Investigation of the Presence and Impact of Social Stigma on Patients with Diabetes in the USA

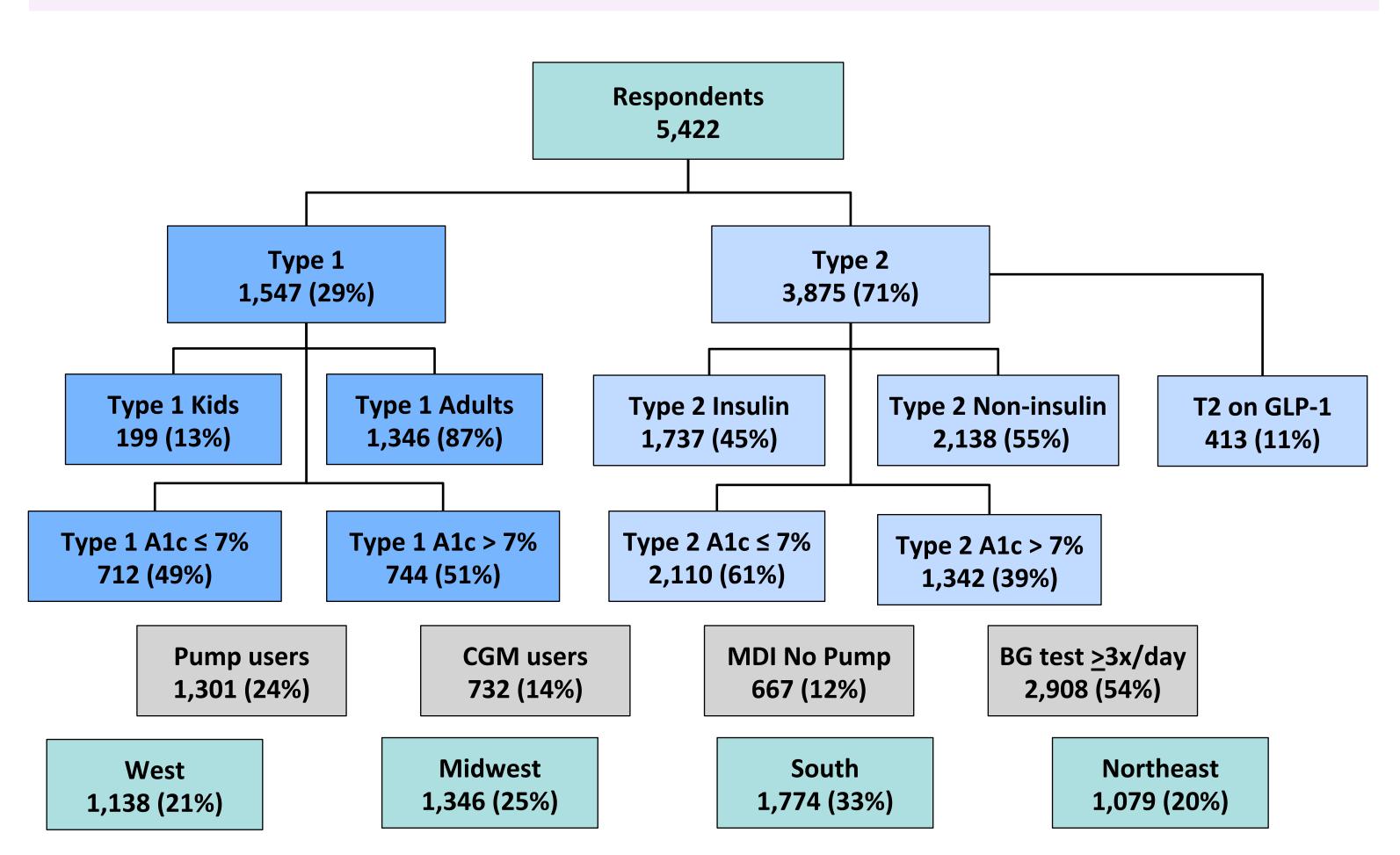
Alexandra E. Folias¹, Adam S. Brown², Jasmine Carvalho¹, Vincent Wu¹, Kelly L. Close² and Richard Wood¹ dQ&A Market Research Inc., San Francisco, CA; ²diaTribe, San Francisco, CA



Introduction

Social stigma is described as a set of negative beliefs, or a mark of disapproval, that society has about a person or group with a particular characteristic (e.g., a health condition). Society's perception of a health condition may often lead to a particular stigma, and how patients feel socially about their disease can have a significant impact on treatment. Our study's goals were to determine whether patients felt a social stigma was attached to diabetes, and to explore the impact of perceptions of diabetes on members of the dQ&A Panel (n=5,410) of Type I diabetes (T1D) and Type 2 diabetes (T2D) patients in the USA. Our data demonstrate that both T1D and T2D patients believe diabetes is accompanied by social stigma — a feeling that increases with intensity of disease and disease treatment — and this stigma ultimately influences the disease management and social interactions of individual patients.

Figure 1. Characteristics of the dQ&A USA Patient Panel (typical survey response).



Does diabetes come with social stigma? Who feels it?

Figure 2. Diabetes stigma presence in the USA. Percentage of respondents who believe diabetes comes with social stigma. Three quarters of T1D respondents (including parents of children with T1D (T1K n =199) and adults with T1D (T1A n = 1,344)) and more than half of T2D respondents (on insulin (T2I n = 1,735), not on insulin (T2NI n = 2,130), and T2D on a pump or multiple daily insulin injections (MDI) (n=550)) felt there was a diabetes stigma presence in the USA.

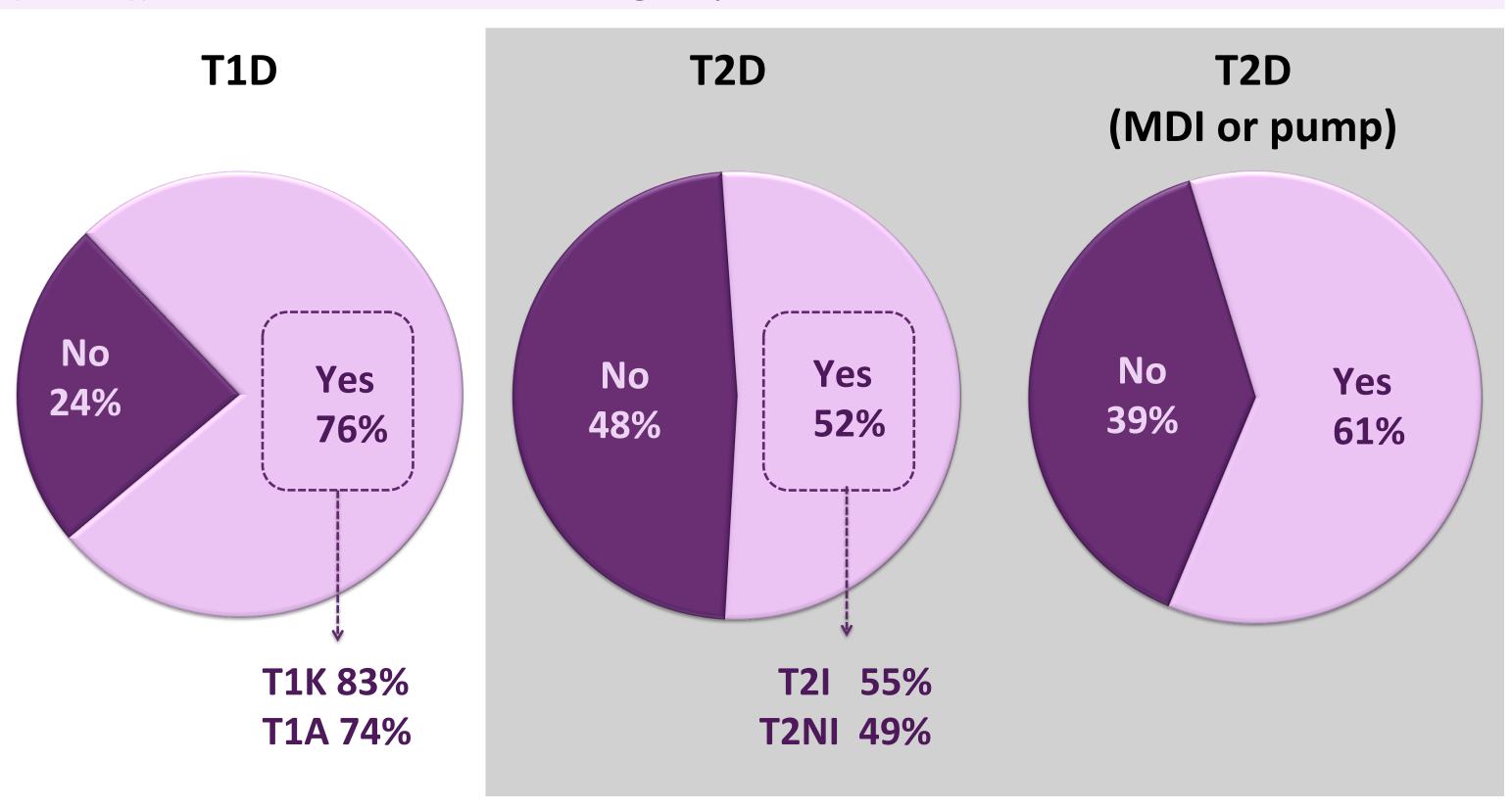


Figure 3. Diabetes stigma presence by demographic group. Percentage of T1 (n=1,178) and T2 (n=3,060) respondents who feel diabetes comes with a social stigma did not vary significantly* by annual household income (below) or by region, education, or duration of diabetes. (*statistical significance tested at the 90% confidence level)

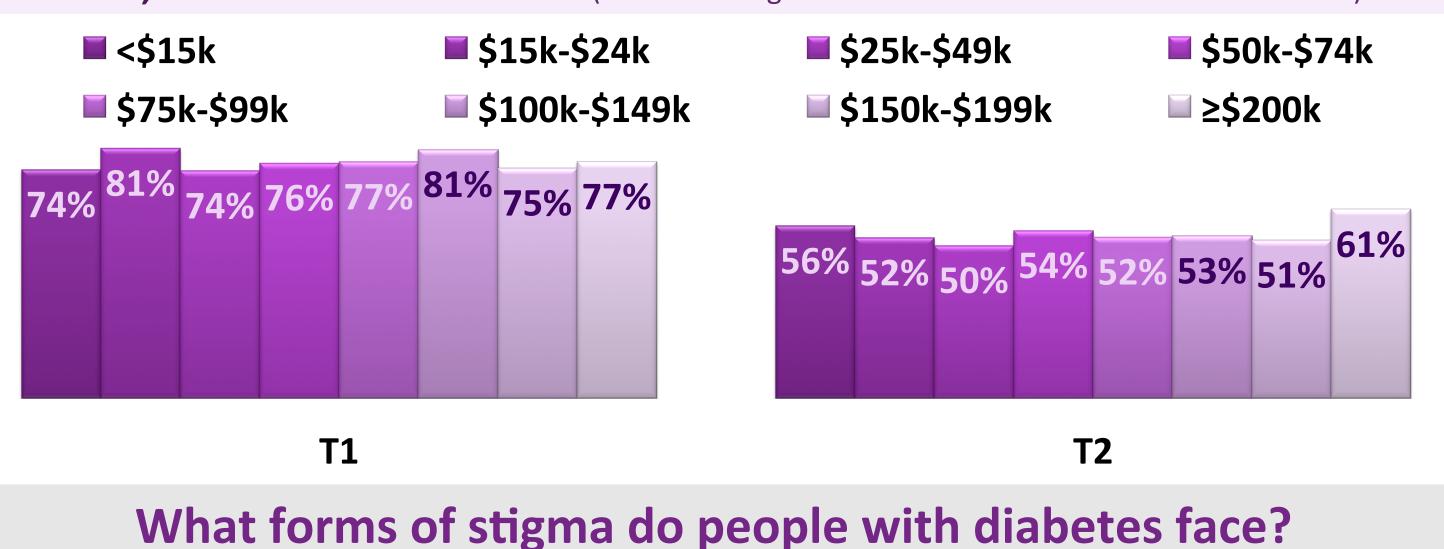
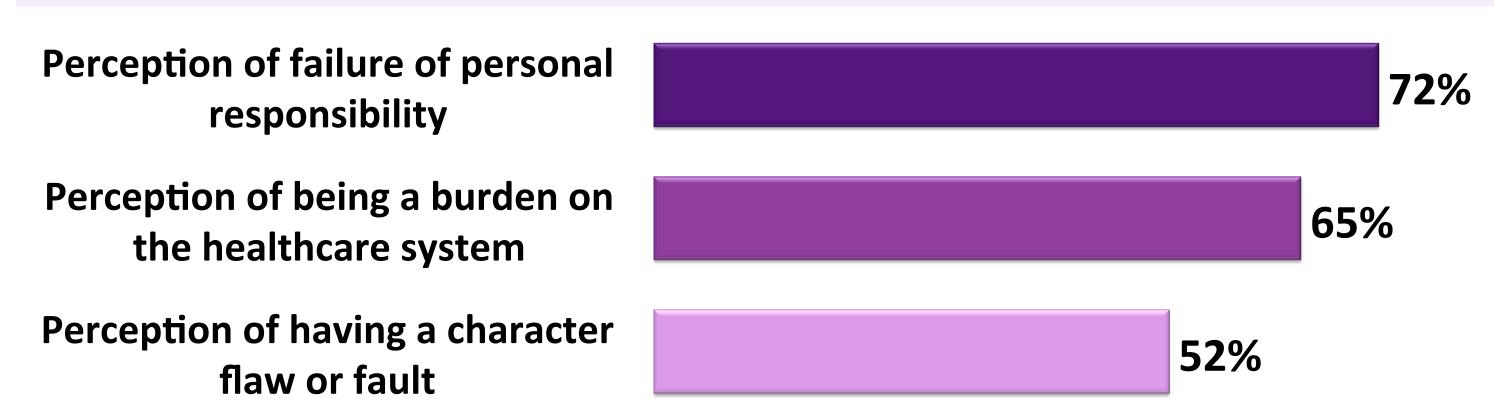


Figure 4. Types of diabetes stigma. Share of respondents who believe people with diabetes face the following forms of stigma (Base: respondents who believe that diabetes comes with social stigma n=3,154).

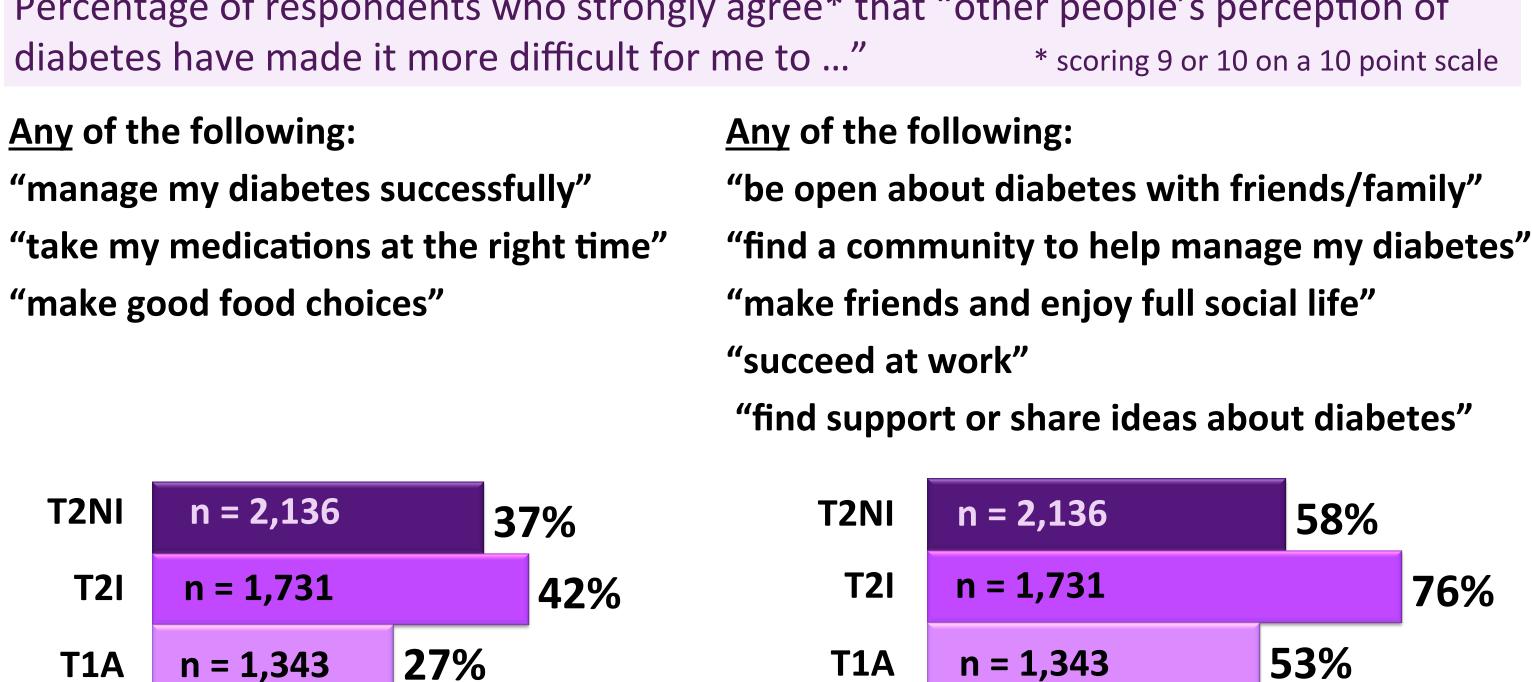


How are the lives of those with diabetes affected by other people's perceptions of diabetes?

Figure 5. Diabetes management and social impact of perceptions of diabetes.

Percentage of respondents who strongly agree* that "other people's perception of diabetes have made it more difficult for me to ..."

* scoring 9 or 10 on a 10 point scale



What feelings have people with diabetes experienced?

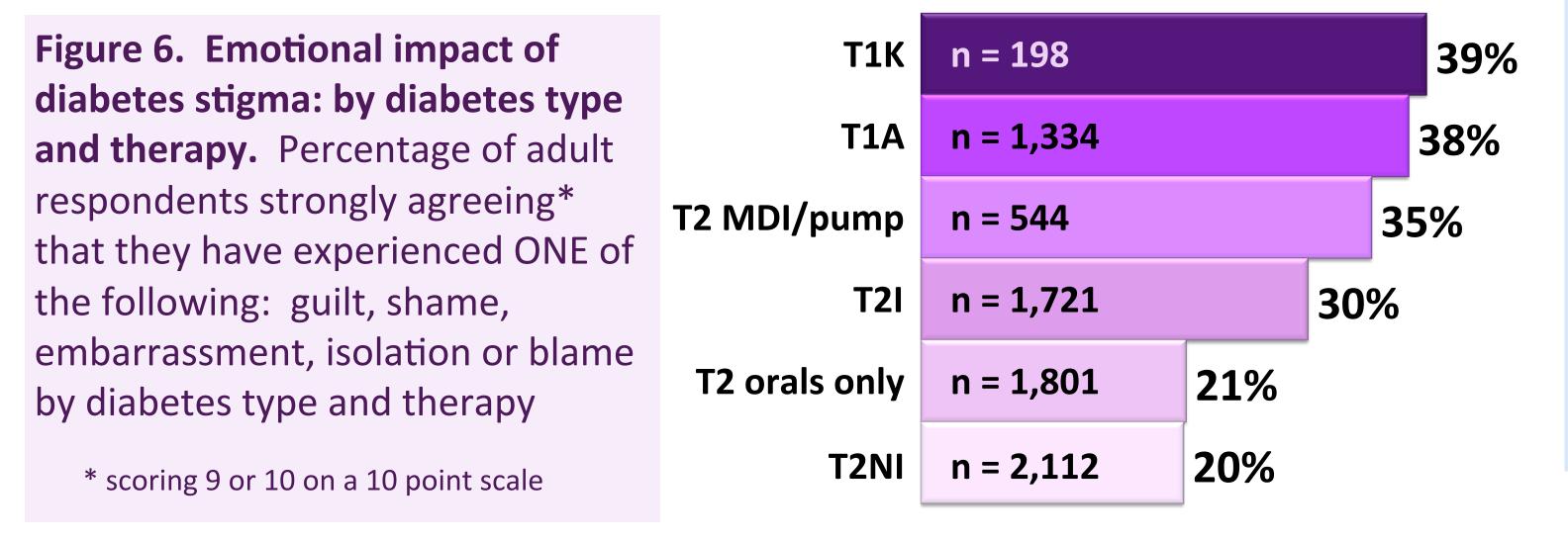
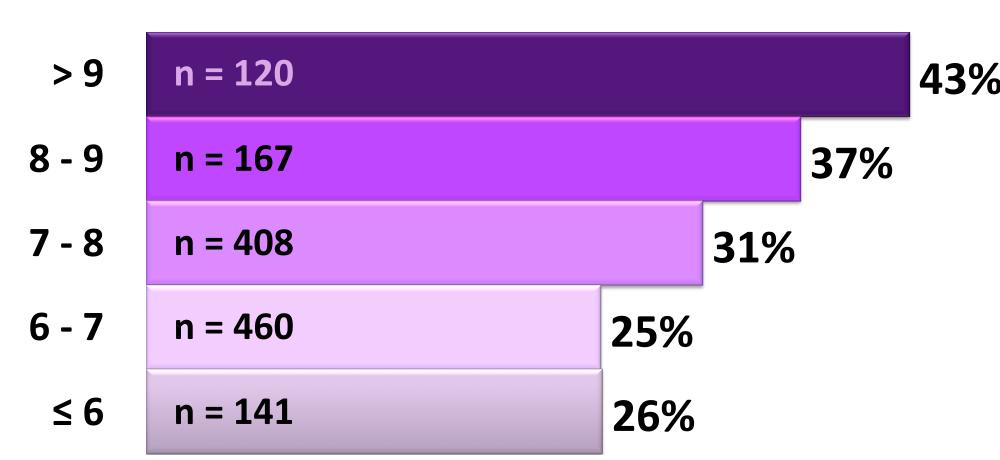


Figure 7. Diabetes stigma presence: by A1c, BMI and diabetes control.

Percentage of adult respondents strongly agreeing* that they have experienced guilt, embarrassment, shame, blame OR isolation by A1c levels (A), BMI (B), and self-reported diabetes control (C).

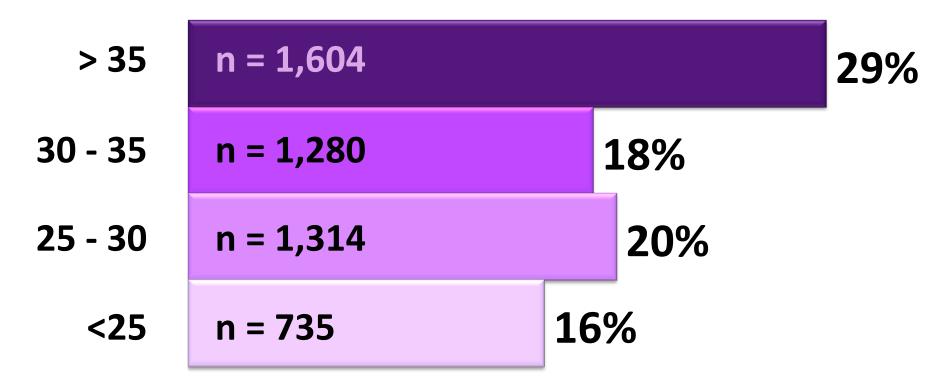
* scoring 9 or 10 on a 10 point scale

A By A1c Levels (adult T1 and T2 insulin users)



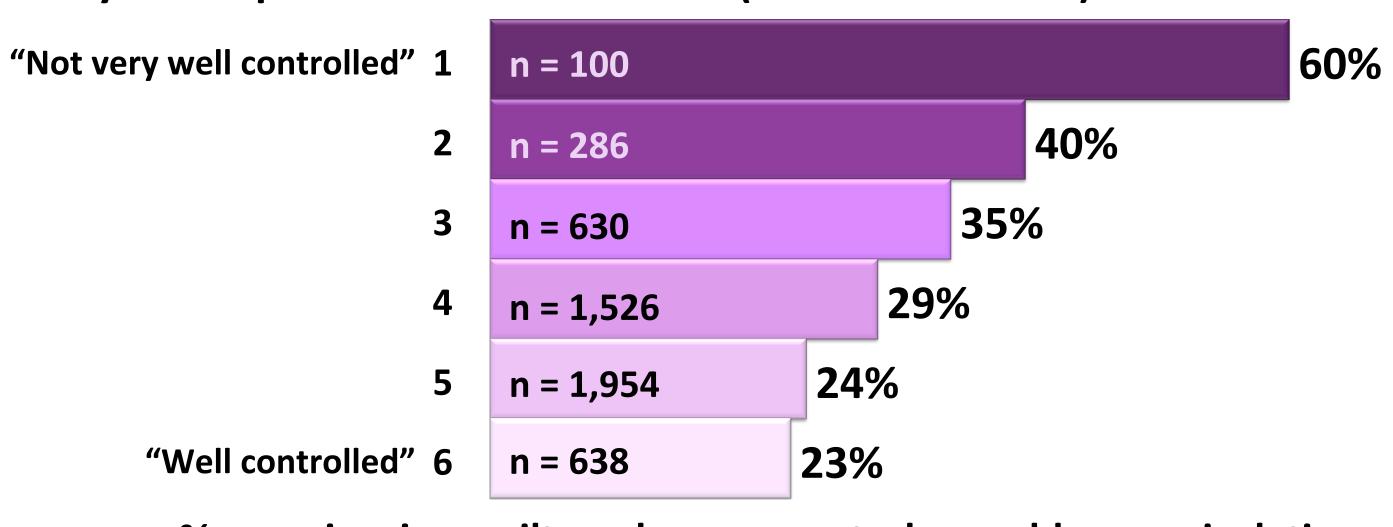
% experiencing guilt, embarrassment, shame, blame or isolation

B By BMI (T1 and T2 adults)



% experiencing guilt, embarrassment, shame, blame or isolation

C By self-reported diabetes control (T1 and T2 adults)



% experiencing guilt, embarrassment, shame, blame or isolation

Conclusions

The answer to whether diabetes comes with social stigma in the USA was a resounding 'yes' among patients who are T1D (76%), T2D on MDI/pump therapy (61%), and T2D who are not on insulin (49%). Additionally, respondents felt other people's perceptions of diabetes have had a negative impact on their diabetes management (27% of T1A, 42% of T2I, and 37% of T2NI) and more notably, in their social lives (53% of T1A, 76% of T2I, and 58% of T2NI). How diabetes stigma is experienced did not vary by demographics or duration of diabetes, but increased with intensity of disease type and therapy. We found that one third of T1 (38-39%) and T2 on MDI/pump (35%) were more likely to experience guilt, embarrassment, shame, isolation, or blame, while this result was lower in respondents on less intense therapies (30% in non-MDI T2 insulin users, 21% in T2 on orals only, and 20% in T2NI). The feeling of stigmatization also increased with poorer glucose control (39% for A1c>8%), higher BMI (29% for BMI >35) and lower self-reported diabetes control. Collectively these data highlight factors that affect the social stigma associated with diabetes and point to the need for more public education to shift perceptions about diabetes, alongside advances in patient treatment.