

## Supplementary Data

**eTable 1**

Literature Search Used to Create the List of Adverse Effects for OCS and ICS

PubMed search: oral corticosteroid[Title/Abstract] AND side effects

Filters: 5 years, Review

Output: 19 articles

Welch Medical Library search: short term + oral corticosteroid + side effects + asthma

Filters: 2015-2020, English

Output: 14 articles

Welch Medical Library search: long term + oral corticosteroid + side effects + asthma

Filters: 2015-2020, English

Output: 27 articles

Welch search: Inhaled corticosteroid + long-term side effects + asthma

Filters: 2015-2020, English

Output: 38 articles

PubMed search: inhaled corticosteroid[Title/Abstract] AND asthma [Title/Abstract] AND side effect [Text Word]

Filters: 5 years

Output: 4 articles

PubMed search: inhaled corticosteroid [Title/Abstract] AND asthma [Title/Abstract] AND adverse effect [Text Word]

Filters: 5 years

Output: 2 articles

PubMed search: inhaled corticosteroid [Title/Abstract] AND adverse effect[Text Word]

Filters: 5 years

Output: 4 articles

PubMed search: inhaled corticosteroid [Title/Abstract] AND side effect[Text Word]

Filters: 5 years

Output: 5 articles

PubMed search: inhaled corticosteroid [Title/Abstract] AND side effects

Filters: 5 years, Review

Output: 63 articles

Abbreviations: ICS, inhaled corticosteroids; OCS, oral corticosteroids.

**eTable 2**

Expert Advisory Panel Members Who Helped Generate the Semistructured Interview Guide

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Asthma and Allergy Foundation of America

**Dorcus Beaton, PhD***Senior Scientist*

Institute for Work &amp; Health

**Thomas Casale, MD***Professor of Medicine and Pediatrics & Chief of Clinical Translational Research*

University of South Florida

Division of Allergy, Asthma and Immunology;

*Past President*

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**Dmitry Galkin, MD, PhD***Clinical Research Physician*

Respiratory, Global Clinical Development

Chiesi USA, Inc

**Florian Gutzwiller, MD, MPH***Worldwide HEOR Director*

Novartis Pharma AG

**Gale Harding, MA***Senior Research Scientist, Patient-Centered Research*

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**Sandhya Khurana, MD***Professor, Pulmonary Diseases & Critical Care Medicine*

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Johns Hopkins Hospital

**David Price, FRCGP, DRCOG***Managing Director*

Optimum Patient Care;

*Fellow, European Respiratory Society;**Allergic Rhinitis and Its Impact on Asthma (ARIA)**Executive Committee*

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**Giselle Mosnaim, MD, MS***Attending Physician*

Division of Pulmonary, Critical Care, and Allergy and Immunology

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**Samantha Walker***Deputy Chief Executive and Director of Research Policy*

Asthma UK and British Lung Foundation Partnership

**Tonya Winders, MBA***President & CEO*

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**eTable 3**  
Major Topics and Themes Discussed by Participants in the Qualitative Group

Major Topics	Themes	Supporting Quotes
Physical Health: <i>Patients experienced substantial physical burden from asthma.</i>	Breathing difficulty: <i>Patients largely lumped respiratory symptoms together (cough, shortness of breath, etc) because they all caused daily activity limitations.</i>	–“...but the coughing, not being able to breathe, having to do a breathing treatment and all this mess, it just don't seem fair.”
	Sleep interruptions: <i>Loss of sleep was a separate issue that indirectly affected daily functioning through fatigue.</i>	–“I don't know how anyone can sleep when they can't breathe,” “Waking up multiple times throughout the night, having to take neb”
Mental Health: <i>Aside from physical effects, emotional burden from disease also caused substantial harm.</i>	Fear/Anxiety: <i>Related to unpredictability of disease and concern of feasibility of control.</i>	–“...that you're scared to have an attack or to be somewhere and not have access to your inhaler or something like that”
	Embarrassment: <i>Owing to both physical symptoms and need of treatment –“Psychosocial Burden Steroids/Inhalers,” later.</i>	–“I'd be embarrassed, 'cause I'm like, 'Okay, they don't understand that I'm not running out of breath 'cause I'm out of shape, but it's because I have asthma.”
	Depression: <i>Outcome of combined physical and emotional burden.</i>	–“I'm not doing the things I wanna do and then you kinda give in to the whole...the depression and the anxiety.”
Impact on Lifestyle: <i>Impact on ability to complete day-to-day activities was important patient measure of disease severity.</i>	Predictable impact: <i>Related to avoidance of activities and related to known triggers. Related to physical and emotional (fear/anxiety, embarrassment) harm.</i>	–“...there's a lot of, 'Yeah, we're just gonna do something else instead.”
	Unpredictable impact: <i>Related to added burden from unexpected exacerbations. Related to physical and emotional harm (fear/anxiety, embarrassment).</i>	–“can go from 0 to 100 quickly and not on schedule”
Access to Care: <i>Patients identified access issues as significant barriers to their ability to control disease.</i>	Cost Barriers: <i>Driver of difficulty accessing medications and providers.</i>	–“Okay, will I be able to afford the copay? Am I gonna have to find an alternative medication? So that can be kind of stressful 'cause you just never know how your insurance company may change your plan each year.”
	Access to providers: <i>Related to local accessibility and to cost.</i>	–“currently, I am just not being treated. I've had, I think about three doctors in the last couple years. . .”
Biological/Physical Burden of Steroids: <i>In treating disease, patients experience additional physical harm from the treatments themselves.</i>	Physical effects of steroids: <i>Patients reported known steroid adverse effects such as weight gain, sleep disturbances.</i>	–“...about the prednisone. It made me gain so much weight that I don't even like taking it.”  –“prednisone as we all know is horrible. It's worse for some people than others, but there have been times when I've gone at least 10 days with zero... With zero, not one minute of sleep. . .”
	Balancing adverse effects with disease management: <i>Patients worked to balance adverse effects of steroids with necessity for controlling disease.</i>	–“So I am stuck on prednisone, but you know what? It's handling me right now and then that's what I have to do.”
Psychosocial Burden of Steroids/Inhalers: <i>Analogous to physical and emotional health, patients experienced emotional harm from treatment in addition to physical harm.</i>	Frustration: <i>Patients were frustrated with the inability to control disease on an acceptable drug regimen.</i>	–“When I do go to the doctor, I just usually end up, burst out crying, because I don't wanna do another round of prednisone.”
	Embarrassment: <i>Patients were also worried about external perception of illness from medication use.</i>	–“If I have to use my inhaler sometimes out, I'll go into the restroom or I'll try to pull it out quickly and put it back. There's still this level of embarrassment of having this condition and having to pull out this medication.”

### eFigure 1. Adverse Effects Patient Survey for ICS/OCS

#### ICS/OCS Adverse Effects Patient Survey

Q1.1. Thank you for participating in this survey to determine the most burdensome adverse effects from oral corticosteroid (OCS) and inhaled corticosteroid (ICS) use. Since we are focused on adverse effects that may be captured within the timeline of phase 3 and 4 clinical trials, only immediate and intermediate adverse effects are included. This is completely voluntary (you may choose not to participate). This survey is also completely anonymous (your identity will not be recorded or documented).

This survey should take approximately 20 minutes to complete. For ease of use, we recommend completing this online survey on a computer or tablet, as opposed to a smartphone.

#### Q2.1. GENERAL INFORMATION

Q2.2. Please select your age.

→ Dropdown menu

Q2.3. Please select the gender you most identify with.

Male / Female / Transgender Male / Transgender Female / Non-conforming

Q2.4. Have you ever been told by a doctor that you have asthma?

→ Yes / No / Don't Know

Q2.5. Have you ever been told by a doctor that you have severe asthma?

→ Yes / No / Don't Know

Q2.6. In the past 12 months, has your doctor ever prescribed you a short course (less than 30 days) of an OCS such as prednisone or dexamethasone, to deal with an asthma attack or flare-up of symptoms?

→ Yes / No / Don't Know

Q2.7. In the past 12 months, have you taken a long course (more than 30 days) of an OCS such as prednisone or dexamethasone, to maintain regular, daily control of your asthma (i.e. not during an exacerbation or flare-up)?

→ Yes / No / Don't know

Q2.8. If you have taken a short or long course of an OCS in the past 12 months, what dosage are/were you taking?

Low-dose (<7.5 mg prednisone / day)

Medium-dose (7.5 – 30 mg prednisone / day)

High-dose (30mg – 100 mg prednisone / day)

Don't know

Q2.9. Do you currently use an inhaled corticosteroid such as fluticasone or budesonide daily?

→ Yes / No

### Q3.1. INSTRUCTIONS

An adverse effect is an undesirable or unexpected event or reaction to a drug. Please rate each of the following adverse effects for oral corticosteroids (OCS) (even if you have not experienced it), on a scale from 1 to 5, where 1 = Least burdensome and 5 = Most burdensome.

Don't know / No opinion – Select if you have no opinion or have uncertainties that would make it impossible to form an opinion.

If you hover your mouse over any of the adverse effects listed below, a definition will pop up.

### Q3.2. OCS ADVERSE EFFECTS

Elevated or high blood pressure

Skin effects (e.g. purpura, atrophy, striae, acne)

Hair loss

Weight gain or obesity

Hyperlipidemia

Hyperglycemia (includes pre-diabetes and diabetes mellitus)

Adrenal suppression or dysfunction

Fluid retention/edema/swelling

Delayed growth (pediatric)

Gastric/Peptic ulcer disease

Diarrhea

Indigestion/GERD/Barrett's esophagus

Fatty liver

Myopathy

Decreased bone mineral density

Decreased bone development (pediatric)

Bone fracture/osteoporosis-related fracture

Osteonecrosis

Glaucoma

Pseudotumor cerebri (increased intracranial pressure)

Sleeplessness

Memory impairment

Mood or behavioral changes

Euphoria

Hypomania

Anxiety

Depression

Delirium/psychosis

Increased risk of infection (e.g. pneumonia) and infectious complications (e.g. sepsis)

Q3.3. If there are additional immediate or intermediate (occurs <3 years after use) OCS adverse effects that we may have overlooked, please suggest and explain them below:

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Q3.4. If you could eliminate just one of these adverse effects by switching treatments, which would it be?

→ INSERT COMMENT BOX

## Q4.1. INSTRUCTIONS

Please rate each of the following adverse effects for inhaled corticosteroids (ICS) (even if you have not experienced it), on a scale from 1 to 5, where 1 = Least burdensome and 5 = Most burdensome.

Don't know / No opinion - Select if you have no opinion or have uncertainties that would make it impossible to form an opinion.

If you hover your mouse over any of the adverse effects listed below, a definition will pop up.

## Q4.2. ICS ADVERSE EFFECTS

Sore mouth or throat

Hoarse or croaky voice

Cough during inhalation

Oral thrush

Tongue hypertrophy

Sensation of thirst

Bronchospasm

Nosebleeds

Pneumonia

Q4.3. If there are additional immediate or intermediate (occurs <3 years after use) ICS adverse effects that we may have overlooked, please suggest and explain them below:

\_\_\_\_\_

\_\_\_\_\_

Q4.4. If you could eliminate just one of these adverse effects by switching treatments, which would it be?

→ INSERT COMMENT BOX

Q5.1. When you click the FORWARD ARROW button below, your answers will be recorded. Please review and change any responses as needed before proceeding to the next page.

## eFigure 2. Semi-structured interview guide created by expert advisory panel

### coreASTHMA QoL Concept Elicitation Semi-Structured Interview Guide

Thank you for agreeing to participate in this research study. As a reminder, the overall goal of the study is to identify and recommend ways to improve how asthma-specific QoL is captured in asthma clinical trials so that it can be more relevant and patient-centered. The purpose of today's interview is to learn more about your experience with asthma and how it's influenced the way you think about quality of life (QoL). You are not obligated to answer every single question. If you would like to skip a question, simply respond by saying "skip". Your participation in today's interview is completely voluntary. You may choose to stop at any time.

I also want to remind you that the interview is being recorded. However, your responses will be kept confidential, and your name will not be shared in any report of project findings.

Do you have any questions before we start?

(INTERVIEWER: *Prompts in italics*)

1. How would you describe asthma – specifically YOUR asthma – to someone who has no experience or familiarity with the disease?
  - a. *What does a "Good day" with asthma look like?*
  - b. *What does a "Bad day" with asthma look like?*
  - c. *Is today a "Good day" or a "Bad day" [or week/month]?*
2. What do you **hope (or aspire) to achieve** with your asthma treatment?
3. What **concerns** you about your asthma treatment plan?
  - a. *Are you currently following your treatment plan?*
4. Tell me about **how you manage your asthma** on a regular basis.
  - a. *Do you feel confident about your ability to manage your asthma?*
  - b. *Are you able to manage your asthma **independently**, or on your own? Explain.*
    - i. *Prompt: do you need help from others?*
5. How does having asthma affect your **daily life**?
6. What comes to mind when I say the phrase "**quality of life**" – what does this phrase mean to you as a person living with asthma?
7. Does living with asthma impact your **ability to do certain activities**?
  - a. *What types of activities are impacted?*
  - b. *How about activities around the home? Or, those you "have" to do vs "want" to do*
  - c. *How about activities beyond the home? Or, activities you want to do, versus have to do?*
8. Is there anything else you would add about the **physical impact** of asthma?
  - a. *How would you summarize the meaning of the phrase "physical functioning"?*
  - b. *How would you summarize the meaning of the phrase "activity limitation"?*
    - i. *Is it different from physical functioning?*
9. I want to talk about how you interact with the **outside environment** – but since people's interactions with the outside have changed over this past year, try to focus on life before COVID for your answers.
  - a. Are there certain asthma "triggers" that you often think about? What are they?
  - b. Are you concerned about these triggers? How do they affect your day-to-day life? [if concern/worry expressed]: How does it make you feel to have to worry about these triggers?
  - c. You've described how your activities are limited due to asthma as [recap]. Would you like to modify or add to that?

10. Before COVID, how would you describe the **social impact** of asthma?
  - a. How does asthma affect your interaction with others?
  - b. How does asthma affect how you feel around others?
  - c. How might asthma affect how others view you?
  - d. Does asthma affect your close relationships? How does it make you feel?
  - e. Does asthma affect your interactions with the general public? How does that make you feel?
  - f. Does asthma affect your sexual/romantic relationships? How does that make you feel?
  - g. Does having asthma cause you to feel isolated or alone? Why?
  - h. How would you summarize the meaning of the phrase “social functioning”?
  - i. Would you like to add anything about the social impact asthma since COVID?
11. How does asthma affect your interactions with your coworkers?
12. [Before/Since COVID], How does asthma affect your role/ability to fulfill duties at **work or school**?
13. On a broader scale, has asthma influenced your career?
14. Before COVID, how would you have described the **mental or emotional impact** of asthma?
  - a. Is there anything about asthma that makes you nervous or worried? Can you explain more?
  - b. Does having asthma or treating your asthma make you angry, sad, anxious, or upset? How?
  - c. How does asthma affect your self-confidence?
  - d. What worries you about the future?
  - e. How would you summarize the meaning of the phrase “mental or emotional functioning”?
  - f. **Would you like to add anything about the mental or emotional impact of asthma since COVID?**
15. Does having and managing asthma affect you **financially**? How so?
16. What does the phrase “overall health” mean to you as a person living with asthma?
17. On a scale from 1 to 5, 1 being very poor and 5 being very good, how would you **rate your own health**? Why did you choose that response?
  - a. Interviewer: e.g. if they say “3” above, ask: What would a “4” look like to you? How about a 2?
18. Do you have anything positive to say about your experience living with asthma?
19. I asked you about “quality of life” at the beginning of this interview. Having spent the past hour sharing your experiences with me, is there anything else you want to tell me about how you would explain the phrase “quality of life” – as in, what does this phrase mean to you as a person living with moderate to severe asthma?
  - a. Can you summarize it for me?
20. What excites you about the future?

### eFigure 3. Virtual focus group facilitator Guide

#### coreASTHMA QoL: Virtual Focus Group Facilitator Guide

##### Slide 1.

Welcome everyone and thank you for participating in today’s virtual focus group, which is part of the “coreASTHMA QoL” project. My name is **\*\*\***, I’m the project lead and will be running today’s discussion.

##### Slide 2.

We’ll go around the virtual “room” and make introductions in just a few moments. I realize that since the start of the pandemic, some of you may now be experts in using ZOOM – but just in case, I find it’s always helpful to point out a few basic controls before getting started. (Point out Mute, Video, Handraise)

##### Slide 3.

So let’s go around the room get to know each other a little bit. We’ll be together for the next 2 hours. When I call you out, please share your name, where you’re joining us from, and in a single sentence (JUST ONE), share, if you’d like, why you decided to participate. I’ll start.

##### Slide 4.

Each of you has received and read the study description and given your informed consent to participate in this study. As a reminder, the overall goal of the study is to identify and recommend ways improve how researchers study the impact of asthma on your quality of life – so that it can be more relevant and patient-centered outcome in asthma trials.

As a token of our appreciation for you sharing your time with us, we will be sending electronic Amazon gift cards to each of you within the next 1-2 days. Your participation in today’s focus group is completely voluntary. You may choose to stop at any time. Also, you are not obligated to answer every single question. As today’s facilitator, I may call on you directly during the discussion. HOWEVER, if you would prefer not to answer, simply respond by saying “skip” or “no answer”. If you feel tired or need a short break, just let me know (I will check in with the group at least once, half-way through.)

##### Slide 5.

The purpose of today’s focus group, which is an important component of the overall project, is to help us understand what are the things you MOST associate with quality of life, which factors that contribute to quality of life are most important, and why. Your experiences as individuals living with moderate to severe asthma will have uniquely shaped each of your opinions, so I encourage you to provide additional context as needed, to help us understand your responses throughout this session. The results of this and the several other focus groups we have planned will be critical to helping us design a survey that will go out this summer to a much broader, larger group of individuals with asthma

This is THE FIRST OF SEVERAL focus groups we plan to host. (So please bear with me, and let me know when something isn’t clear). This list is just an illustration of what may be covered, but every group is unique and I’m sure will have its own organic discussion.

**Slide 6.**

Expect to be involved in active conversation for approximately the next two hours. When we reach about 10 minutes remaining on the clock, we'll wrap up our discussion and use the time for each of you to complete a short survey online before you leave the group. If at any point you need to take a break, please feel free to do so. You can write to me directly using the "chat" function, or else simply mute yourself and turn off your camera, so I know not to call on you.

As I mentioned at the start of this discussion, I may call on you! You are not obligated to answer – you can just say, not sure, no opinion, or "next".

One final reminder– today's session interview IS being recorded. However, your responses will be kept confidential, and your name and image will not be shared in any report of project findings.

With about 10 minutes remaining, we will break and leave time for each of you to complete a prioritization survey on your own, before hanging up, based on the material we have discussed.

**Slide 7.**

There are just a couple GROUND RULES to ensure today's discussion is civil and enjoyable to most:

- Please be polite when others are speaking. Try to wait until a speaker has finished his or her thought before you jump in. You may use the hand raise function (bottom left) to let me know you'd like to speak next. Alternately, you can type in your comment or question via the chat box (*Note to facilitator: try to encourage dialogue vs overuse of chat box.*)
- Please be respectful to other participants when you don't agree with their views. There are no right or wrong answers, just many unique experiences and perspectives.
- If you don't understand a question, I DO want you to feel comfortable speaking up and asking me to clarify what I mean

**Slide 8. ICE BREAKER**

We're going to test out our polling capability with a couple short ice breaker questions. (We may use polling later on as part of this focus group.)

- How many of you have participated in an asthma research study?
- How many of you have ever filled out a questionnaire about your quality of life?

*FACILITATOR: Limit to 1 minute for responses. Share results after each poll. Was everyone able to respond? Trouble shoot any difficulties.*

**Slide 9. Great. Ok let's dig in.**

You are all here today to discuss quality of life as individuals with moderate to severe asthma. But we didn't provide you with a definition because we want YOU to help us define what it means. Mentally set aside whatever definitions you may have seen in previous research studies. Think about what quality of life means to you as a person living with asthma: How you would define it? What things you would consider as you think about and evaluate your current quality of life?

***If I were to say, Quality of Life is . . . and then ask you to FILL IN THE BLANK – what would you say?***

***Follow-up: what is it about you asthma that MOST affects YOUR quality of life?***

**Slide 10.**

When included in research things – and, as evidenced by your different responses – quality of life is usually combination of many different things. So we did some 1:1 interviewing with about a dozen patients with moderate to severe asthma. And based on those interviews, we have identified some of the major building blocks that might factor in to how we describe and assess Quality of Life among individuals living with moderate to severe asthma. Today we will spend time looking in-depth at each of these individual blocks (time permitting), getting feedback from you on how meaningful each building block is, and the most important aspects of each you would want researchers to understand. For example:

- Physical health – symptoms, ability to sleep, lack of energy, ability to exercise, etc
- Mental Health. . . - anxiety and worry, anger and frustration, finding happiness, having self confidence
- Daily Life/Lifestyle –having disruptions, feeling like you're missing out on things you want to do, if you like to travel or go to art shows, the ability to travel or go to art shows
- Treatment Satisfaction – we'll talk about different concerns around treatments, level of happiness with current treatment plan, etc.
- Financial well-being: financial stress, taking time off work, dealing with insurance, etc.
- Health Care & Access – do you have a good relationship w/ your provider, do you feel comfortable communicating w/ doctor, can you access your doctor when you need to, do you have access to enough information to help you manage your asthma, etc.
- Social Impact – ability to engage in social activities, impact on friendships, on relationships, etc.
- Impact on family – how asthma affects quality time, stress, relationships

As we do, I want you to remember – *we are working within the boundaries of measuring the impact of asthma on quality of life in a research setting.* We want to enable researchers to better understand which of the many building blocks that influence quality of life are the best determinants, or indicators, of how *asthma* influences *your* quality of life.

**Looking at these building blocks, do any jump out at you as being most important? Why?**

Prompts:

- Consider: which areas of your life are most impacted by asthma – and of those, which matter most to you, to your quality of life? Is that clear? Anyone have questions?
- Are there any blocks here for which you think asthma has NO impact? OR very little impact?
- Are there certain blocks that are closely related?
- Is something missing from this list?
- Can someone explain to me, based on your own experience, how asthma might affect [BLOCK] and how that impacts your quality of life?

After ~10 min:

OK – since we have a lot of material and may not get to all of it in 2 hours, I'm going to put a shot poll up on the screen for some informal prioritization. We'll use the results to decide the order in which we talk about each of these buckets.

*FACILITATOR: PULL UP POLL QUESTION 1.*

Any reactions to these results before we continue?

**SLIDE 11. PHYSICAL HEALTH AND FUNCTIONING**

Take a moment to think about your own experiences with asthma, and how asthma affects your physical health and functioning. If you said to yourself, I am physically functioning WELL, because... how would you FILL IN THE BLANK? How do you evaluate whether you are PHYSICALLY functioning well or poorly?

The column on the left are all potential FACTORS or building blocks that make up physical health and functioning. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of your physical health and functioning?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am physically functioning WELL because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?
- Which Symptoms are most bothersome?

Before we move on from Physical Health and Functioning, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?

**SLIDE 12. MENTAL HEALTH AND EMOTIONAL WELL-BEING**

Take a moment to think about your own experiences with asthma, and how asthma affects your mental health and emotional well-being. If you said to yourself, I am mentally and emotionally functioning WELL, because... how would you FILL IN THE BLANK? How do you evaluate whether you are mentally and emotionally doing well or doing poorly?

The column on the left are all potential FACTORS or building blocks that make up mental health and emotional well-being. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of your mental health and emotional well-being?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am mentally and emotionally functioning WELL because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from Mental health and emotional well-being, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?

### SLIDE 13: IMPACT ON LIFESTYLE

Take a moment to think about your lifestyle – what hobbies do you like to pursue? Do you like to travel? Are you into art, music, or other cultural events? How would you evaluate asthma's effect on your lifestyle? And does that impact your quality of life?

The column on the left are all potential FACTORS or building blocks that may make up asthma's impact on lifestyle. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of the impact of asthma on your lifestyle?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am happy with my lifestyle because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from Lifestyle, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?

### SLIDE 14: TREATMENT SATISFACTION

Take a moment to think about your own experiences with asthma. How would you evaluate whether you are satisfied with your current asthma treatment plan? What would run through your head?

If you said to yourself: I am satisfied (or unsatisfied) with my asthma treatment *because...* (FILL IN THE BLANK) what would it be?

The column on the left are all potential FACTORS or building blocks that may make up treatment satisfaction. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of asthma treatment satisfaction?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am satisfied with my asthma treatment because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from Treatment Satisfaction I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?



**SLIDE 15: FINANCIAL WELL-BEING**

Take a moment to think over your personal/family finances and how your asthma fits into that picture. How would you evaluate the impact of asthma on your financial well-being? If you said to yourself: My financial well-being is good (or poor) because... how would you fill in the blank? As an individual living with moderate to severe asthma, what would be the biggest factors or burdens?

Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of your financial well-being?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am financially WELL because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from financial well-being, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?

**SLIDE 16. HEALTH CARE AND ACCESS**

Take a moment to think about the care and help you receive managing your asthma from your medical care team. Think about your interaction with the health care system (e.g. through your doctor, hospital, pharmacy, specialty clinic, insurance company, etc.) As you think things through, how does it make you feel? Are the experiences

The column on the left are all potential FACTORS or building blocks that may make health care and access. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of health care and access?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am happy with my health care and level of access because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from Health care and access, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min.

Any reactions to these results before we continue?

**SLIDE 17. SOCIAL IMPACT**

Take a moment to think about the impact of asthma on your social life, how it affects the way you interact with and feel about others.

The column on the left are all potential FACTORS or building blocks that may make up social impact. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of the social impact of asthma?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, I am happy (or unhappy) with my social life because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from social impact, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min. Any reactions to these results before we continue?

### SLIDE 18. IMPACT ON FAMILY

Take a moment to think about how your asthma affects your family.

The column on the left are all potential FACTORS or building blocks that may make up impact on family. Looking at just the left, are there particular FACTORS that you think are the most important or BEST indicators of asthma's impact on family?

Prompts:

- Which FACTORS jump out at you as being best, or *really important*? Why?
- If you said to me, asthma is impacting my family because... how would you FILL IN THE BLANK?
- Is something missing from this list?

NEXT: It sounds like [FACTOR] is important to several people. Let's say we were trying to measure how your asthma affects [FACTOR] in a questionnaire. We want to draft a really clear question that leaves no doubt about what it means. Based on some initial work and the language from some existing questionnaires, we've attempted to do that in the right hand column. But these are NOT set in stone.

Do any of the statements to the right of [FACTOR] jump out at you as being most fitting or most important? Why?

Prompts:

- Are any of the statements unclear?
- Can you help me understand what would be the right way to phrase a question about [FACTOR]? For example: [read DESCRIPTION].
- Is there one you might tweak to be more accurate?
- What is it about [FACTOR] that you think is most important for researchers to understand?

Before we move on from Impact on family, I'd like to ask the group to try prioritizing the FACTORS we covered. We'll put up the poll for 1 min. Any reactions to these results before we continue?

### SLIDE 19. Trigger Avoidance/Tolerance

We didn't talk about triggers yet, which is why I set aside time toward the end of today's discussion. We know triggers play a big role in life with asthma. What we're less sure about is how triggers fit in when assessing the impact of an asthma treatment on your quality of life.

→ Are there any triggers in particular that you informally use to evaluate the level of your asthma control based on your ability to tolerate them?

Prompts:

- Which of these are the most bothersome?
- In what ways, if any, has the environment changed?
- Looking at this list, are there certain triggers you are more likely to avoid and others you maybe don't avoid but plan to just deal with the after-effects?
- How has COVID influenced the environment/triggers?

### Slide 20. Building Blocks of QoL (copy)

Recall this slide from the beginning of our discussion – the building blocks of QoL for individuals living with moderate to severe asthma. As we prepare for the next focus groups, do you think we should give Trigger Avoidance/Tolerance a place in one of these color blocks?

### Slide 21. New Technologies and Treatments

This slide is not exhaustive but lists some of the newer treatment options and technologies that have become available in the last few years.

- Are there any new technologies or asthma treatments that have significantly changed your baseline quality of life?

## Prompts:

- Does everyone know about/recognize these things?
- Has your healthcare provider talked to you about these technologies?
- If you've tried any of these technologies and are willing to share (totally voluntary), could you tell us:
  - What were your expectations for that technology going in, and how did it measure up?
- What is missing from this list?

**KITCHEN SINK**

Worry about the future: are people more optimistic? Is asthma less of a mortality risk/concern?

How do we define/separate activities . . .

Need to understand nuances between physical functioning, leisure/every day activities, Talk about self-care activities (shower, get dressed) – more of a bad day issue, or every-day issue? leisure/at home/low impact activities – physical exertion

**Existing items unmatched to CE interview themes**

A-IQOLS	2 (health and personal safety), 10 (understanding oneself), 13 (expressing oneself)
ABP	3.4 ("cough and <b>colds</b> "), 4.4 (fear of asthma/ability getting worse - perhaps reverse tied to transformative experience of biologics?), 5.2 (confidence in managing next attack),
AIS-6	
ALMA	3-6 (triggers),14 (wheeze), 15, 16 (visit hospital), 17 (rescue meds use), 18 (meds effectiveness)
AQ-20	5 (triggers), 9 (emotions), 16 (impatient), 18 (cold)
AQL-5D	3 (weather and pollution)
AQLQ, or AQLQ-J	9, 17, 23, 26 (exposed to triggers), 10 (wheeze), 11, 19, 25, 28 (avoid trigger), 20 (morning symptom), 22 (heavy breathing)
AQLQ-J-S or AQLQ(S)	9, 17, 23, 26 (exposed to triggers), 10 (wheeze), 11, 19, 25, 28 (avoid trigger), 20 (morning symptom), 22 (heavy breathing)
AQLQ-M, or AQLQ-S	1.2 (wheeze), 3.3 (avoid triggers), 3.5 (restricted), 4.1, 4.2 (worry about future, death)
mini-AQLQ	2 (dust), 7 (cigarette), 10 (wheeze), 11 (weather/cold)
BBQ	
EQ-5D	2 (Self Care)
ITG-ASF	3 (future concern), 12 (wheeze)
JACS	2 (wheeze), 6 (avoid triggers), 10 (triggers), 13, 14, 15 (taking meds)
LCQ	4 (in control), 9 (triggers), 14 (hoarse voice)
LWAQ	5 (avoidance), 16 (be conscious of cold), 27, 47, 36 (colds), 58, 57 (future), 56 (sexually frustrated), 43 (control emotions), 19 (forget meds), 25 (holiday), 50 (future), 21, 61(relax)
PACT	1 (wheeze), 4 (restricted), 7 (die), 12 (forget to take meds), 13 (not take meds), 14 (ways to deal with out of control asthma)
QDIS-7	
QOL-RIQ	A (wheeze, heavy breathing, itchy throat, clear throat, recurrent cold, stuffed up nose) B (sleeping limbs, pins and needles, heart racing, morning symptom, poor appetite) C (feeling puzzled, future concern, upset by too much sympathy of others) E (triggers)G (sex)
QOLS	2 (health), 10 (understanding oneself), 12 (expressing oneself)
RAND-IAQL	1 (long-term effect), 7 (frustrated over can't make plans), 10 (feeling different)
RhinAsthma	7 (avoidance), 12, 14 (eyes), 18 (wheeze), 4, 23, 27 (smell), 28 (carry tissue)
RAPP	3
SAQ	16 (problems with food), 17a-c (self-perceived QoL based on symptoms, SEs)
SF-12	1 (health), 9 (calm, peaceful)
SGRQ	1.4, 1.8 (wheezing), 2.5 (meds effectiveness)
WHOQOL-Bref	1 (QoL), 2 (health), 3 (pain), 8 (safety), 9 (environment), 13 (information access), 21 (sex), 24 (living place), 25 (transportation)
CAS	