Supplementary File: Survey Instrument

The Global Patient Perspective on Uncontrolled Moderate-to-Severe Asthma: Reducing Delays in Diagnosis and Treatment

Karen Rance DNP[1], CPNP, Brenda Young[2], Gretchen McCreary BA[3], Stephanie Williams BS RRT[4], Marilyn Urrutia-Pereira MD, PhD[5], Kristen Willard MS[6], Ghulam Mustafa MD[7], Purvi Parikh MD[8], Tonya Winders MBA[9], Ruth Tal-Singer PhD[10]

[1] Chief Medical Officer, Global Allergy & Airways Patient Platform (GAAPP), Vienna, Austria
[2] Patient Advocate, GAAPP, Vienna, Austria
[3] Senior Research Coordinator, GAAPP, Vienna, Austria
[4] Project Lead, Speak Up for COPD, GAAPP, Vienna, Austria
[5] Assistant Professor of Pediatrics, Faculty of Medicine, Federal University of Pampa, Brazil
[6] Vice President of Education, GAAPP, Vienna, Austria
[7] College of Medicine, Shaqra University, Shaqra, Saudi Arabia
[8] Clinical Assistant Professor of Medicine and Pediatrics, NYU Langone School of Medicine, New York, NY, USA
[9] President and CEO, GAAPP, Vienna, Austria
[10] Chief Scientific Officer, GAAPP, Vienna, Austria

Corresponding Author:

Karen Rance, DNP, CPNP
452 Seagrove Way
Port St. Joe, FL 32456, USA
Email: **krance@gaapp.org**

GAAPP Community Survey on living and managing asthma

Thank you for following the link to this survey. there are no right or wrong answers, it's all about you!

This is your chance to review what you know about your condition. We hope this will also give you some useful choices to help in discussions with health care providers.

This survey is promoted by GAAPP member organizations with financial support from Astra Zeneca. The survey is anonymous, and your personal identifying information will not be collected.

To consent to this survey and answer the questions, please click the "NEXT" button below.

GAAPP Community Survey on living and managing asthma

Informed Consent

Introduction

Thank you for considering participating in our survey on living with asthma. Your insights are invaluable in helping us understand the experiences of patients. This study is being conducted by the Global Allergy and Airways Patient Platform Research team in collaboration with the Innovative Respiratory Endpoints Network which is a group of experts focused on improving respiratory care. This survey is funded by a research grant from AstraZeneca.

Eligibility Criteria:

Are you:

- 18 years old or older?

- A person diagnosed with asthma

- Living in the US?

If you meet these criteria, we invite you to participate in our research study!

Purpose of the Survey:

This anonymous survey aims to gather information about living with and receiving treatment for severe asthma. The insights gained will support educational programs designed to enhance care for people like you.

Survey Details:

- Duration: Approximately 15 minutes to complete.

- Participation: Your participation is voluntary. You can skip any questions you prefer not to answer and may withdraw at any time.

Confidentiality Assurance

- No information is collected in the study that can identify you, it is an anonymous survey

- There are no known risks associated with participating in this study.

- While there are no direct benefits to you and you will not be paid for the survey, your responses will help improve the design of clinical trials in asthma and create valuable educational materials for patients and healthcare providers.

- Your participation is free of charge, and your responses will remain anonymous; no personal

identifying information will be collected.

- Your information collected as part of this research study will be used for the purpose of developing tools for clinical trials amd educational materials and will be integrated with information gathered from other global research studies.

Questions:

If you have any questions about this study, you may contact the GAAPP research study team at Research@GAAPP.org

If you have any questions concerning your rights as a research participant you may contact the Biomedical Research Alliance of New York Institutional Review Board at +1-(516) 318-6877 or https://www.brany.com/concerns-about-research.

Consent Statement

By clicking the link below, you consent to participate in this survey.
Click NEXT to start the survey:

GAAPP Community Survey on living and managing asthma

Demographics and Eligibility for the Survey

* What is your gender?

- ◯ Male
- ◯ Female
- ◯ Non-binary
- ◯ Prefer not to answer

* In what country is your primary residence?

- ◯ United States
- ◯ Canada
- ◯ UK
- ◯ India
- ◯ Germany
- ◯ Slovenia
- ◯ Other

* What is your age? We need this information to support research but mostly because we must make sure that you are over 18 years old.

- ◯ Under 18
- ◯ 18-24
- ◯ 25-34
- ◯ 35-44
- ◯ 45-54
- ◯ 55-64
- ◯ 65+
- ◯ I prefer not to say but I am 18 or older

GAAPP Community Survey on living and managing asthma

Diagnosis

* How long ago were you first diagnosed with asthma by a medical professional? (Select one response)

- ◯ Less than 1 year ago
- ◯ 1-2 years ago
- ◯ 3-5 years ago
- ◯ More than 5 years ago
- ◯ Not sure
- ◯ I was not diagnosed with asthma

* Have you experienced the following symptoms of asthma?

	Daily	Weekly	At least once a Month	A few times a year	Every few Years
Chest tightness	◯	◯	◯	◯	◯
Coughing	◯	◯	◯	◯	◯
Wheezing	◯	◯	◯	◯	◯
Mucus	◯	◯	◯	◯	◯
Shortness of breath/Air hunger	◯	◯	◯	◯	◯
The need to use a "rescue inhaler"	◯	◯	◯	◯	◯
I am not sure	◯	◯	◯	◯	◯

GAAPP Community Survey on living and managing asthma

Impact on life

* In general, how easy or difficult is it for you to manage your asthma?
(Select one)

- ◯ Very difficult
- ◯ Difficult
- ◯ Neither easy nor difficult
- ◯ Easy
- ◯ Very easy

* Have you ever needed to visit the emergency department/ ER because of your asthma, had to stay in hospital because of your asthma, or had to take steroid pills (tablets) for your asthma?
(Select all that apply)

- ☐ Visited the emergency department/ ER for asthma
- ☐ Stayed in hospital because of asthma
- ☐ Taken oral steroid pills/ tablets for asthma worsening
- ☐ None of the above

* How often, do you think about the overall management of your asthma? (examples: arranging time off work for clinic appointments, etc.)

- ◯ Constantly, at least once a day
- ◯ Regularly, at least once per week
- ◯ Seldom, less often than once per week
- ◯ I never think about the overall management of my asthma and/or nasal polyps
- ◯ Other (please specify):

[ ]

* To what degree do your asthma impact your quality of life in the following ways?

	5 (Very Much, often)	4 (a lot, often)	3 (Neutral)	2 (A little, sometimes)	1 (Not at All)	0 Does not apply to me/ Not interested in responding
Lead to more hospital/Emergency Room visits	○	○	○	○	○	○
Interfere with working, studying or meeting my goals	○	○	○	○	○	○
Impact my ability to go shopping, or take care of my home or garden	○	○	○	○	○	○
Limit my participation in leisure activities (community activities, hobbies, sport or exercise)	○	○	○	○	○	○
Cause problems with my partner or close friends and relatives	○	○	○	○	○	○
Cause sexual difficulties	○	○	○	○	○	○
Take up a lot of my time	○	○	○	○	○	○
Interfere with my sleep (quality and amount of time sleeping)	○	○	○	○	○	○
Impact my mental health (feeling anxiety or depression)	○	○	○	○	○	○

GAAPP Community Survey on living and managing asthma

Treatment and Medications

* Which of the following types of healthcare providers do you see to manage your asthma? Please focus on those who make decisions about your treatment plan.
Select all the answers that apply to your condition (s).

- [ ] General Practitioner/ Primary Care Provider
- [ ] Pulmonologist/ Lung specialist
- [ ] Allergist/ Immunologist
- [ ] Respiratory Therapist
- [ ] Nurse
- [ ] Pharmacist
- [ ] Other/I do not remember

* To what extent do you feel comfortable that you had a sufficient amount of information from your doctor or clinician about the benefits and risks associated with the treatment(s) and medication(s) that you are taking for your asthma? (Select one)

- ◯ Not at all comfortable, I need information
- ◯ Could be better
- ◯ Neutral
- ◯ Comfortable
- ◯ Very comfortable, I am well-informed

To what extent have you experienced any improvement in your quality of life since using treatment(s) and/or medication(s) for your asthma? (Select one)

- ◯ No improvement at all
- ◯ Minor improvement
- ◯ Significant improvement
- ◯ Other (please specify)

_____

* What type of medications do you take now for your asthma? (select all that apply)

- [ ] Daily inhaler medications
- [ ] Rescue inhaler medications, when needed
- [ ] Steroid tablets/pills
- [ ] Other types of tablets/pills (anti-inflammatory medications)
- [ ] Injected medications (biologics)
- [ ] Nebulizer medications
- [ ] Natural medicines/alternative health treatments
- [ ] I do not get any treatments right now
- [ ] Not sure
- [ ] Other (please specify)

GAAPP Community Survey on living and managing asthma

Questions on disease management

Based on your own experience, how well do these measures reflect your level of asthma control?

	0 Not at all/not sure	1 A bit	2 Neutral	3 Slightly important	4 Very important
My symptoms (for example: shortness of breath, cough, wheezing)	○	○	○	○	○
Results of lung function test	○	○	○	○	○
Reliever Inhaler use	○	○	○	○	○
exacerbation/flare up	○	○	○	○	○

Other (please specify)

Based on your own experience, how easy is it for you to to get or report these measures?

	0 challenging	1 difficult	2 neutral	3 easy	4 very easy
Report my symptoms	○	○	○	○	○
Lung Function testing	○	○	○	○	○
Reliever inhaler use	○	○	○	○	○
Exacerbations/flare ups	○	○	○	○	○

Other (please specify)

In your opinion, which of the below is one most concerning when managing or controlling your asthma?

- ○ Decline in lung function
- ○ Increased asthma symptoms
- ○ Increased use of reliever medication
- ○ More frequent of more severe asthma exacerbation (flare up) events
- ○ Other (please specify)

Based on your experience, which lung function test does your healthcare team use when assessing your level of asthma control? (click all that apply)

- [ ] Measure of peak flow
- [ ] Fractional exhaled nitric oxide (FeNO) test
- [ ] Bronchial challenge test
- [ ] Bronchieal reversibility teat
- [ ] Spirometry
- [ ] Other (please specify)

- [ ] Not sure/I don't know

How valuable would a combined measure of asthma control (that uses different measures together when discussing asthma control with your doctor) be for you?

0 Neutral/Not Sure 10

In which areas would the use of digital devices most improve your asthma disease monitoring? Please select all relevant options

- [ ] Reporting and tracking your asthma symptoms
- [ ] Monitoring your lung function
- [ ] Tracking exacerbations/flare-ups
- [ ] Tracking your reliever medication use
- [ ] I would not use a digital device
- [ ] I am not sure
- [ ] Other (please specify)

* Are you using a digital device now to manage your asthma?

- ( ) Yes
- ( ) No

If yes, what device do you use?

If No, what has prevented you from using digital monitoring devices? Please select all relevant options

- [ ] Unaware of any digital monitoring devices
- [ ] High Cost/Too Expensive
- [ ] No access to devices (not covered by my insurance)
- [ ] I did not have enough information about digital devices
- [ ] Other (please specify)

GAAPP Community Survey on living and managing asthma

Free text

In your own words, what do you think is the best way for you and your care team to track your asthma control (optional)

GAAPP Community Survey on living and managing asthma

Interest in clinical trials

* Have you ever considered participating in a clinical trial for new treatment approaches for your asthma? (choose one option)

- ◯ Yes, I participated or am currently participating in a clinical trial
- ◯ I have discussed clinical trials with my healthcare provider but have yet to participate in one
- ◯ No, it was discussed with me but I am not interested
- ◯ No, it was never discussed with me
- ◯ Other (please specify)

Which of the following best describes the neighborhood where you currently live? (Select one)

- ◯ Major city/Metropolitan area
- ◯ Small city
- ◯ Suburb of a city
- ◯ Rural area (village, farm)
- ◯ I prefer not to respond