

# **Objectives**

- American Diabetes Association (ADA) engaged a full-service research and accounting firm, Vault Consulting, LLC, to explore perceptions & behaviors related to insulin affordability among insulin users in the United States.
- Information objectives:
  - Changes (+/-) in amount individuals pay for insulin
  - Impact of cost on insulin prescription, purchase, and use, if any
  - Feelings related to insulin cost
  - Role of insurance coverage, if any
- Data are intended to increase understanding of the issues around cost.



# Methodology

- Online survey among 535 individuals across 3 segments →
- 10 minute online survey
- Data collection: February 12 March 7, 2018
- Conducted by third-party, independent research firm, Vault Consulting, LLC

Seg	gments:	# Surveys
A.	Caregivers of Child Insulin Users -Note: 31% of these caregivers also use insulin)	64
В.	Adult Insulin Users	255
C.	Caregivers of Adult Insulin Users	216



# **Methodology – Sample Plan:**

Screening methodology was designed to ensure insulin usage representivity:

- 1. Sample source = programmatic sample exchange for breadth of reach
- 2. Census balanced "general population" screening:
  - Designed to ensure that qualified survey respondents are representative of insulin users
- Criteria for qualified respondents included:
  - Have diabetes and currently use insulin, or
  - Care for a dependent child or dependent adult who has diabetes and currently uses insulin

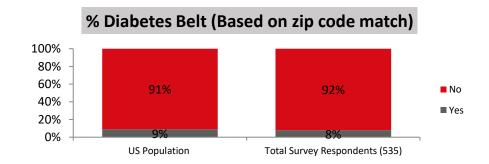
	Compariso	on of Respondent to Cen	sus
	Census	Actual % Screener Starts	Total Respondents (representing insulin user/ HH)
GENDER			
Male	50%	50%	56%
Female	50%	50%	44%
AGE			
18-24	13%	13%	10%
25-44	41%	41%	46%
45-64	30%	30%	29%
65+	16%	16%	16%
ETHNICITY			
Caucasian	76%	76%	76%
African American	13%	13%	14%
Other	11%	11%	10%
HISPANIC VS NOT			
Hispanic	14%	13%	18%
Not Hispanic	86%	87%	82%
INCOME			
Less than \$25K	25%	25%	16%
\$25K - \$50K	25%	25%	26%
\$50K - \$75K	18%	18%	23%
\$75K - \$100K	11%	11%	14%
\$100K - \$125K	8%	8%	8%
\$125K+	13%	12%	14%



# **Methodology – Sample Plan:**

## Geographic representivity also assured:

	Comparison of Respondent to Census								
	Census	Actual % Screener Starts	Total Respondents (representing insulin user/ HH)						
REGION									
Midwest	22%	22%	22%						
Northeast	18%	18%	18%						
South	37%	37%	40%						
West	23%	22%	20%						





# **EXECUTIVE SUMMARY**

2018 Insulin Affordability Study



# **Executive Summary**

- Overall, 39% of insulin users experienced an increase in the amount they personally pay for insulin over the past year. Of these, 72% indicated it increased slightly and 17% indicated it increased greatly.
- Thirty seven percent of insulin users indicated their cost of insulin had increased from December of 2017 to January of 2018. This was true for more than half the dependent child insulin users.

	Total	Dep. Child	Adult Self	Dep. Adult
\$ Increase over past year	39%	49%	39%	36%
Price paid Jan '18 is > Dec '17	37%	52%	35%	36%

 Nearly a fifth of insulin users say their doctors have prescribed different insulin due to cost (18%) or that they have been required to change insulin by their insurers (22%).



# **Executive Summary**

- Roughly a quarter (27%) of respondents indicate insulin cost has affected their past year purchase or use of insulin - more so in the case of dependent child insulin users (34%).
- Affected users all segments respond in a number of ways, including:
  - Regularly taking less than prescribed (26% of those impacted by cost)
  - Changing to less expensive types/brands with doctor (23%)
  - Missing doses weekly (23%) or monthly (20%)
  - Choosing between insulin and other health-related purchases, e.g. other medications (36%), fruits/vegetables (34%), doctor visits (32%), and health insurance (26%)
  - Made choices between insulin and transportation (32%), utilities (30%), housing (27%), and non-essential purchases like vacations (41%) and entertainment (43%).



## 2018 Insulin Study

# **Executive Summary**

Insulin users for whom cost affected their purchase/use of insulin experience adverse health effects at higher rates than those for whom cost did not affect purchase/use.

	All	Cost Affected Purchase/Use	Cost Did NOT Affect Purchase/Use
Experience severely low blood sugar episodes past 3 months	54%	72%	42%
Have had at least 1 ER visit in past 3 months	32%	53%	22%
Last A1C 7.5 and above	65%	80%	59%
<16 hours/day spent in recommended blood glucose range	62%	80%	56%

Those experiencing a price increase also experience negative emotions (e.g. stress, anxiety, roughly 73%) at over twice the rate of those not experiencing a price increase (about 31%).



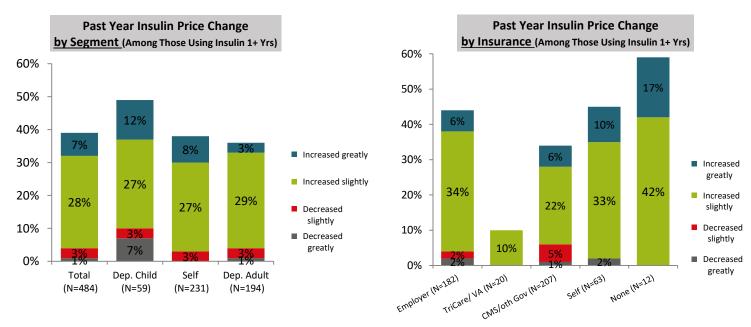
# **DETAILED FINDINGS – Insulin Cost & Impact**

2018 Insulin Affordability Study





Among those using insulin for 1+ years, 39% of adults responding for themselves and 49% of respondents answering for dependent children report past-year price increases. Most of those respondents indicated slight price increases. Increases are more often reported by those without health insurance.

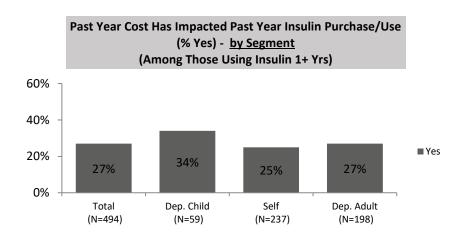


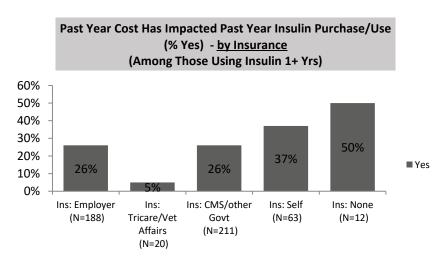
Q9/Q9A: Has the price you personally pay for insulin changed in the past year, or not?/How has the amount you personally pay for insulin changed in the past year?





Among the population of those using insulin for 1+ years, 27% report the <u>past year</u> <u>cost</u> of insulin has impacted their past year insulin purchase/use.





Q17: Please think about the amount you have personally paid for insulin in the past year. Has the cost of insulin affected how you have purchased or used insulin in the past year, or not?





### **Insurance Type and Insulin Cost Per Month**

Insurance Type	Respondents	2016 National *
Insurance bought through employer or spouse's employer	37%	49%
Insurance bought individually	13%	7%
Medicare	28%	19%
Medicaid	13%	14%
TRICARE or Veterans Affairs	4%	20/
Other Government health insurance plan	3%	2%
No current health insurance coverage	3%	9%

Deductible Type	Respondents
I have one deductible that covers both doctor visits and prescriptions	41%
I have separate deductibles for doctor visits and prescriptions	27%
I don't have a deductible	24%
I don't know	9%

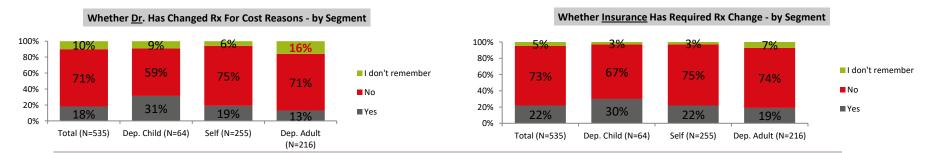
Insulin Cost per Month	January 2018	December 2017
Range of responses	\$0-\$5,000	\$0-\$5,500
Mean	\$192.05	\$139.49
Median	\$50.00	\$45.00

2016 National Statistics from Kaiser Family Foundation: <a href="https://www.kff.org/other/state-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22united-indicator/total-population/?currentTimeframe=0&selectedRows=%78%22wrapups%22:%78%22:%78%22wrapups%22:%78%22wrapups%22:%78%22wrapups%22:%78%22wrapups%22:%78%22wrapups%22:%78%22:%78%22wrapups%22:%78%2 states%22:%7B%7D%7D%7D%sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D





Nearly a third (30%) have had their prescription changed, either by a doctor for cost reasons, or by insurance – more so in the case of dependent children insulin users.



#### Summary of Dr. and/or Insurance Rx Change - by Segment and Insurance

	Total	Dep. Child	Self	Dep. Adult	Ins: Employer	Ins: Tricare/Vet Affairs	Ins: CMS/ other Govt	Ins: Self	Ins: None
	(A)	(B)	(C)	(D)	(K)	(L)	(M)	(O)	(P)
Base: Total	(535)	(64)	(255)	(216)	(198)	(20)*	(235)	(68)	(14)*
Dr. and/or Insurance Changed Rx	30%	38%	32%	26%	33%	0%	32%	28%	14%
Dr. Changed Prescription	18%	31%	19%	13%	22%	0%	17%	18%	7%
Insurance Changed Prescription	22%	30%	22%	19%	24%	0%	23%	22%	7%

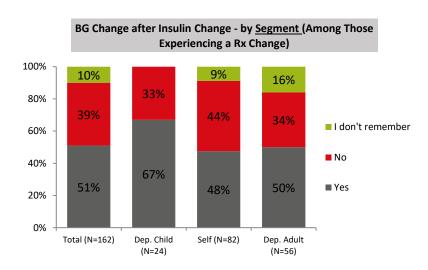
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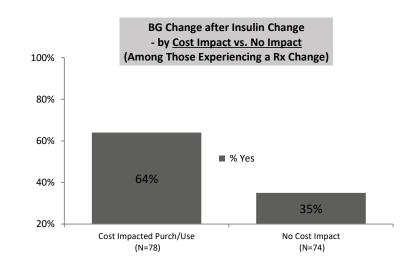
Q12: Has your doctor ever prescribed different insulin (another brand and/or regular human insulin) so that it would cost less, or not? Q13: Has your insurance ever required you to change insulins, or not?





Overall, half (51%) of respondents overall and 67% of children who experienced a Rx change also experienced a change in blood glucose (BG).





Q14A: After you changed insulins, did your blood glucose control change, or not?





Behaviors resulting from the impact of cost on insulin purchase included the following: taking less insulin, missing doses, using a less expensive prescription, and not filling prescriptions.

Ways In Which Past Year Cost Has Affected Past Year Insulin Purchase/Use - by Segment							
	Total		Dep. Child	Self	Dep. Adult		
	(A)	]	(B)	(C)	(D)		
Base: Amount personally paid affected how purchased insulin in past year in Q17	(133)		(20)*	(60)	(53)		
Regularly take less than the prescribed dose	26%		15%	27%	30%		
Missed 1-2 doses per week	23%		10%	27%	23%		
Dr/I chose a cheaper insulin	23%		35%	18%	23%		
Missed 1-2 doses per month	20%		20%	15%	25%		
Used a patient assistance program	20%		30%	15%	23%		
Used a discount drug website/program	20%		20%	25%	15%		
Did not fill at least one prescription	18%		20%	23%	11%		
Used a rebate or coupon	17%		15%	15%	21%		
My health/Rx plan chose a cheaper insulin	14%		10%	12%	19%		

<sup>\*</sup>Small base

Q18: In which of the following ways, if any, has the amount you have personally paid for insulin affected the way you have purchased or used insulin over the past year? As a result of the cost I had to pay for insulin over the past year.





Respondents using Medicare and Medicaid insurance are more likely to regularly take less than the prescribed dose, than respondents with employer-provided or individually purchased insurance.

Ways In Which Past Year Cost Has Affected Past Year Insulin Purchase/Use - by Insurance							
	Total		Employer	Individual	Medicare	Medicaid	
	(A)						
Base: Amount personally paid affected how purchased insulin in past year in Q17	(133)		(49)	(23)*	(35)	(16)*	
Regularly take less than the prescribed dose	26%		18%	17%	26%	63%	
Missed 1-2 doses per week	23%		10%	22%	31%	25%	
Dr/I chose a cheaper insulin	23%		18%	13%	31%	31%	
Missed 1-2 doses per month	20%		22%	9%	20%	19%	
Used a patient assistance program	20%		18%	30%	20%	29%	
Used a discount drug website/program	20%		27%	26%	11%	6%	
Did not fill at least one prescription	18%		20%	17%	14%	13%	
Used a rebate or coupon	17%		16%	35%	6%	25%	
My health/Rx plan chose a cheaper insulin	14%		12%	9%	23%	19%	

<sup>\*</sup>Small base

Q18: In which of the following ways, if any, has the amount you have personally paid for insulin affected the way you have purchased or used insulin over the past year? As a result of the cost I had to pay for insulin over the past year.





# Affected participants also report a variety of health and lifestyle impacts due to dose/prescription adjustments (as a result of price personally paid).

# How Insulin Cost-Related Decisions Impacted Normal Daily Activities - by Segment (Among Those Who Adjusted Dose, Reduced Prescriptions Filled, Dr/Ins/Self Chose Cheaper Insulin)

	Total		Dep. Child	Self	Dep. Adult
	(A)	1	(B)	(C)	(D)
Base: Adjusted Dose/Filled Rx; or changed Rx	(110)		(16)*	(48)	(46)
Health Effects (Net)	34%		19%	33%	39%
Safety/Side Effects (Subnet)	18%		19%	10%	26%
Made me sick/very ill	7%		-	4%	13%
Felt sluggish/tired/had no energy	7%		6%	4%	11%
Negative Effect On Diabetes (Subnet)	17%		•	27%	13%
Blood sugar levels were high/much higher	8%		-	12%	7%
Effect On Lifestyle (Net)	27%		31%	23%	30%
Unable to do/go out as much/participate in many activities	9%		6%	10%	9%
Had to watch my diet/cut back on certain foods	6%		12%	-	11%
Emotional Effects (Net)	9%		-	12%	9%
Caused me stress/anxiety	5%		-	6%	4%
RX Adjustment /Non-Compliance (Net)	5%		-	2%	9%
None	25%		31%	29%	20%

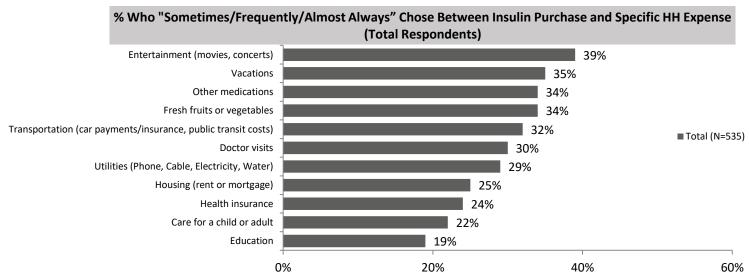
\*Small base

Q19: Please describe how, if at all, the decisions you indicated you made in the prior question (shown above) impacted your health or your ability to do normal daily activities? Please describe any impact in as much detail as possible.





The cost paid for insulin most often affected decisions related to non-essentials (entertainment & vacations) followed by "health-related" necessities (other medications, fresh fruits/ vegetables, doctor visits) and transportation.



Q20: Thinking about your insulin purchases in 2017, and using the scale shown, about how often did you have to choose between paying for insulin and paying for the expense shown? \*\*Top Three Box Summary\*\* N/A Excluded





# Choosing between insulin and other household expenses is more evident among households with dependent child insulin users.

# % Who At Least "Sometimes/Frequently/Almost Always" in 2017 Chose Between Insulin Purchase and Specific HH Expense (by Segment, Cost Impact vs. No Impact, and Insurance)

(by segment, cost impact vs. No impact, and insurance)											
	Total		Dep. Child	Self	Dep. Adult		Ins: Employer	Ins: Tricare/ Vet Affairs	Ins: CMS/oth er Govt	Ins: Self	Ins: None
	(A)		(B)	(C)	(D)		(K)	(L)	(M)	(O)	(P)
Base: Total	(535)		(64)	(255)	(216)		(198)	(20)*	(235)	(68)	(14)*
Entertainment (movies, concerts)	39%		61%	35%	38%		42%	10%	36%	50%	50%
Vacations	35%		58%	30%	35%		40%	10%	30%	46%	43%
Other medications	34%		53%	31%	31%		32%	5%	34%	47%	36%
Fresh fruits or vegetables	32%		53%	29%	30%		30%	-	33%	43%	36%
Transportation (car payments/insurance, public transit costs)	30%		55%	25%	29%		30%	5%	29%	41%	50%
Doctor visits	30%		50%	25%	30%		34%	-	26%	40%	43%
Utilities (Phone, Cable, Electricity, Water)	29%		50%	24%	28%		28%	5%	27%	43%	36%
Housing (rent or mortgage)	25%		45%	20%	25%		24%	-	23%	38%	36%
Health insurance	24%		47%	20%	22%		24%	-	23%	35%	36%
Care for a child or adult	22%		52%	16%	21%		22%	•	21%	34%	21%
Education	19%		45%	17%	14%		21%	5%	16%	32%	7%

\*Small base

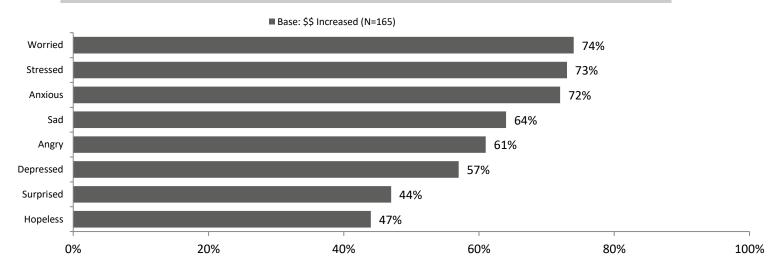
Q20: Thinking about your insulin purchases in 2017, and using the scale shown, about how often did you have to choose between paying for insulin and paying for the expense shown? \*\*Top Three Box Summary\*\*





Those experiencing a price increase experienced negative emotions related to the amount paid for insulin. Specific negative emotions were reported two to three times more often by those who experienced a price increase compared to those who did not experience a price increase.

#### Past Year "Feelings" As A Result of Amount Paid for Insulin - Among Those Experiencing a Price Increase



Q21: Thinking about the past year, which, if any, have you, yourself, experienced as a result of how much you personally pay for insulin\*\*% Yes Summary\*\*



