

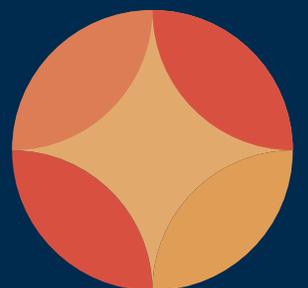


EXECUTIVE INNOVATION LAB IN  
DIABETES AND PREDIABETES

PARTICIPANT PRE-READER

MODULE 2

MAY 25, 2021



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# AGENDA

## MODULE 2: HONING PATHWAYS FOR CHANGE

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

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

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

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



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.<sup>1,2</sup>

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.<sup>2</sup> Moreover, adults with diabetes have reported that stigma and discrimination exist in the workplace, in travel, in maintaining friendships, and even in adopting children.<sup>1</sup> 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.<sup>3</sup>

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:<sup>4,5</sup>

	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. <sup>4-8</sup>
Structural level	Combat stigma that is purported by institutions, laws and policies, and the media – this requires collective action and widespread social pressure. <sup>4</sup>	Protest and advocacy, legislative and policy change, social marketing and media campaigns, and involving community members (“from self-help to social reform”). <sup>4-8</sup>

## 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).<sup>5</sup>
- They can also provide practical skills for working with stigmatized groups or addressing stigma when it is encountered (skills-based).<sup>4</sup>
- 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.<sup>4-8</sup> It's important to note that information-only campaigns have been shown to be less effective than those which also include some skills-building<sup>4</sup> and that educational interventions are much more effective at reducing stigma in youth and adolescent groups than in adults.<sup>4,5</sup>

## 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.<sup>9</sup> 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.<sup>10</sup> 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"> <li>• Simply saying that certain groups are stigmatized does little to help combat stigma and can even backfire. Show people what stigma looks like.</li> <li>• 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.</li> </ul>
<p>Start with what you want people to know about diabetes instead of repeating damaging myths.</p>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> <li>• Always try to avoid repeating false information about diabetes, and if you have to refute false information, start with the facts.</li> </ul>
<p>Explain equity and always link it to clear solutions.</p>	<ul style="list-style-type: none"> <li>• Racial inequities affect every aspect of our lives, including our health outcomes. Diabetes is no exception.</li> <li>• 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.</li> </ul>
<p>Avoid crisis: instead talk about how we can tackle diabetes, together.</p>	<ul style="list-style-type: none"> <li>• Talking about diabetes as a public health crisis makes sense, but crisis messaging often presents problems as too big and overwhelming to solve.</li> <li>• When everything appears to be a crisis, crisis fatigue begins to set in. Rather than engage, people tune out.</li> <li>• 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.</li> </ul>
<p>Talk about what we all need to be healthy, while still discussing people's specific needs.</p>	<ul style="list-style-type: none"> <li>• In our society, people are thought to be solely responsible for our own health.</li> <li>• 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.</li> </ul>

(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.<sup>11</sup> One of the most vital ways for a person to reduce stigma is directly interacting with groups that are experiencing it.<sup>4-8</sup>

- Contact interventions aim to create in-person interactions between majority and minority individuals which can lead to reductions in prejudice between the groups.<sup>4</sup>
- This could include actual one on one connections, or facilitating spokespeople to educate groups and present an actual face for the stigmatized condition.<sup>5</sup>
- 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.<sup>4</sup>

## 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.<sup>4-8</sup>
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.<sup>4,6</sup> 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.<sup>4</sup>
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.<sup>5</sup>
  - These interventions have proven to be particularly successful in the LGBTQ and Civil Rights movements and in reducing HIV stigma.<sup>5,6</sup>

#### 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.<sup>4,5</sup>
- 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.<sup>5</sup>

## 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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