotional motivation research:

1. Ganz, Marshall. 2011. "Public Narrative, Collective Action, and Power." In *Accountability Through Public Opinion: From Inertia to Public Action*, eds. Sina Odugbemi and Taeku Lee: 273-289. Washington D.C: The World Bank.
2. Berger, J. 2013. *Contagious: Why Things Catch On*, New York, NY: Simon & Schuster.
3. The research of the Frameworks Institute, which informed our d20 diabetes stigma brief.

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EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

POWERED BY

THE **diaTribe**
FOUNDATION

WRITTEN BY

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EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

LIGHTNING TALKS & MODULE 3
SUMMARY AND HIGHLIGHT



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TABLE OF CONTENTS

Lightning Talks: Stigma and the Stories We Tell	2
Module 3: Shaping Stories for Change	6
Storytelling as the key to shift diabetes stigma	6
Integrating storytelling into each action area	7
Onward to d22: What comes next for stigma?	9
Appendix	10
Module 3 Storytelling Worksheet	10
“Take It in” by Josh Kuntzman	14

Lightning Talks: Stigma and the Stories We Tell

The [d21 Lightning Talks](#) focused on the power of storytelling – beginning with a [Ted Talk](#) from the author Chimamanda Ngozi Adichie, which diaTribe used as the foundation of this year's program. By listening to Adichie describe the danger of a single story, we were inspired to create a tapestry of many stories by people with diabetes. Click on each picture below to [watch](#) the speakers share their experiences.

Eileen Opatut – Former Senior Vice President of Programming, The Food Network

Eileen Opatut
What we tell ourselves

Struggled w/ weight in college

I have gestational diabetes ... but why?

Look at your feet

I didn't take it seriously, I didn't have information

Confusion

Take these pills

Food Network

As a society we love food porn

My thin brother has diabetes!?!

I have a genetic disease

~~I am a failure~~

d21 July 20, 2021

LIGHTNING talks

willmannstudios.com

Phyllisa Deroze – Founder, Black Diabetic Info

2011
I ain't telling no one but God ...

Phyllisa Deroze

And I started telling my **STORY**

S Silent
I have diabetes
If I hid and remained SILENT, I could have died

T Talking/Distracted
I felt isolated

I Ignoring my Diabetes Management
Blogged under an alias for 6 yrs.

G Getting Overwhelmed
COMING OUT

M Missing Out
Diagnosed 0 Defeated

A Ashamed
Assuming I did this to myself
I was misdiagnosed Type 1.5

2011
Pushed through it

TOLD MY STORY:
Beneficial for others more so than me

LIGHTNING talks

wittmannstudios.com

David Lee Strasberg – CEO and Creative Director, Lee Strasberg Theatre and Film Institute

David Lee Strasberg

The STORY a PARENT tells a CHILD

Thank you for taking my "NO" so well

Stories change our view of ourselves

me?

We are here to communicate, to share. To be empathetic.

This is how your story changed me

Ground Rules:

- 1 Listen... ^{Empathize} we can improve this skill
Resist urge to identify
Be patient... w/ teller w/ yourself
- 2 Permission to re-tell the story
Am I aligned w/ their intention?
- 3 Acknowledge your Source
maintain the connection **share?**
- 4 Use the story w/ Love & Compassion

All of us are STORYTELLERS
What we SAY MATTERS

- reflect back
- what we tell or re-tell
- amplify perspectives
- introduce a new image
- new understandings

LIGHTNING talks

wittmannstudios.com

d21 July 20, 2021

Community Sessions – Cherise Shockley, Renza Scibilia, Julie Heverly, T'ara Smith, and Josh Kuntzman

COMMUNITY SESSION:

Julie
A decade of being in the closet
Diagnosed at 21

Renza
The value of this COMMUNITY ... Cherise
Language IMPACTS
Diabetic vs Living w/ Diabetes

Tara
Jumped In & Have always been OPEN... maybe it will help someone else

Cherise
The message I hear!
Just lose weight

Diabetes Stigma

Do you have REAL diabetes?
Do you have a REAL medical degree?

Words can stigmatize us for a long time

for Type 2 especially internalized & by healthcare professionals

Wow, I'm using lots of insulin

Social Media's ROLE

Our lives are greatly affected by this disease ... tell our stories for them to understand

Remission???

Talking about it can cause more harm/ false hope

What about the bad days? ... only the good stories

Lack of Conversation

Journey of Type 2

Missing Story

180 decisions/ each day

the Imposition

Now: Simplistic View

Emotional

STIGMA MESSAGES

Burden

Family + Friends who are impacted

stories from them

Stories of empowerment

Accountability ... allow for failure

Diabetes Sticks

Delicious Food has nothing to do with Diabetes

Personal Responsibility

Complications ... be compassionate ... tell those stories

In order to end the stigma ...

- Tell honest (the good, the bad) stories
- Open about diverse & inclusive stories, racism & discrimination

Diabetes - A History of Race & Diversity
Arleen Tuchman

willmannstudios.com

[Jump to the appendix to read Josh Kuntzman's poem on diabetes stigma. "Take It In."](#)

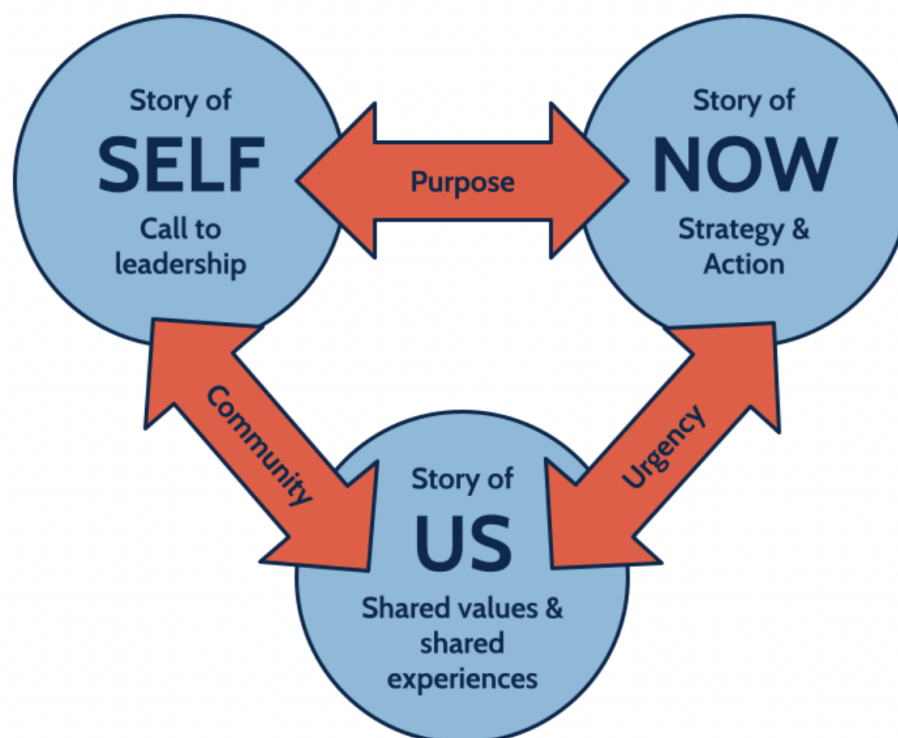
Module 3: Shaping Stories for Change

Storytelling as the key to shift diabetes stigma

There is research that shows one-to-one, contact-based education strategies and storytelling can be some of the most powerful ways to shift people's behaviors on stigma. Drawing inspiration from the d21 Lightning Talks, Module 3 focused on a storytelling workshop – designed to help participants learn and practice crafting an effective story for their audiences.

Brookline Gatewood began the storytelling workshop by introducing participants to the public narrative approach developed by researchers at Harvard University, which breaks down a method to create and tell a story with the goal being to change the public narrative of an issue. This framework combines a story of self, a story of us, and a story of now.

Public narrative combines a story of self, a story of us, and a story of now.



The workshop then focused on clarifying our audiences. Gatewood asked participants to think about where they have the highest leverage opportunity to influence others. These key audiences may be people with diabetes, healthcare providers, journalists and the media, medical school students, industry leaders, or others.

Next, participants fleshed out the key ideas they wanted to convey in their story. Part of this task means focusing less on the facts themselves, but rather on the messaging and how the facts are crafted for a specific audience. There is a difference between telling a narrative and a story: telling a narrative is about stringing together a series of ideas with a logical connection, while a story has a greater personal element that elicits an emotional response from people.

Finally, participants were given time to work on crafting their story – whatever that may look like. They were divided into breakout groups of three to practice sharing their stories aloud and receive feedback from group members. These sessions allowed participants to refine their stories and identify ways to maximize their impact on the listener.

[The storytelling workshop can be found in the appendix.](#)

Integrating storytelling into each action area

Participants explored in their action area groups how storytelling insights could be integrated into both a collective plan and individual influencer actions over the next year.

Research: Setting an agenda for academic research to better understand diabetes stigma

- Jim Carroll led the research group through a brainstorming session to determine the first steps needed to create a research agenda.
- They also discussed ways to engage with diverse audiences from people with diabetes to healthcare providers to better understand how stigma exists within the general public.
- When considering sources of funding for a research agenda, the group talked about the framing of stigma and the importance of adopting separate frames such as health equity when presenting the problem of diabetes stigma.

Healthcare Provider Engagement: Reducing stigmatizing information and interactions in healthcare settings

- Brooking Gatewood led the healthcare professional group through a discussion on the importance of language and communication in different interactions involving healthcare providers: between diabetes communicators and HCPs, between HCPs themselves, and between HCPs and people with diabetes.
- The group agreed that scientific and medical progress is limited by stigmatizing language, and they felt that addressing harmful language is a crucial effort that needs to involve all HCPs, not only those who already recognize stigma as an issue.

- Group members suggested looking to the LGBTQ+ rights movement as a model for how to integrate respect and inclusivity into the clinical space and apply it to caring for people with diabetes.

Media Advocacy: Advocating for accuracy and empathy in media

- Matthew Garza facilitated this group's discussion on the value of representing the stories of people with diabetes in the media, leveraging the influence of popular media personalities with diabetes, and shifting the way we talk about diabetes stigma in the media.
- Participants agreed that less focus should be on the split between people with type 1 and type 2 diabetes and instead there could be benefits to joining forces by generating more buzz about diabetes as a whole.
- The group concluded with a brainstorming session around what a stigma media campaign would look like including: speaking to the impact of bringing together coalitions for public service announcements, harnessing the power of celebrity voices, and expanding campaign messaging to mediums outside of digital media such as print and public messaging at bus stops.

dNetwork Development and Stigma Information Hub: Growing a cultural movement to address diabetes in the US

- Chris Barnes facilitated this group's discussion of what to include and prioritize in the creation of an online stigma-busting resource – agreeing to make language guidance a significant focus of the website.
- Group members brought up the issue of stigmatizing language used among HCPs and industry professionals and how this language can pass down from generation to generation – highlighting the need for both a grass-roots and grass-tops approach to create change.
- The group also identified smaller website ideas including short written or video stories to represent the complexity of stigma and a pledge to indicate an active commitment to combating stigma.

All of the action area groups concluded by revisiting their written action commitments from the end of d20 – making collective and individual commitments to reframe the narrative of diabetes stigma through their personal and professional conversations, organizational decisions, and project ideas.

Onward to d22: What comes next for stigma?

“I’ve gotten to work on a lot of cool, interesting efforts in my time, but none with the potency and potential of what you all are doing here with this dNetwork effort,” said Gatewood, as she closed out Module 3 of d21. “I feel like we’re just at the beginning. I’m just reflecting on when I started at d17; we didn’t have a dNetwork, we didn’t have a systems map, and we didn’t have a steering committee. Since then we have done so much shared learning and growing to really understand this space and I know at times it can seem slow but from a movement perspective, we’re moving at a pretty quick pace. I am really excited to keep watching and supporting as this grows and evolves.”

Looking to the future, we shared the name and vision for the stigma hub website: dStigmatize.org. With dStigmatize.org, diaTribe aims to synthesize the learnings from d20 and d21 and expand on the dNetwork’s mission to address stigma by creating an online resource. The website will consolidate information about diabetes stigma into a curated, easily-accessible, and easily-shareable resource.

The goal of dStigmatize.org is to be a “one-stop shop,” for people (from diabetes communicators to HCPs to loved ones of those with diabetes, and many more) to visit and learn about the kinds of stigma that affect people with diabetes, including tips and guidance on how to combat stigma.

dStigmatize.org is set to be launched in 2022.

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Appendix

Storytelling Worksheet

GOAL: Craft a two to three minute story to inspire others to become part of our stigma-busting movement!



Solo reflection & refinement time	<ol style="list-style-type: none"> 1) Clarify key audience(s). 2) Identify the key idea(s) you want to convey. 3) Craft a story to shift mindsets and inspire action.
<i>Practice and test</i>	4) Practice the story and receive feedback from peers. Iterate and refine.
<i>Implement</i>	<ol style="list-style-type: none"> 5) Integrate into your personal action plan! How will you spread the message and enroll others in our shared work of stigma-busting?

1) CLARIFY YOUR AUDIENCE

Think about where you have the highest leverage opportunity to influence others, shift mindsets, enroll key players, and inspire action to reduce stigma. You might focus on one representative individual, or a group of individuals in the diabetes ecosystem. Once you have these people in mind, consider these questions to help craft an effective story for them:

Who is this audience?	Why them?
What's unique about them?	What are your instincts about how to engage them effectively? (<i>tone, style, timing, context, etc.</i>)



2) IDENTIFY KEY IDEAS

Review our [Core Ideas list](#) and select a handful of messages that seem essential for this audience to achieve the desired result:

<i>Insert core messages here...</i>		

3) CRAFT YOUR STORY

The worksheet below offers starter questions to help you think about elements of your experience that might inform your story.

- This is an invitation for those who like prompts, but feel free also to skip to the blank story-writing page first to work on your story. You may want to come back to these questions after as a sort of check-list (we all have different creative processes).
- Remember you can draw on your personal *why* (why are you working to eliminate diabetes stigma?), even if you don't have a personal story about diabetes stigma.
- You can also choose to incorporate or amplify other people's stories as well as intersectional topics where it might help you inspire and engage your audience.
- If you feel stuck, just start writing! Get started on what Anne Lamotte calls the *Sh*tty First Draft!* As the great storyteller Truman Capote once said: *"Failure is the condiment that gives success its flavor."* All good stories get polished through the practice of telling them.

STORY OF NOW WHAT is the change you want to make in the world?	STORY OF SELF WHY are you called to make that change? What specific experiences have shaped your story of self?



STORY OF US WHAT personal story can you tell (yours or someone else's that has impacted you and you have permission to share) that will help others understand why you want to be part of that change?		
Challenge Why did you feel it was a challenge? What was challenging about it? Why was it your challenge?	Choice Why did you make the choice you did? Where did you find the courage (or not)? Where did you get the hope (or not)? How did it feel?	Outcome How did the outcome feel? Why did it feel that way? What did it teach you? What does it make you wonder?
What do you want to teach us? (What's the moral?)	How do you want us to feel?	What action are you wanting those feelings to inspire?
What question might you ask us to invite us into the story and/or your sense-making?	THINKING AHEAD: How might you use other media – visual art, music, advertisements, events, etc. – to help tell this story?	

WRITE OUT YOUR STORY HERE



4) PRACTICE SESSIONS

Run through a few sessions with family, friends, and colleagues to help you practice telling your story and receiving feedback. Be sure to get their opinions on:

- What was the emotional impact of the story?
- When were they the most engaged?
- What worked well?
- What questions came up?
- What did they want to know more or less about?

5) PREPARE TO SHARE YOUR STORY MORE WIDELY!

Now that you've practiced and dialed in your story a few times, keep sharing it! The next time you have a chance to influence those core audiences you identified in step 2 — you'll now have a new tool at your disposal to help you!

“Take It In”

By Josh Kuntzman (2021 July 20)

Listen to the poem [here](#).

I wouldn't say lazy.
I'd say angry. "Seeing red." "My blood boils."
I'd say angry, if I had to pick
A feeling, an outlook, a way of life
At the top of my emotion/spirit list.
Of course, I went through the
other steps of grieving:
Saying "no way" and disbelieving
Because I didn't even feel the disease—
Just a little bit dizzy and a lil bit thirsty—
And of course that turned to "Please.
Don't let this be real."
But it was, and it is.
And it seems like it always will be:
Stomach, pancreas, liver, blood,
Misaligned dominoes of flesh—thud, thud, thud—
Falling inside of me.
"You have diabetes." Okay, then I was angry:
Where was my sin? The rot in my soul.
Because I know diabetes: it's fat, lazy, unaware,
Balloon-people whose legs fall off because
They have no self-control.
But I? — okay, maybe the occasional Arby's,
And big bones run in my family—
But can we make a deal? A barter, a bargain,
A trade-off? Don't take this from me.
And that was the start of my life as a number;
My skin full of pinholes, my blood full of math:
My CGM, my A1C? No DKA, take TZDs.
Shit, I'm at 200... now 153.

Is this just at random? God's playing with me?
I Hate it. And it's work:

Constant hunger, excessive thirst.
I miss buffets. (Heh) miss Taco Bell...
If that doesn't make you depressed, how's this:
I'm so Tired, that my version of peace
Is a cool-quiet place to poke a needle in my skin,
Without someone making the same goddam joke
About me doing heroin.
And these are the people who'd say "I'm his friend";
Who don't even listen, before saying, again,
"You just need to do X, and then you'll be okay"
Repeating false-hopes, like a Gut-punch replayed:
Chromium & Cinnamon, Hydrogen Peroxide & Magnet Shoes, Glymetrol & Exotic Herbs—
"100% effective!" It's Facebook-true.
But—God grant me serenity—
I accept that I'm not alone in this flood;
That for every 10 men I see checking their watch,
... one of them's checking his blood.
That for every pregnant woman (who's obese, non-white, or over 25)
There's a chance, while she's busy growing that life,
... that her glucose is on the rise.
That my roommate's first boyfriend in the schoolyard
... always carried an orange juice, just in case.
That my partner's dad
Couldn't feel his foot bleeding, then stopped breathing
... had his heart-valve and carotid replaced.
That the father of the bride had two metal legs.
That the baseball coach now avoids broccoli.
That my neighbor had a block in his infusion tubes
... and was over 400 before he got some insulin.
That my student pulled through 5 all-nighters,
Trying to get an A ... knowing that she'd take a hit
When her lab results came in.
So here I go, getting all angry again,
When it attacks my blood while you attack my pride:
As I fail to control unstoppable pumps,

And forego comforts like a monk,
While you say "Why don't you just (pfft)—
Be different inside?"
Because it's easy:
Exercise & Diet fixes Fat & Lazy.

Pearls? Meet Swine.
That's your view. But in reality? YOU
Want an easy pivot from seeing this reality of mine.
Take it in. The pricks and needles,
Doctors, drugs, blood every morning.
Every hour. Every meal.
Ketones, glucose, ... are You absorbing?
Take it in: this is not simple choices.
Take it in: this is not moral failing.
Take it in. What I control, what I don't;
The dangers, and the stressors
That compound my ailing:
All that I love, that I've let go and miss.
The normal excesses that make life... lived.
All that I fear—drugs, tools, insurance,
... my own body—that I must accept and forgive.
All those around me, who I need to love me,
Who head-shake at tired eyes and discolored skin.
All those who judge me, as I try to live
While my blood boils inside me; my life.
Take it in.

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