

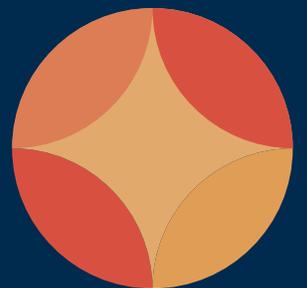


EXECUTIVE INNOVATION LAB IN
DIABETES AND PREDIABETES

PARTICIPANT PRE-READER

MODULE 3

JULY 20-21, 2021



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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.](#)

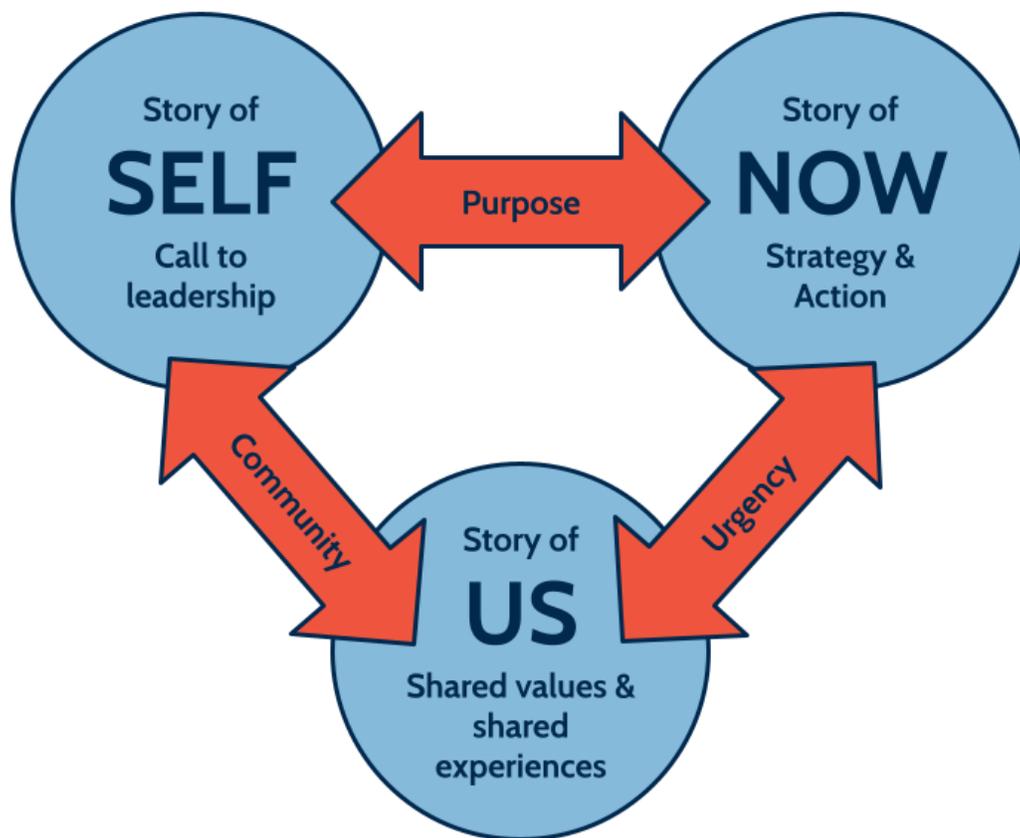
Telling the Story Without Storytelling

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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POWERED BY

THE **diaTribe**
FOUNDATION

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