# SUPPLEMENTARY MATERIAL

Patient perceptions of their glycemic control and its influence on type 2 diabetes outcomes: an international survey of online communities

Kristina Simacek1,\*, Christopher Curran1,\*, Peter Fenici2, Ricardo Garcia-Sanchez3

1PatientsLikeMe, Inc., Cambridge, MA, USA

2AstraZeneca, Cambridge, UK

3AstraZeneca, Gaithersburg, MD, USA

Correspondence: Kristina Simacek and Christopher Curran, PatientsLikeMe, Inc., 160 Second Street, Cambridge, MA 02142, USA. Tel: +1 617-499-4003. Email: ksimacek@patientslikeme.com and ccurran@patientslikeme.com

**Table S1.** Prevalence of diabetes and national T2D management guideline-stipulated A1C target by study country

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **USA** | **Canada** | **Germany** | **Mexico** | **Spain** | **UK**  |
| Diabetes prevalence, %(95% CI)a  | 13.0(12.4, 13.7) | 9.6(9.2, 13.3) | 12.2(9.9, 13.5) | 14.8(7.4, 17.6) | 10.4(8.2, 14.6) | 5.9(5.2 ,7.6) |
| National guideline target A1C, % | < 7.0b | ≤ 7.0c | 6.5–7.5d | < 7.0e | < 7.0f | 6.5 / 7.0g |

aNational prevalence in adults aged 20–79 years.1

bA reasonable A1C goal for many nonpregnant adults.2

cRecommended target for most adults with type 1 or type 2 diabetes.3

dAn A1C range of 6.5% to 7.5% is generally recommended to prevent secondary complications.4

eIn patients treated with monotherapy who have uncontrolled diabetes, a goal of A1C below 7% should be used.5

fIn general, target figures under 7% for A1C are recommended.6

gFor adults with T2D managed either by lifestyle and diet, or by lifestyle and diet combined with a single drug not associated with hypoglycaemia, support the person to aim for an A1C level of 48 mmol/mol (6.5%). In adults with type 2 diabetes, If A1C levels are not adequately controlled by a single drug and rise to 58 mmol/mol (7.5%) or higher, support the person to aim for an A1C level of 53 mmol/mol (7.0%).7

A1C, glycated hemoglobin; CI, confidence interval.

**Table S2.** Theme of each survey question as it relates to the themes of the study

|  |  |
| --- | --- |
| **Theme** | **Question number** |
| Demographics | A1, A2, A3, G1, G2 |
| Clinical characteristics | B1, B2, B3, B4, B5 |
| Awareness of glycated hemoglobin (A1C) testing and targets | B6, C1, C2, C3, C5, C6 |
| Perceived level of glycemic control | C4, C7, C8 |
| Risk of complications | C9, C10, C11 |
| Attitudes towards medications | D1, D2, D3, D4, D5, D6, D7, D8, D9 D10, D11, F1, F2, F3, F4, F5 |
| Self-management and regimen-related distress | E1, E2, E3, E4, E5, E6, E7, E8 |

**Table S3.** Survey response rates by study country

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **USA** | **Canada** | **Germany** | **Mexico** | **Spain** | **UK**  |
| Invitations sent, n | 2234 | 291 | 607 | 57 523 | 516 | 1710 |
| Recipients started the questionnaire, n (%) | 154 (6.9) | 137 (47.1) | 206 (33.9) | 246 (0.4) | 178 (34.5) | 216 (12.6) |
| Recipients completed the questionnaire, n (%) | 148 (6.6) | 113 (38.8) | 100 (16.5) | 104 (0.2) | 100 (19.4) | 100 (5.8) |

**Appendix S1**

**Survey**

**Introduction**

Who knows better about dealing with your type 2 diabetes than you? From day-to-day routines to challenges to treatment decisions – you’re in it. And since there’s still a lot we don’t know about this disease, your responses here can help us and our partners at AstraZeneca better understand how you manage things like your A1C levels, set goals, and make treatment decisions.

Add your voice to this research!

1. {Q’s - Demographics}

Before we begin the survey, we have a couple of questions about you.

* 1. In what country do you live? [*will be modified to reflect country of patients invited]*

a) US

b) Canada

c) UK {SCREEN OUT}

d) Other {SCREEN OUT}

* 1. When were you born?
		1. <Numeric>
	2. What is your sex?
		1. Female
		2. Male
		3. I prefer to skip
1. {Q’s – Diabetes Care}

Let’s start off by learning a bit more about your history with type 2 diabetes. This will help our researchers better understand your individual health.

* 1. How long ago were you diagnosed with type 2 diabetes by a healthcare provider? Please use your best guess.
		1. Less than 6 months {SCREEN OUT}
		2. 6 months to less than 1 year
		3. 1-5 years
		4. 6-10 years
		5. 11-15 years
		6. 16-20 years
		7. 21 or more years
	2. Has a doctor or other health care provider also diagnosed you with any of the following conditions? Please select all that apply.
		1. High blood pressure (hypertension)
		2. Overweight/obesity
		3. Heart Attack (myocardial infarction)
		4. High Cholesterol (hypercholesterolemia)
		5. Depression (major depressive disorder, dysthymia)
		6. Diabetes affecting your nerves/nervous system (neuropathy)
		7. Diabetes affecting your eyes (retinopathy)
		8. Chronic kidney disease
		9. Heart disease
		10. Stroke
		11. Leg pain or ulcers due to diabetes (Peripheral vascular disease)
		12. Does Not Apply
	3. People with diabetes may have the following symptoms. Which ones have you experienced in the last month? Please select all that apply.
		1. Hypoglycemia (episode of low blood sugar)
		2. Fatigue
		3. Insomnia or difficulty sleeping
		4. Dizziness or fainting
		5. Nerve pain
		6. Problems concentrating
		7. Joint stiffness
		8. Frequent urination
		9. None of these {exclusive option}
	4. Who do you routinely see to treat your type 2 diabetes? Please select all that apply.
		1. Primary Care Physician or General Practitioner
		2. Endocrinologist
		3. Diabetologist
		4. Cardiologist
		5. Pharmacist
		6. Nurse Practitioner
		7. CDE (Certified Diabetes Educator)
		8. Physician’s Assistant
		9. Podiatrist (foot-care specialist)
		10. Dietician
		11. Psychologist or Psychiatrist
		12. Other
		13. I do not receive routine care for my type 2 diabetes
	5. These days, people are very busy and sometimes things come up that get in the way of appointments with our doctors. How often do you miss or skip appointments, for any reason, with a health care provider to discuss or review your diabetes?
		1. Never
		2. Occasionally
		3. Sometimes
		4. Often
		5. I don’t know
	6. What tests does your doctor normally do to check on your diabetes? (check all that apply)
		1. A1C (sometimes called HbA1C)
		2. Fasting plasma glucose (a blood test before breakfast in the morning)
		3. Checking for sugar in the urine with a dipstick
		4. Self-monitoring with a blood sugar meter at home
		5. None of the above
1. {Q’s – Awareness of A1C levels}

In the next section we would like to ask you some questions specifically about your blood glucose (blood sugar) control. Most health care providers measure your blood glucose control with a blood test to assess your A1C (sometimes called HbA1C) level, which provides an accurate measure of your average blood glucose control over the last 2 or 3 months. The test is used to give you and your health care provider an idea of how well your diabetes treatment plan is working.

* 1. Has your health care provider ever tested your A1C?
		1. Yes
		2. No {skip to D.7}
		3. I don’t know {skip to D.7}

* 1. When did you last have an A1C test?
		1. Within the last 3 months
		2. More than 3 months but less than 6 months
		3. More than 6 months but less than one year
		4. One year or more
		5. I don’t know
	2. What was your last A1C value? Please enter a percentage*.[local units will be used by country]*
		1. <Numeric>
		2. I don’t know {skip to D.7}
	3. What do you think your last A1C test result means? It means I am doing…
		1. Very well
		2. Fairly well
		3. Fairly poorly
		4. Very poorly
		5. I don’t know
	4. Do you and your health care provider have a specific A1C target or goal?
		1. Yes {ask D.6, otherwise skip}
		2. No {skip to D.7}
		3. I don’t know {skip to D. 7}
	5. What is your A1C goal or target? Please enter a percentage. {Programming note: use local units}
		1. <Numeric>
		2. I don’t know
	6. To what extent do you believe your diabetes is under control?
		1. Very well controlled
		2. Fairly well controlled
		3. Poorly controlled
		4. Not at all in control
		5. I don’t know
	7. How high would your A1C test result have to be for you to ask your doctor to do something about it, such as make a change to your treatment plan? Please enter a percentage.
		1. <Numeric>
		2. I don’t know
	8. If you were to stay at your current level of diabetes control, for how long do you think you could avoid any serious complications due to your diabetes?
		1. Less than one year
		2. 1-5 Years
		3. 6-10 Years
		4. 11-20 years
		5. More than 20 years
		6. I do not expect any future complications due to my diabetes if I stay at the same level of control {skip to section E}
		7. I don’t know
	9. What do you think is likely to happen to you in the short term (within one year) if your diabetes stays at the same level of control? Please select all that apply.
		1. I will be in good health without any problems {exclusive option}
		2. Kidney problems
		3. Heart problems
		4. Problems with eyes/vision
		5. Sexual dysfunction
		6. Ulcers or sores on feet
		7. Nerve pain
		8. Hearing problems
		9. Skin problems
		10. Insomnia
		11. I don’t know
	10. What do you think is likely to happen to you in the long-term (after five years) if your diabetes stays at the same level of control? Please select all that apply.
		1. I will be in good health without any problems {exclusive option}
		2. Kidney problems
		3. Heart problems
		4. Problems with eyes/vision
		5. Sexual dysfunction
		6. Ulcers or sores on feet
		7. Nerve pain
		8. Amputation
		9. Hearing problems
		10. Skin problems
		11. Insomnia
		12. I don’t know
1. {Q’s – T2D Treatments}

Next we would like to ask you a few questions about the things you do to help manage or control your type 2 diabetes.

* 1. What has your doctor told you to do to better manage/control your diabetes? Please select all that apply.
		1. Change my diet
		2. Exercise
		3. Take tablets or pills for diabetes {ask E.2 to E.4, otherwise skip}
		4. Take insulin {ask E.5 to E.6, otherwise skip}
		5. Take injectable medication other than insulin (GLP-R agonists such as such as exenatide (Byetta, Bydureon), liraglutide (Victoza), albiglutide (Tanzeum), dulaglutide (Trulicity), pramlintide (Symlin)) {ask E.7 to E.8, otherwise skip}
		6. None of these {exclusive option}

* 1. {ask If selected “take tablets or pills” on E.1} Which of the following types of pills or tablets are you currently using to treat your type 2 diabetes?
		1. Sulfonylureas (such as glimepiride (Amaryl), glipizide (Glucotrol), glyburide (Diabeta, Glynase), nateglinide (Starlix), repaglinide (Prandin))
		2. Biguanides (such as Metformin (Glucophage), or a combination of these)
		3. Thiazolidinediones (such as pioglitazone (Actos), rosiglitazone (Avandia))
		4. DPP-4 inhibitors (such as sitagliptin (Januvia), saxagliptin (Onglyza), linagliptin (Tradjenta), alogliptin (Nesina))
		5. Alpha-glucosidase inhibitors (such as acarbose (Precose), miglitol (Glyset))
		6. Sodium-glucose cotransporter 2 inhibitors (such as canagliflozin (Invokana), dapagliflozin (Farxiga))
		7. Combination medications (such as sitagliptin-metformin (Janumet), metformin-glyburide (Glucovance), saxagliptin-metformin (Komblyze), canagliflozin-metformin (Vokanamet), dapagliflozin-metformin (Xigduo))
	2. {ask If selected “take tablets or pills” on E.1} Do you always take your pills or tablets as directed by your health care provider?
		1. Yes
		2. No {ask E.4, otherwise skip}
		3. I don’t know
	3. {ask If selected “no” on E.3} Why do you NOT take your pills or tablets as directed? Please select the main reason.
		1. Cost
		2. I have too many pills to keep track of
		3. Had to take them too many times a day
		4. I did not agree with my health care provider that I needed it.
		5. I did not think it would be effective
		6. I’m concerned about the potential side effects
		7. I'm am trying other things, like changing my diet or exercise
		8. Other
	4. {ask If selected “take insulin” on E.1} Do you always take your insulin as directed by your health care provider?
		1. Yes
		2. No {ask E.6, otherwise skip}
		3. I don’t know
	5. {ask If selected “no” on E.5} Why do you not take your insulin as directed? Please select the main reason.
		1. Cost
		2. I don’t like injections
		3. I didn’t think it would be effective for my T2D
		4. I did not agree with my health care provider that I needed it
		5. I am concerned it could interfere with my work
		6. I don’t want to be stuck using it for the rest of my life
		7. It is too inconvenient
		8. I was worried about hypoglycemia (low blood glucose)
		9. I was worried about weight gain
		10. Other
	6. {ask If selected “take injectable medication other than insulin” on E.1} Do you always take your injectable medications (besides insulin) as directed by your health care provider?
		1. Yes
		2. No {ask E.8, otherwise skip}
		3. I don’t know
	7. {ask If selected “no” on E.8} Why do you not take your injectable medications (besides insulin) as directed? Please select the main reason.
		1. Cost
		2. I don’t like injections
		3. I didn’t think it would be effective for my T2D
		4. I did not agree with my health care provider that I needed it
		5. I am concerned it could interfere with my work
		6. I don’t want to be stuck using it for the rest of my life
		7. It is too inconvenient
		8. Other
	8. {Ask if d or e on E.1} How burdensome would you say it is to take your injectable medication for your type 2 diabetes?
		1. Not at all burdensome
		2. A little burdensome
		3. Moderately burdensome
		4. Very burdensome
	9. {Ask if c, d, or e on E.1} How important are medicines in helping you achieve your diabetes goals?
		1. Very unimportant
		2. Unimportant
		3. Neither important nor unimportant
		4. Important
		5. Very important
		6. I don’t know
	10. {Ask if c, d, or e on E.1} People with diabetes usually take many different medicines, and it is common to miss or skip medications because of cost, convenience, or side effects. In the past 30 days, how many days did you skip or miss treatments? Please use your best guess. If none, enter 0.
		1. <Numeric>
1. {Q’s – Diabetes Distress & Concerns about hypoglycemia}

Who knows better about managing your type 2 diabetes than you? In this next section we’ll ask how you are managing your diabetes and to consider the degree to which each of the following have distressed or bothered you during the past month.

* 1. How much has this problem bothered you during the last month? **Feeling that I am not testing my blood sugars frequently enough.**
		1. Not a problem (1)
		2. A slight problem (2)
		3. A moderate problem (3)
		4. Somewhat serious problem (4)
		5. A serious problem (5)
		6. A very serious problem (6)
	2. How much as this problem bothered you during the last month? **Feeling that I am often failing with my diabetes regimen.**
		1. Not a problem (1)
		2. A slight problem (2)
		3. A moderate problem (3)
		4. Somewhat serious problem (4)
		5. A serious problem (5)
		6. A very serious problem (6)
	3. How much has this problem bothered you during the last month? **Not feeling confident in my day-to-day ability to manage diabetes**
		1. Not a problem (1)
		2. A slight problem (2)
		3. A moderate problem (3)
		4. Somewhat serious problem (4)
		5. A serious problem (5)
		6. A very serious problem (6)
	4. How much has this problem bothered you during the last month? **Feeling that I am not sticking closely enough to a good meal plan**
		1. Not a problem (1)
		2. A slight problem (2)
		3. A moderate problem (3)
		4. Somewhat serious problem (4)
		5. A serious problem (5)
		6. A very serious problem (6)
	5. How much has this problem bothered you during the last month**? Not feeling motivated to keep up my diabetes self-management.**
		1. Not a problem (1)
		2. A slight problem (2)
		3. A moderate problem (3)
		4. Somewhat serious problem (4)
		5. A serious problem (5)
		6. A very serious problem (6)
	6. Please rate how much you agree or disagree with the following statement: **I spend so much time worrying about the possibility of a low blood sugar episode that it interferes with my ability to do the things I really want to do.**
		1. Completely agree
		2. Agree
		3. Disagree
		4. Completely disagree
		5. Does not apply
	7. Please rate how much you agree or disagree with the following statement: **To avoid serious problems with low blood sugar, I tend to keep my blood sugars higher than I probably should.**
		1. Completely agree
		2. Agree
		3. Disagree
		4. Completely disagree
		5. Does not apply
	8. Please rate how much you agree or disagree with the following statement: **I am confident that I can avoid serious problems due to low blood sugar when I am alone.**
		1. Completely agree
		2. Agree
		3. Disagree
		4. Completely disagree
		5. Does not apply
1. {Q’s – Medication Changes}

In this section, we’ll ask you a few questions to understand how you and your health care provider(s) make decisions about the medications you take.

* 1. When did you last have any change in your diabetes medications (such as stopping an old medication, starting or adding a new medication, changing your dosage)?
		1. Within the last 3 months
		2. More than 3 months but less than 6 months
		3. More than 6 months but less than one year
		4. One year or more
		5. I have not had any changes to my medication {skip to G.5}
		6. I don’t know
	2. Thinking about the last time your medication was changed, what changes were made? Please select all that apply.
		1. Stopped taking a medication and did not take a new one
		2. Stopped taking a medication and started taking a new one
		3. Started taking medication for type 2 diabetes for the first time
		4. Added a medication to my existing medications for type 2 diabetes
		5. Changed the dose of a medication I was already taking
		6. Other
	3. Who was responsible for suggesting the medication change?
		1. My health care provider suggested it
		2. I suggested it
		3. Both my health care provider and I thought a change was needed
		4. I’m not sure how the change happened
	4. Why did you have a change to your diabetes medication(s)? Please select all that apply.
		1. My A1C was too high
		2. I was able to control my diabetes through lifestyle changes (diet and/or exercise)
		3. Side effects of the previous medication were too burdensome
		4. Cost / out-of-pocket
		5. My health care provider felt my diabetes was not well controlled
		6. Other,
		7. I don’t know {exclusive option}
	5. {ask only if E on G.1} Why have you not had any changes to your diabetes medication? Please select all that apply.
		1. Just recently diagnosed
		2. My health care provider did not think I needed to change medication
		3. My health care provider suggested a different medication but I chose to stay on the same medication
		4. I am inconsistent about taking my medication so I need to improve that before trying another medication
		5. Other
1. Q’s – Demographics

Almost done! We just have a few more questions about your background.

* 1. What kind of health insurance do you have?
		1. Have no health insurance
		2. National/public health insurance (including coverage by public welfare)
		3. Private insurance
		4. Employer/union based insurance
		5. National/public health insurance AND private complementary insurance
		6. Public/national AND employer/union based insurance
		7. Employer/union based and private/complementary insurance
		8. Employer/union based, private/complementary and national/public health insurance
		9. Military/ veterans {US only}
		10. Other
	2. What is your highest level of education? *[Note: local equivalents to be used]*
		1. 8th grade or less (left school around 14)
		2. Some high school, but did not graduate (left school around 16)
		3. High school graduate or GED (left school around 18)
		4. Some college but less than a bachelor's / undergraduate degree
		5. College bachelor's / undergraduate degree
		6. Postgraduate degree (Master's, doctorate, etc.)

*For EU participants the following will be added:*

*If you get any side effects of your medicines talk to your doctor, pharmacist or nurse. You can also report side effects directly at [country-specific link to be added, e.g.*[*www.ansm.sante.fr*](http://www.ansm.sante.fr)*]*

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# Contributions

Kristina Simacek – conception and design of the study, acquisition and interpretation of data, and drafting and review of manuscript. Christopher Curran – conception and design of study, acquisition and interpretation of data, and review of manuscript. Peter Fenici and Ricardo Garcia-Sanchez – conception and design of the study, interpretation of data, and review of manuscript. All authors reviewed and approved the final version of the manuscript.

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