

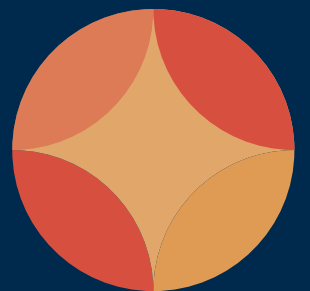


EXECUTIVE INNOVATION LAB IN  
DIABETES AND PREDIABETES

PARTICIPANT PRE-READER

MODULE 1

MARCH 30, 2021



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# 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.

	<b>Diabetes World</b> People who think or talk about diabetes	<b>Non-Diabetes World</b> People who don't think or talk (much) about diabetes
<i>What challenge should we focus on?</i>	<p>Diabetes? Blame &amp; Shame</p> <p><b>STIGMA</b></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><b>AWARENESS</b></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 <b>individuals</b>	Improve things for <b>population</b>
<i>Who is involved?</i>	<p>Who is doing the talking?</p> <ul style="list-style-type: none"> <li>• HCPs</li> <li>• PWD</li> <li>• Industry</li> <li>• Advocates</li> <li>• Friends and family</li> <li>• Media (only a little, what does portrayal look like?)</li> </ul>	<p>Who is doing the not-talking?</p> <ul style="list-style-type: none"> <li>• General public (mostly non-diagnosed, but also diagnosed)</li> <li>• Media</li> <li>• PWD and friends and family</li> <li>• HCPs (primary care)</li> <li>• Research funders (Congress)</li> </ul>
<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"> <li>• research</li> <li>• core story</li> <li>• message testing</li> <li>• spokespeople</li> </ul> <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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