Focus Group Report:

People with Asthma & Caregivers of Children with Asthma

February 2007

Oregon Asthma Program

Helping you keep your asthma under control

Oregon Department of Human Services

Oregon Asthma Program

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SUMMARY OF RESULTS

The Oregon Asthma Program contracted with Schulman, Ronca, and Bucuvalas, Inc. (SRBI), based in Rockville, Maryland, to conduct a series of four facilitated discussions in Portland and Eugene - two groups of people with asthma and two groups of caregivers of children with asthma. The groups were composed of men and women with asthma 18 years of age or older and parents or grandparents of a child with asthma, respectively.

Participants were recruited using an online methodology by filling out a short web questionnaire to screen for eligibility. Each individual who participated in the facilitated discussions was paid an honorarium of $60. All respondents were re-screened upon arrival at the facility to ensure that they had asthma or cared for a child with asthma. A total of 43 participants met the criteria (9 and 10 in Portland and 14 and 10 in Eugene, people with asthma and caregivers, respectively).

The focus group discussions focused on the following topics: 1) being diagnosed with asthma, 2) the perceived severity of asthma, 3) asthma control and management, 4) interactions with the health care system and providers, 5) asthma medications, 6) asthma education, 7) community support, and 8) smoking and secondhand smoke. Participants responded to questions on these topics that were asked by an SRBI moderator.

Based on the results from these focus groups, SRBI suggested some possible activities to be undertaken by the Oregon Asthma Program. First, emphasizing the need to take controller medications and to use rescue inhalers when necessary might encourage patients to be more proactive in their treatment of the disease, rather than waiting for an attack to occur. Second, information might be provided to educate school administrators about asthma so that their students have better and timelier access to their asthma medication and treatment during school hours. Third, maintaining the Oregon Asthma Program Web site with useful information and promoting the Web site should continue to be beneficial to those who are seeking information about their disease.

Summary of Findings:

Being Diagnosed with Asthma

- An asthma diagnosis was more difficult to establish for some respondents than others

Perceived Severity of Asthma

- Asthma is perceived as a major, and sometimes life-threatening, illness
- Respondents generally agreed that asthma can be controlled but not cured
- The timing and unpredictable nature of asthma episodes seems to contribute to the perception of asthma as a serious disease, especially for caregivers

Asthma Control and Management

- Respondents report a variety of asthma triggers
- Asthma takes an emotional toll on adults and children
- Finances sometimes represent a barrier to asthma care, particularly with respect to lack of insurance and the high cost of medications
- Distance to providers and securing a timely appointment are also issues for some respondents; taking time to see a provider was more an issue for adults than for caregivers
- There is a disconnect among some respondents and caregivers with respect to knowledge about asthma control versus actually taking action on that knowledge
- While asthma action plans are perceived as useful by some respondents and caregivers, most did not have such a plan from their provider

Interactions with the Healthcare System and Providers

- Adults and children with asthma see both primary care providers and specialists for their asthma; some mentioned that their PCP is a physician's assistant
- Adults and caregivers sometimes struggle to find a provider with whom they feel comfortable
- Access to medical providers can be an issue, with long waits for emergency room treatment and appointments with specialists
- Overall, it appeared that the caregivers were more likely than the asthma patients to arrange a doctor's appointment for their child's asthma on a regular basis
- While some respondents are satisfied with the care they or their child receive, others have difficulty finding providers with whom they can develop a rapport

Asthma Medications

- Adults and children with asthma take a wide variety of medications for their asthma
- Physicians and pharmacists are the main source of information about asthma medications
- Not all adults or children with asthma are doing a good job of controlling their asthma; many take only rescue inhalers and do not take controller medications
- Both adults with asthma and caregivers have some concerns about steroid use; some do not differentiate between systemic steroids and inhaled corticosteroids, so this may be an area to focus on with respect to patient education
- While flu shots are recommended by providers for many adults and children with asthma, most do not receive them; fear of shots, time issues, and cost are factors that play into making a decision about whether to get a flu shot

Asthma Education

- Health care providers are the main source of asthma information for both adults with asthma and caregivers of children with asthma
- The Internet is also an important information source
- One respondent had used the website maintained by the Oregon Asthma Program
- One area respondents wanted additional information is the topic of asthma medications

Community Support

- Schools present a particular issue for parents of children with asthma; lack of understanding of the disease and the inaccessibility of students' asthma medications at school are particular problems
- Lack of understanding of asthma by others is a cause of frustration to adults and children with asthma

Smoking and Secondhand Smoke

- Most adults and children with asthma are susceptible to cigarette smoke and try to avoid public places where smoking is allowed
- A few adults with asthma continue to smoke cigarettes

METHODOLOGY

The Oregon Asthma Program (OAP) contracted with Schulman, Ronca, and Bucuvalas, Inc. (SRBI) to conduct four focus groups, two groups with people with asthma and two with caregivers of children with asthma. The groups were conducted in Portland and Eugene, as shown in Table 1:

TABLE 1
ASTHMA FOCUS GROUP SUMMARY

LOCATION	NUMBER OF GROUPS	DAY AND DATE	TIME	SEGMENT	NUMBER OF PARTICIPANTS
Portland	2	Wednesday, December 6	6:00 PM 8:00 PM	People with Asthma Caregivers of children with asthma	9 10
Eugene	2	Thursday, December 7	6:00 PM 8:00 PM	People with Asthma Caregivers of children with asthma	14 10

The groups in Portland were conducted at BN Research, a traditional focus group facility with a meeting room observable from a client room via a one-way mirror. The groups in Eugene took place at the Hilton Hotel and Conference Center using adjoining meeting rooms, with a closed-circuit television feed from the meeting room to the client room. All groups were both audio- and video-taped.

Working closely with the Oregon Asthma Program, SRBI developed a screener for the focus groups that was used to identify potential respondents with asthma and caregivers of children with asthma. A copy of the screener used to recruit participants for the focus groups is provided in Appendix 1.

The participants for the focus groups were recruited using an online methodology. Internet recruitment was restricted to online panel members located in Portland and Eugene, selected from a national online panel maintained by Survey Sampling, Incorporated. These individuals were sent an e-mail invitation to complete a short web survey to screen for eligibility. Those eligible as either a person with asthma or a caregiver of a child with asthma were invited to participate in the appropriate focus group discussion in their location.

Each respondent received a confirmation e-mail with directions to the facility, and then a confirmation call from an SRBI interviewer a few days prior to the group. A copy of the confirmation

letter for recruited participants is contained in Appendix 2. The text of the reminder call made one day prior to the group is included in Appendix 3.

An effort was made to recruit 14 potential participants for each group to ensure that eight to ten actually attended. In Eugene, we also used the services of a local mall research facility (in addition to online recruitment) to fill out the groups, as the online recruitment did not yield the desired number of potential participants. Each individual who participated in the focus groups was paid an honorarium of $60. All respondents were re-screened upon arrival at the focus group facility to ensure that they fulfilled the criteria for participation.

Provided in Appendix 4, the moderator's guides for these focus groups explored the following issues with respect to asthma:

- Being diagnosed with asthma;
- Perceived severity of asthma, especially compared with other diseases such as diabetes or heart disease;
- Asthma control and management;
- Interactions with the health care system and providers;
- Asthma education;
- Community support; and
- Smoking and secondhand smoke

The focus groups were moderated by Carla Jackson of SRBI and attended by representatives of the Oregon Asthma Program. Marilyn Wilkinson of SRBI also observed all of the focus groups.

The following sections describe the major themes which emerged from the focus groups. Since focus groups are a qualitative methodology, the report describes these themes and provides direct quotations from the respondents, but does not attempt to quantify the results. Each section of the report details the questions asked on that topic and the responses from people with asthma and caregivers of children with asthma, followed by a summary of major findings in that section.

BEING DIAGNOSED WITH ASTHMA

Questions asked in this section of the focus group addressed the following topics:

- How long ago you were first diagnosed with asthma.
- What was your asthma like when you were first diagnosed? What is your asthma like now?
- If asthma were an animal, what animal would it be? (People with asthma)
- What word would you use to describe asthma? (Caregivers of children with asthma.)

People with Asthma

People with asthma reported a variety of experiences in being diagnosed with asthma. Some of the adults had been diagnosed as a child. For example, one participant in Portland noted that, *"I remember being up all night a lot of times when I was a child, gasping for air and not being able to breathe, just gasping."*

Other respondents said they were diagnosed after a specific episode occasioned by allergies or stress, or after a bout with pneumonia. A Portland respondent noted that, *"I had actually had a full-blown attack, the wheezing, the very difficult breathing, tight chest – and I had never... experienced anything like that before. I ... saw a doctor the next day. Even though I was breathing fine at that point, just listening to my chest he said, 'Oh, asthma.'"* Some participants said that they were diagnosed as adults rather than when they were children.

In the Eugene group, there were several respondents who developed asthma only after they had stopped smoking. They said they were surprised by this, but one respondent said his physician told him it was not that uncommon for some people to develop asthma after quitting smoking.

"It started out with just allergies, for 20 years it was just allergies and all of a sudden it was asthma and I didn't even know you got it when you were an adult, I thought only as a child – I was wrong." — Woman with asthma, Eugene

Another Eugene respondent also noted that, *"We've lived here in the Springfield/Eugene area for 20 years now and I was told when we first moved …that 'you'll have asthma or … some kind of lung problems within ten years after you've moved here', that everybody does. I mean it took me 20 years, but I (did)."* Several other respondents noted that the Eugene/Springfield area was called the "Valley of Death" by the Indians, likely due to the area's mold, pollen, and wetness.

Respondents also reported that their asthma diagnosis was not always an easy one. For example, a Portland respondent noted that *"I was actually misdiagnosed and was being treated by a doctor for what he called a 'persistent sinus infection'. And I went to a different doctor because I just wasn't getting any better…I had…been on antibiotics for… two to two-and-a-half months."*

Respondents in the focus groups for people with asthma were also asked what animal asthma would be, if it were an animal. The most common responses were:

- A *boa constrictor* that squeezes the breath out of you, *"tightening, tightening, and tightening so your eyes pop out."*
- An *elephant*, because it is like something sitting on you.
- A *tiger* who takes you by the tail.
- A *leech*, because a person can have it for years before knowing about it.
- A *baby possum* stuck on its mother's back.

Respondents had no difficulty in comparing asthma to an animal and their images were quite specific. The boa constrictor was the animal most commonly mentioned in both groups of people with asthma.

Caregivers

Most of the children of the respondents in the caregivers groups had been diagnosed at a very early age, some as early as less than one year of age. Others were in their early teens before experiencing asthma symptoms.

As with the adults in the focus groups, the diagnosis was not always easy. A Portland caregiver noted that, "I had to (take my child) to four different doctors before one would listen. Because my daughter, she would gasp. She would take like four regular breaths and then she would gasp and I was like, 'There's something wrong there.' And my first two doctors kept telling me she has a cold and I'm like, 'Well, she's had one for ten months!'" Several other caregivers said their children were initially diagnosed with colds or bronchitis that would not go away, and only then was it determined that they had asthma.

In the caregiver groups, instead of what animal asthma would be, respondents were asked to use a word to describe asthma. Respondents offered the following words:

- Bothersome
- Challenging
- Frustrating
- Inconvenient
- Manageable
- Scary
- Serious
- Unpredictable

The words selected by caregivers to describe asthma indicate it makes a difference in the lives of their children (and in their lives as well).

MAJOR FINDINGS

- An asthma diagnosis was more difficult to establish for some respondents than others.
- Respondents had no difficulty comparing asthma to an animal or describing asthma with a single word.

THE PERCEIVED SEVERITY OF ASTHMA

Questions asked in this portion of the focus groups included:

- What do you think about the statement: *"asthma cannot be cured but it can be controlled"*?
- How serious is asthma as a disease? What about asthma compared to heart disease or diabetes? How is asthma different from heart disease or diabetes? How is asthma similar?

People with Asthma

Most people with asthma characterized asthma as a very serious disease. As one Eugene respondent noted, *"Nobody knows (how serious asthma is) until they've got an asthma attack."* A few respondents said they had almost died from an asthma attack. A Portland respondent summarized by noting that, *"It's a scary disease. You never know when you're going to have a flare-up. There's something a little unsettling about not being able to breathe. So, I think most of us probably avoid the triggers and situations that cause that kind of thing"*.

The difficulty of diagnosing asthma in some instances also makes it scary to patients. Having had a persistent cough that failed to respond to antibiotics or other treatments led to the eventual diagnosis of asthma for some respondents. In some instances, however, it took months before an asthma diagnosis was rendered, and these were particularly difficult and frustrating times for respondents, as they did not know what was wrong with them.

While some respondents anticipate an eventual cure for asthma, most agreed that asthma cannot be cured, but it can be controlled. A few respondents said that a friend or relative had *"grown out"* of asthma as s/he got older. A respondent in Portland was told that he would grow out of it, but he has not done so. Avoiding asthma triggers and using asthma medications were viewed by both people with asthma and caregivers as effective in controlling asthma. However, a Portland

"'Controlled' also means that I know what triggers it and I stay away from the triggers." — Woman with asthma, Portland

respondent noted that it can be particularly difficult to control exercise-induced asthma except by refraining from exercise.

Compared to other diseases such as diabetes and heart disease, asthma was viewed by respondents as controllable and usually not life-threatening, but still serious. A Portland respondent said that he had recently been diagnosed with the early stages of Type II diabetes, and he saw diabetes as a bigger problem because it will eventually prove fatal.

During the discussion comparing asthma to other diseases, several respondents in the Portland group volunteered that that they had been diagnosed with acid reflux disease, but had adjusted their diet and/or taken medicine to deal with it. They seemed surprised that asthma was associated with acid reflux disease.

Caregivers

Caregivers generally echoed the opinions of adults with asthma when asked their opinions about the severity of asthma. For example, a Portland caregiver said that asthma is particularly scary because her son has no known triggers for his asthma, so she never knows when he is going to have an attack. Several respondents in the caregivers' groups remarked that asthma is particularly scary when a child is little and unable to articulate the symptoms s/he is having.

In describing asthma episodes that their children had experienced, respondents most often seemed to recall problems that occurred in the middle of the night requiring a trip to the emergency room because it was outside their physician's regular office hours. Timing and unpredictability seemed to contribute to caregivers' perceptions of asthma severity. Most concurred with the idea that it is possible to control asthma, but did not anticipate a "cure" for asthma.

"…especially when they're little, it's so scary because they don't have a way of telling you what their problem is or anything. It is very scary."

— Parent of a child with asthma, Portland

MAJOR FINDINGS

- Asthma is perceived as a major, and sometimes life-threatening, illness.
- Respondents generally agreed that asthma can be controlled but not cured.
- The timing and unpredictable nature of asthma episodes seems to contribute to the perception of asthma as a serious disease, especially for caregivers.

ASTHMA CONTROL AND MANAGEMENT

Questions asked about asthma control and management included the following:

- Have you/has your child had an asthma attack in the past year? How did you/your child feel? What did you do about it?
- Have you had/Has your child had any asthma symptoms without having a full-blown attack in the past year? How did you/ s/he feel? What did you do about it?
- What causes you/your child to have (worse) asthma symptoms? What do you do to avoid these things? How does this affect your/your child's daily life or your activities?
- Do you/Does your child change any of your plans or activities because of asthma? (Probe for sports and recreation, normal physical activity, choice of jobs or careers, social activities)
- Have you/ Has your child had times in the past year of a week or more when you weren't having asthma symptoms? What were you/was your child doing? Were you/your child:
  - Taking asthma medications?
  - Limiting your/your child's activities?
  - Something else?
- Have you/Has your child ever received an asthma action plan from your doctor/provider? If yes, how did the asthma action plan help you manage your asthma?
- Are there any barriers to doing the things you know you can do to prevent your/your child's asthma symptoms and attacks?

Asthma triggers

A wide variety of asthma triggers were mentioned in the focus groups, including:

- Animals
- Allergies (especially seasonal)
- Cigarette smoke
- Campfires
- Candles
- Change of season
- Chemicals
- Climate differences when traveling
- Cold air
- Dust particles
- Dust mites
- Exercise
- Excitement
- Food allergies
- Fragrances
- Incense
- Milk products
- Mold
- Pollen
- Stress
- Stuffed animals
- Trees
- "The Valley"
- Weather
- White board markers
- Wind
- Wine

Most people with asthma and caregivers mentioned multiple triggers that impact their or their child's asthma.

"...I can keep everything going as far as taking my medications, not exposing myself to [dust] or animal hair or smoking environments. Keep exercising, keeping in a good frame of mind ... helps me not have the symptoms quite as much."

— Man with asthma, Eugene

People with asthma

Most people with asthma characterized their asthma as currently under control. To respondents, controlling their asthma means:

- Not having an asthma episode;
- Knowing what triggers their asthma; and/ or
- Not having to use a rescue inhaler.

A Eugene respondent said that control means *"...that I can be more active."* Another respondent in the same group said that controlling asthma *"... is if I can get my asthma attack down to less than five minutes and be calm after that. Because if it lasts longer than that, it's taking away time off of stuff I want to do. So, if my asthma attack lasts like longer than five minutes, I'm not controlling it, it's controlling me."* Another respondent in the same group remarked, *"To me, controlling asthma is kind of like having a plan, knowing what you're going to do if 'this' happens, what you're going to do if 'that' happens. Listening to your body, knowing where you are and then just tailoring your activities so you're maximizing your potential activity for the day, that's what I like to do. It lets 'me' feel that I'm in control."*

Avoiding pets, fragrances, smoke, and other triggers also helps some respondents keep their asthma under control. While some respondents described severe asthma episodes, others said that their attacks were generally not severe. But having asthma often curtails regular activities:

- One respondent said that the possibility of an asthma episode curtailed her activities in the following way: *"This time of year is really hard for me because the cold, windy weather really aggravates my asthma. ... you can't go Christmas shopping, you don't want to go to parties, you don't want to hang-out with your friends because you just don't know."*

- Another respondent in the same group noted that, *"Sometimes I get angry at it. Having it all my life,... – no matter how long you've had it and how well you have it under control, sometimes it's irritating, it makes you angry that you can't do everything that other people can do, there's limitations."*

These comments indicate that although people can list the elements associated with having good control, their asthma is not necessarily in good control. If respondents' asthma is under good control, then they should be able to go Christmas shopping, go to parties, and interact with friends without having to worry about an asthma episode. In addition, the respondent who believe that an attack of less than five minutes means her asthma is under control clearly has no idea what asthma control involves (this person also mentioned having multiple rescue inhalers and using Benadryl as a controller, which indicates she does not use asthma controller medications at all).

In the Eugene groups, there was considerable discussion about the smoke in the area at certain times of the year. As one respondent explained, *"...they grow grass seed especially between here and... Corvallis, which is 40 miles north. And they say the only way to regenerate is to burn the grass. So, what happens is there's...just horrendous fires and the smoke that comes out of it is just incredible."*

Asthma also takes an emotional toll on its sufferers, sometimes causing patients to feel panicky, scared, and embarrassed. As one Eugene respondent noted, *"It makes it real hard to get around to do anything, to go anywhere. I have to do the grocery shopping and all the errands ... and it's real difficult for me to go shopping anywhere unless they have an electric shopping cart because I can't walk far enough and it makes me feel helpless."* Another respondent in the same group said, *"It's very uncomfortable... when you can't breathe! Just the shortness of breath! Walking 20 feet and you've got to stop and catch your breath, it's very uncomfortable."* Again, these comments indicate that there are respondents whose asthma is out of control and underscores the "disconnect" between knowledge and actual behaviors among respondents.

Respondents try to avoid the triggers of their asthma. Although a few respondents said they need to keep their windows open so they feel like they can breathe, most shut their windows to keep out

"I have not been physical…And so my whole life I've been overweight because I was so scared of doing any type of physical activity." — Woman with asthma, Portland

dust and pollen, and avoid restaurants and other public places where smoking is allowed or where fragrances are prevalent. Some respondents have replaced carpeting with wood, tile, or other types of flooring; vacuum their homes frequently; and use air purifiers. Family members and visitors to the home who smoke are asked to go outdoors to do so. The entrances to malls and businesses where smokers congregate are avoided by many people with asthma (and also by some caregivers with their children). One respondent in Portland said that she avoids the supermarket aisle with laundry and other soap products. A respondent in Portland noted that, *"... I find myself just avoiding lots of social situations where there's smoke or perfumes or that kind of thing, which is really kind of a bummer, especially this time of year. You're not going to parties and hanging out with friends and family and stuff."*

Another Portland respondent noted that asthma had always made her afraid to exercise and as a result, she has always been overweight: *"Another frustrating thing I find is, like I said before, I've been overweight my entire life – doctors and people in general, even doctors – I complain about the stuff and they say, 'Oh, well you just need to lose weight.' Which is really tough! Because the symptoms of asthma can be shortness of breath, difficult breathing, loss of energy – these things."*

Relatively few respondents have received an asthma action plan from their health care provider. While most asthma action plans appeared to address the need to avoid triggers and to take medication as prescribed, one Portland respondent mentioned that her asthma action plan advised her to give away her pets. One Eugene respondent said he had an informal asthma action plan: *"My doctors, we pretty much agreed what I need to do and when I need to take things. To me, it's kind of like a juggling act. It's if I can keep everything going as far as taking my medications, not exposing myself to real dusty or animal hair or smoky environments. Keep exercising, keeping in a good frame of mind, the medicine -- all of those, keeping those all going kind of helps me just not have the symptoms quite as much."* These comments highlight the importance of good communication between patient and providers. The patient did not have a formal action plan but had discussed the items necessary to keep his/her asthma under control.

"I just don't have a lot of energy, I feel kind of lethargic. When you can't breathe you just don't want to do anything!" — Participant with asthma, Portland

There are many barriers to asthma control, most notably finances. Replacing carpet, buying HEPA filters, and installing air-conditioning were viewed as very costly. For example, one Portland respondent noted: *"Because the things that they give you, I mean, a lot of times aren't realistic in terms of ripping up all the carpet out of your house and putting down wood floors! I mean, that would be nice if we were all millionaires...."* A Eugene respondent noted, *"I look at it this way; I get less than $800 Social Security a month and my medications are $600-and-something a month. What would I do if I had to pay for it? I'd be living under a bridge!*"

Also with respect to the cost of treating asthma, one Portland respondent noted, *"I'm on disability and limited income, and I know what it's like where you have to plan, 'Are you going to able to afford your medication, your bills, or your food?' Which one are you going to be able to do at this time? ... there are certain things that Medicare will pay for and won't pay for. And Advair is very expensive. If you had to pay for that without having insurance I wouldn't be able to afford it. It's like over $200 for just one 30-day supply."*

While the need to have multiple inhalers was a priority for caregivers of school age children with asthma, this is also an issue for adults with asthma. For example, one Eugene respondent said, *"I keep one in the drawer at work, I keep one in my glove box, I keep one in my purse."* Some respondents had pestered their insurance company until they were able to obtain multiple inhalers, and others had gotten professional samples from their physician.

In addition, several respondents mentioned their reluctance to get rid of family pets which contributed to asthma problems, although this was more a problem mentioned by adults with asthma than by caregivers. Having spouses or family members who smoke was also an issue for some respondents, although all of these respondents said that the smokers in their household went outside to light up.

Other barriers to asthma care mentioned by respondents included the lack of health insurance, which respondents said not only limited treatment in general but also access to specialists.

"It doesn't have to like make life miserable, it can be controlled."

— Parent of a child with asthma, Portland

Caregivers

Caregivers said that, for their children, asthma control means being able to do everything that others do, including playing sports. But control can be elusive: as one Portland caregiver noted, her son has *"... missed one day of school a week for the last three weeks and each one is the same thing, where he's coughed the night before and he's not getting enough sleep. .... (but what) is causing it? Is it the nutrition, the sleep, the asthma, the whatever – so that in itself can cause problems, and then that stresses him out about school because he's missing stuff that he can't afford to miss."*

More frequently than adults with asthma, caregivers said that their child has experienced an asthma attack within the last year requiring hospitalization or an emergency room visit. Several say that they have to tell their children to calm down. For example, a Portland caregiver noted that *"... (I) just make him slow down a little bit, which makes him mad because he wants to be out there with his friends doing it all, you know – playing basketball or riding the bikes or whatever. I tell him, 'You've got to slow down, you just can't do it this long.' And he does, but he doesn't like it, at all!"* This again illustrates the disconnect in asthma control between knowledge and action. When asthma is controlled, most children are able to be physically active with few, if any, symptoms.

Distinguishing asthma from colds and flu also represents a challenge for many caregivers that is less evident among adults with asthma. Caregivers said that many of the symptoms of colds, flu, and asthma are similar, and it is sometimes difficult to know whether or not to start their child's asthma medication. On one hand, caregivers felt that they might be unnecessarily medicating their children, but at the same time, failing to begin the timely administration of asthma medicine is also a concern. Adults with asthma are, on the other hand, more readily able to distinguish asthma from other illnesses.

Most, but not all, caregivers had identified the asthma triggers for themselves or their child. However, one Portland caregiver noted that identifying asthma triggers is *"... easier said than done"* in some cases. But there were also respondents in the adult focus groups who were unable to determine the

"One of the things she said was, "Just avoid the known allergens," and it's just easier said than done!" — Parent of a child with asthma, Portland

triggers of their asthma. However, it should be noted that there is some evidence in the literature that people do not always understand their asthma triggers, particularly in the absence of specific testing with allergens.

Particularly in the caregivers groups, respondents noted that their children sometimes want to do too much, and it can be a challenge to get them to slow down so they avoid an asthma attack. One Portland caregiver said that his son had substituted karate for soccer and had far fewer asthma problems since doing so. Eugene caregivers said that having asthma makes their children feel "helpless" and "inferior," and that the inability to participate in sports is a particular issue for some children and young people with asthma. Once again, this illustrates the poor asthma control which precludes children from taking an active role in sports and other activities.

While formal asthma action plans are somewhat uncommon, according to caregivers, a Portland caregiver said that it had been very helpful to her son to have everything about his asthma written down, and that following the plan has helped him to control his asthma. In contrast, one Portland caregiver said that her daughter's asthma action plan consisted of the doctor saying, *"Here's her rescue inhaler if she needs it."*

A Portland caregiver said that her son had an asthma action plan dealing with knowing and recognizing asthma symptoms and the medication to take, and that the plan, overall, had been helpful in avoiding attacks. A Eugene caregiver said that her son had an asthma action plan when he was young. *"His was color-coded, which was really helpful because he was little. And, 'If you blow and it's this color, you need to take this matching color. And if you blow and it's 'this' color, then you need to call someone right away. It was very helpful to him because he was kind of freaked-out about it once in awhile when he was little. So, the color-coding is really, really good for little kids. Because then they can look at it and know what's going on...."*

Also with respect to the cost of asthma medications, caregivers in particular mentioned the need to have rescue inhalers in a variety of locations, such as home, school, and automobile, but that insurance often refuses to pay for multiple inhalers.

Several respondents in Eugene said that the distance to the physician's office from some of the outlying areas was also a barrier to treatment. For example, one respondent said that it was a 45-minute drive from her home to her child's doctor in Eugene.

MAJOR FINDINGS

- Respondents report a variety of asthma triggers.
- Asthma takes an emotional toll on adults and children.
- Finances sometimes represent a barrier to asthma care, particularly with respect to lack of insurance and the high cost of medications.
- Distance to providers and securing a timely appointment are also issues for some respondents. Taking time to see a provider was more an issue for adults than for caregivers.
- There is a disconnect among some respondents and caregivers with respect to knowledge about asthma control versus actually taking action to do so.
- While asthma action plans were perceived as useful by some respondents and caregivers, most did not have such a plan from their provider.

INTERACTIONS WITH THE HEALTH CARE SYSTEM AND PROVIDERS

Questions asked in this section of the focus groups included:

- When do you decide to see a health care provider for your/your child's asthma?
- Where do you go when you see a health care provider for your/your child's asthma? (i e.g., clinic, ED) Who do you see? (e.g., doctor, nurse, PA, NP, naturopath, other)
- How do you feel about talking with your/your child's health care provider about asthma?
- Are there any barriers that affect whether you go in for your/your child's asthma care or get your/your child's prescriptions? (money, transportation, time off work, etc.)
- When you go in for asthma care, do you get any information on how to manage your/your child's asthma? What kind of information does the provider give you? Information about:
  - Medications?
  - Triggers?
  - When to seek care?

People with Asthma

Respondents see a variety of health care providers for their asthma, including family physicians, allergists, and/or pulmonologists. Some respondents say that they see their health care provider for asthma on a regular basis. One Portland respondent noted, *"I go once a year when I need my meds refilled."* While some respondents said that they go to their physician at regular three, four, or six month intervals, some seek treatment only in the event of an asthma episode. One Portland respondent said he tends to let an episode go on too long and then has to go to the emergency room for treatment.

Many respondents say that they see a specialist for their asthma. Sometimes they do so on the recommendation of the primary care physician. As one Portland respondent noted, *"I see a physician's assistant as my primary care and when what she was trying didn't work, she immediately referred me to the pulmonologist."* But other respondents said they were seeking better care from a specialist than from their family physician: as one respondent noted, *"I decided to go straight to an allergist this last time because my general provider was too busy, too much of a hurry, makes*

assumptions, doesn't know enough about specific problems like that. And he would just give me a rescue inhaler and say, 'Take this when you need it'. Whereas the allergist has put me on the Asthmanex and the medications that have helped me to control it instead of just treat it with a Band-Aid".

Some respondents have a very good experience with their health care provider: one Portland respondent noted, *"I've been pleased with the pulmonologist, he does seem to give you undivided attention when he's in there. But you're very aware when you're in there it's taken you two months to get that appointment and you're in there maybe ten minutes, if you're lucky."* Another respondent in the same group noted, *"And then the doctor, yeah, they don't have the time to explore you and your triggers and what makes your asthma flare and so you have to do a lot of that on your own."*

Timely access to health-care providers can also be an issue. While some respondents noted that they experience no difficulty in getting an appointment related to their asthma, others said that waits of six weeks or more are not uncommon. Respondents also noted that asthma attacks do not always occur when their doctor's office is open, so they end up at an urgent care clinic or the emergency room, which can be more expensive than seeing their regular physician. A respondent without health insurance said the clinic she goes to will not allow her to see a specialist, such as an allergist, for her asthma.

Several respondents mentioned that you learn about asthma as you go along. But another Portland respondent cautioned that, *"...you have to be ready for the information. If you're newly diagnosed, there's no way that anybody could give you all the information that you need and there's no way that you could accept it. Because there's things that I can accept today that I couldn't have accepted a few years ago as being something to use to control it."*

Caregivers

As was the case with adult respondents, caregivers said that their children see a variety of providers for asthma care, including both family practice physicians and specialists. Sometimes, seeing one's own physician instead of another provider in the same practice can also make a difference in dealing with asthma. A Eugene caregiver noted that, *"...my son went to (the pediatrician's office but did not see his regular pediatrician). (My son) was blue, (the doctor) gave him a nebulizer treatment, my son was still blue and he was going to send him home! Said there was nothing else that he could do for him, that he just needed to have another nebulizer treatment at home. The next day we went in, had the same problem and he saw his regular pediatrician and they didn't even wait to do a nebulizer treatment, they sent him right over to the hospital...."*

One Eugene caregiver said that she had taken her child to an allergist for a year, but her child did not really improve, so the specialist told her there was no reason to pay her to give the same advice that the family practitioner would. Another Eugene caregiver complained that her child's physician was not willing to explore alternative approaches to the treatment of her child's asthma: *"Just always assuming that it's the same thing and that it's not what it is and put him on the same medicine over and over again instead of realizing that it's not working and change it to something else. Or saying that the kid is not doing the inhaler right or they're not doing 'this' right with it."*

However, one Portland caregiver noted that her son's doctor is very accessible over the phone when there is a problem. In contrast, another Portland caregiver said it had been difficult to find a doctor to treat her son's asthma: *"It's kind of hard going through four different doctors to find one that will actually listen to me."* One Portland caregiver noted, "I feel like I'm at a cattle ranch just kind of being herded through." Another Portland caregiver said that she had taken her daughter to the emergency room and it took three hours to see someone, during which time she got better on her own.

MAJOR FINDINGS

- Adults and children with asthma see both primary care providers and specialists for their asthma. (Some mentioned that their PCP is a physician's assistant.)
- Adults and caregivers sometimes struggle to find a provider with whom they feel comfortable.
- Access to medical providers can be an issue, with long waits for emergency room treatment and appointments with specialists.
- Overall, however, it appeared that the caregivers were more likely than the asthma patients to arrange a doctor's appointment for their child's asthma on a regular basis.
- While some respondents are satisfied with the care they or their child is receiving, others have difficulty finding providers with whom they can develop a rapport.

ASTHMA MEDICATIONS

Questions about asthma medications included the following:

- How many medications do you/does your child take for your asthma?
- How often do you/does your child take asthma medication?
- What do you/your child take the medications for? Are they to stop asthma problems when they happen? Prevent asthma symptoms?
- How do you/does your child feel about taking asthma medications?

Both adults and children with asthma take a variety of asthma and allergy medications, including the following:

- Advair
- Albuterol
- Altravent
- Benadryl
- Claritin D
- Flonase
- Flovent
- Asthmanex
- Allergy shots
- Proventil
- Pulmicort
- Q-Var
- Singulair
- Spiriva
- Zyrtec

People with Asthma

Several respondents mentioned that they like to have inhalers in multiple locations such as home, automobile, and work or school, but that their insurance will not allow them to get multiple inhalers. In some instances, respondents reported that their physician is able to provide professional samples to accommodate their needs. Another problem mentioned with respect to medications is that sometimes a prescription may not be on their health plan's list of approved asthma drugs. One Eugene respondent said she takes herbs.

Virtually all respondents said they have a rescue inhaler, but not everyone said they are taking an asthma control medication. It appeared that some adults in the focus groups were not taking their control medication but dealing only with asthma attacks.

In Eugene, some respondents said that they are concerned about taking too many medications, the side effects of the medicines they are taking, and potential interactions among various medications, but did not offer any specifics on the side effects or kinds of medications that produced these side effects.

Many respondents said that a flu shot had been recommended for them or their child. Some respondents had followed the recommendation but others had not done so. Cost and concern about allergic reactions or getting a case of the flu were mentioned as reasons for not getting a flu shot. For example, a Eugene respondent noted that a flu shot at the physician's office was $66 compared with $20 or $25 at some grocery or drug store clinics.

Caregivers

Some caregivers said that they had gotten information about various asthma medications from their physician, but others indicated that their pharmacist is an important source of information, particularly with respect to medications that may interact with each other. Others said that their medications are driven by those for which their child's health plan will pay.

Caregivers said that taking prescribed medicine is generally not a problem for their child. One Portland caregiver said that his son is very motivated to take his asthma medications: *"For mine, we go ahead and up his dosage, because he knows that if it goes to the next level of steroids or whatever, it makes him so hyper he can't sleep. And he knows that experience from many times over his lifetime. So, he's pretty agreeable to working with trying to medicate enough to keep it from going to that point."* Other caregivers agreed, saying that getting their child to take their asthma medication was not a problem because they understood the consequences if they failed to do so.

Particularly among the caregivers, there are concerns about the impact of steroids. One Portland caregiver said, *"My rule of thumb is no more than five days in a row (for my child to take steroids)."* A Eugene caregiver noted, *"(I'm) worried about taking the steroid inhalers. My son (was) just switched him from Q-Var to Flovent and he's been taking that since he was six months old, so it's that whole 'steroid thing' that worries me. You know, the doctor keeps going, 'There's nothing wrong with doing it long-term,' but it's a steroid! I'm not comfortable with that."* Another Eugene caregiver noted that, *"(I'm glad my daughter's) taking the steroid inhaler and not the whole steroids like Prednisone. And with my son, they make him like a totally different person – he's moody and hungry and thirsty and cranky. I'd rather have him on the steroid inhaler than the whole steroid"*. Some respondents apparently fail to differentiate between steroids (e.g., prednisone) and inhaled corticosteroids (e.g., Flovent, Q-Var). This is an important point because the medications are quite different and act at different levels (e.g., systemic medication vs. affecting only airways).

Like the adults, many of the children with asthma had been advised to get a flu shot. Some had done so, but their children's fear of needles was cited as a barrier by some caregivers. Cost was also an issue for some caregivers.

MAJOR FINDINGS

- Adults and children with asthma take a wide variety of medications for their asthma.
- Physicians and pharmacists are the main sources of information about asthma medications.
- Not all adults or children with asthma are doing a good job of controlling their asthma. Many take only rescue inhalers and do not take controller medications.
- Both adults with asthma and caregivers have some concerns about steroid use. Some do not differentiate between systemic steroids and inhaled corticosteroids, so this may be an area to focus on with respect to patient education.
- While flu shots are recommended by providers for many adults and children with asthma, most do not receive them. Fear of shots, time issues, and costs are factors which play into making a decision about whether to get a flu shot.

ASTHMA EDUCATION

Questions about asthma education included the following:

- Where do you get information on asthma?
- How valuable are these sources of information to you?
- What information on asthma have you looked for?
- How do you like to receive information on asthma? (e.g., Internet, doctor, brochure, telephone counseling)

People with Asthma

The health care provider is viewed as the primary source of information about asthma, but the Internet is also widely used by respondents to obtain information about their condition. Particularly helpful Web sites were considered to be WebMD, drugstore.com, Kaiser, Quarterly Health, Centers for Disease Control, the American Lung Association, and the Asthma Online Association(?). One Portland respondent had also found information on the Oregon Department of Health Web site. Particular topics of interest included self-management of asthma, alternative asthma treatments, and clinical trials.

As one Portland respondent noted, an advantage of finding asthma-related information on the Internet is that, "*You can spend as much time as you want instead of having a 15-minute appointment or 10-minute appointment with the doctor. You can just spend hours, really, on one subject if you want.*" A Portland caregiver noted, "*...I like the Internet sites because they tend to compile a lot of information in one spot.*"

Usually what I will do is read the information on the Internet and then if it's something that I might be interested in, I'll ask my doctor about it when I go in and see her"

— Woman with asthma, Eugene

Some respondents also mentioned advertisements as an information source: one respondent noted that was how she learned about Advair, about which she then asked her health care provider. One respondent in Portland said that she now has the ability to email her doctor and obtain information that way: *"I'll get one question in mind and I'll want that answered and then I'll go on. But to sit and just spend time reading a lot of information, I usually can't sit still for that long and so it's been great when you can email a doctor and just get it right back. Or they send you somewhere where you can find the information."* Pharmacists are also a source of information about asthma medications, as mentioned previously.

Caregivers

Like the adults with asthma, caregivers of children with asthma are seeking information about asthma from a variety of sources. In addition to the information sources mentioned by adults with asthma, a Portland caregiver mentioned seeking information at health fairs, while a respondent in the same group had consulted a nutritionist and a naturopath. Books are also a source of information for some respondents, both those related specifically to asthma and the Physicians' Desk Reference for information about medications.

MAJOR FINDINGS

- Health care providers are the main source of asthma information for both adults with asthma and caregivers of children with asthma.
- The internet is also an important information resource.
- One respondent had used the Web site maintained by the Oregon Asthma program.
- One area in which respondents wanted additional information relates to asthma medications.

COMMUNITY SUPPORT

Questions in this section of the focus groups addressed the following issues:

- What kinds of things do people in your family/people you live with do to help you/your child with asthma?
- What kinds of things does your workplace/your child's school do to make the workplace/school safe for people with asthma?

People with Asthma

In general, respondents say that they have support from their family, friends and co-workers in avoiding asthma triggers. Some examples they gave included the following:

- Family members who smoke do so outside the home.
- Family and friends carefully vacuum their home prior to a visit;
- Odor-free board markers are provided in school classrooms.
- Employers had eradicated mold in carpets and insulation.
- Coworkers and family members avoid the use of perfumes and fragrances. For example, one respondent noted that *"(When)... my son was diagnosed with asthma he worked in a call center and they immediately banned anyone wearing perfume to work. They found out that's why a lot of people were missing work is because they were getting sick."*

On the other hand, one respondent said that some people who have not had asthma tend *"...to discount it. They think that it's not such a big deal."* A respondent noted, *"I think it's hard for people who don't have asthma to grasp the concept that very innocuous things can trigger you to have an attack, like a glass of milk, a bowl of ice cream, winter weather, walking around the block, perfume, or fabric softener"* Another respondent in the same group noted that, *"It's not that we're trying to be bitchy or difficult or don't have better things to do, but these are things that we have to take very seriously because it's our health at stake. And a lot of people don't take that seriously. I think people take a lot for granted. You adapt, you spend life living with this disease and so you learn how to adapt and how to avoid certain things or to deal with your bad days when you're not breathing as good"*. Several respondents noted that some people do not understand the impact of fragrances, and sometimes even smoking, on people with asthma. This seems to contribute to a sense of frustration with the disease for some respondents.

Caregivers

Some caregivers said that not everyone understood asthma. One Eugene caregiver said that people kept thinking that her daughter was "wimping-out" when she really had asthma. Schools represent a particular problem for some caregivers. While some schools are very attuned to the needs of children with asthma, others are not. As one Eugene respondent noted, *"Sometimes the schools have to be educated."* One Portland caregiver noted that she heard about her daughter's asthma attacks only at the end of a school week, not the day when they occurred. Another respondent in the same group noted that *"It took me to the point of taking my son out of school because they would not notify me when he had attacks; plus, they kept it [inhaler] in the office and made him walk across campus – they would not let him have it on him."* Some schools require that inhalers have to be kept in the nurse's office, which is often across the campus and sometimes not even staffed full-time.

Several parents said they had just *"gotten in the face"* of school officials until their children were allowed to keep their inhalers with them. A few caregivers said that the school principal asserted that the classroom teachers would not want to have inhalers in their classrooms, but upon checking with the teachers, the parents had found the teachers had no problem with having the inhaler in the classroom and thought it was preferable to having a child with an asthma attack walk across campus for help. A Eugene caregiver recalled, *"Our daughter started playing basketball and the inhaler was at the school, but she had an asthma attack and the coach couldn't get to the inhaler because it was 4:00 p.m. and there was no one there to release it."* Another Eugene caregiver said that the school had called an ambulance twice when her daughter had an asthma attack, because her inhaler was inaccessible in the school. This parent said she finally told the principal that the school would have to pay for the ambulance the next time they called it and that they needed to ensure that her daughter was able to use her inhaler. While some caregivers said that they had a note from their pediatrician to allow an inhaler in school, another said that their principal would not accept a note and had to speak with the doctor himself.

"It took me to the point of taking my son out of school because they would not notify me when he had attacks; plus, they kept it in the office and made him walk across campus – they would not let him have [his rescue medication] on him."

— Parent of a child with asthma, Portland

Several respondents in the Portland caregivers group said that their parents did not understand asthma or why they could not smoke around their grandchild with asthma. Some of these respondents said they had given up going to the grandparents' homes to protect their child.

One Portland caregiver said that she had been in a support group for mothers of children with asthma and that the information she received through that network, as well as some classes she had taken for parents of children with asthma, had been helpful. However, this was the only respondent in any of the groups to mention their participation in a support network.

MAJOR FINDINGS

- Schools present a particular issue for parents of children with asthma. Lack of understanding of the disease and the inaccessibility of students' asthma medications within the school are particular problems.
- Lack of understanding of asthma by others is a cause of frustration to adults and children with asthma.

Smoking and Secondhand Smoke

Questions on this topic included:

- How does cigarette smoke affect your/your child's asthma?
- Are you/Is your child around cigarette smoke at home? Work? Other places?
- How do you/ does your child feel about being around cigarette smoke?

People with Asthma

Smoking and second-hand smoke are considered important issues by virtually all of the respondents and caregivers. Cigarette smoke leads to breathing difficulty for many of the respondents, and most also noted that they are very sensitive to the smell of smoke. Two Portland respondents even complained about smoke from their neighbors who smoke outside, including one who noted that, *"Our neighbors, both of them, two houses down, smoke. And in the summer time it's almost impossible to have the windows open because when they smoke, the wind just carries it into our house, and the next thing you know, I can't breathe!"*

Adults with asthma said they avoid clubs, restaurants, and other public locations where smoking is allowed. Many said they are particularly sensitive to the odor of cigarettes on clothing and furnishings.

Some respondents said that they had previously smoked cigarettes but then quit. Among these respondents, several experienced the onset of asthma only after they had stopped smoking. One Portland respondent said he currently smokes even though he also has asthma.

Other types of smoke also create a problem for some respondents. One Portland respondent noted that, *"I had a research site down in Medford, and they had really bad forest fires last summer and the summer before. And there was a couple of weeks where I couldn't fly in down there, because in the valley, the smoke from all these fires settles in the fire and I just couldn't."* Smoke from field burning in Eugene was also a particular problem. In addition, woodstoves, incense, and campfires present problems for some respondents.

Caregivers

Several of the caregivers said that their children are very opposed to smoking and will make comments to people they see smoking in public. Some caregivers said they had had to caution their children to be polite when encountering smokers in public. Other caregivers said that they just did not allow their children to be around people who smoke.

While air pollution did not appear to be an asthma trigger among these respondents or their children (with the exception of field burning in the Eugene area), several respondents noted that they or their children had experienced a problem when traveling to California. As one Portland caregiver noted, *"when we went down to San Francisco,...we had to leave after two days – we were supposed to be there for a week, and we had to leave after two days, she just could not breathe."*

MAJOR FINDINGS

- Most adults and children with asthma are particularly susceptible to cigarette smoke and try to avoid public places where smoking is allowed.
- A few adults with asthma continue to smoke cigarettes.

DISCUSSION

This series of four focus groups with people with asthma and caregivers of children with asthma provided considerable insight into the issues facing adults and children with asthma in the State of Oregon. Participants in all of the groups were candid in describing their experiences in dealing with their disease, and the information they provided should be very useful to the Oregon Asthma Program.

Focus group participants indicated that they experience a variety of asthma triggers. Seasonal and pet allergies, stress, fragrances, and exercise were among the most common triggers mentioned by respondents. With the exception of smoke from grass burning in the Eugene area, air pollution does not appear to be a major asthma trigger, at least among the respondents in these focus groups.

While patients and caregivers report that they are using a variety of asthma medicines, some respondents indicate that they are not taking control medications but are instead relying upon their rescue inhaler once they experience an asthma attack. The focus groups suggest that caregivers seemed to do a better job of ensuring that their children use control medications than do adults with asthma who are responsible for their own care. Overall, it seemed that some respondents failed to understand that the regular use of control medications might decrease the need for rescue inhalers. *Recommendation: In its informational materials, the Oregon Asthma Program should emphasize the importance of controlling asthma before an attack occurs. One focus group observer suggested that education should be offered about inhaled corticosteroids, how they are useful controllers, and how they're different from systemic steroids.*

Adults and children with asthma face many barriers in dealing with their disease. Even when their triggers are known, it is not always possible to avoid them. Other issues include finding a physician they can trust and who seems knowledgeable about asthma, the cost of medications (particularly if they do not have health insurance), and lack of understanding of the disease on the part of some relatives and co-workers. For some children with asthma, their schools represent another barrier which must be faced, particularly where there is lack of understanding of asthma on the part of some school personnel and policies that require rescue inhalers to be kept in difficult-to-access locations within the school. *Recommendation: The Oregon Asthma Program should work with school districts to encourage them to make it convenient for children with asthma to access their medications.*

Adults (and even some children) with asthma are searching for information about their disease and report that their physician and the Internet are the primary information sources they utilize. While only one respondent was aware of the Web site maintained by the Oregon Asthma Program, she said that she had found some very helpful material when she had visited the Web site. *Recommendation: The Oregon Asthma Program needs to publicize its Web site and the useful materials it contains.*

To reiterate, these focus groups with adults with asthma and caregivers of children with asthma suggested some possible activities that the Oregon Asthma Program could undertake to assist adults and children with asthma in the state. First, emphasizing the need to take controller medications as well as to use rescue inhalers when necessary, might encourage patients to be more proactive in their treatment of the disease, rather than waiting for an attack to occur. Second, information might be provided to educate school administrators about asthma so that their students have better and more timely access to their asthma medication and treatment during school hours. And third, maintaining the Web site with useful information and promoting the Web site should continue to be beneficial to those who are seeking information about their disease.

Appendix 1: Focus Group Screener

Oregon Asthma Program

Invitation to Online Panelists

Dear Panelist:

We invite you to participate in an important and interesting survey to provide input to the State of Oregon.

The survey will take five minutes or less to complete. It is being conducted for the State of Oregon by an independent survey research organization, SRBI, which is pledged to protect the confidentiality of your responses.

If you complete the survey, your name will be entered by Survey Sampling, Incorporated, (SSI) into the monthly drawing for one of over 100 prizes worth a total of $10,000.

To start, please click on the link below, or copy the URL into your browser:

(link here).

Thank you in advance for your assistance.

Carla Jackson
Vice President
SRBI

Oregon Asthma Program

Focus Group Screener

Online Panelists in Portland, Oregon, and Eugene, Oregon

Please answer each of the following questions.

1. Has a doctor or other health professional ever told you or anyone in your household that they have asthma?
   1 Yes
   2 No SCREEN OUT

2. Who in your household has been diagnosed with asthma – is it you, or a child?
   1 Respondent
   2 Child -> Can you tell me the age of this child? (RECORD) _____

3. (IF Q2 = 1) Do you still have asthma?
   1 Yes
   2 No

4. (IF Q2 = 2) Does your child still have asthma?
   1 Yes
   2 No

5. (IF Q4 = 1) How involved would you say you are in your child's asthma care? Are you
   Very involved
   Somewhat involved
   Not involved

SELECTION CRITERIA (Recruit 16 for each group)

For Adults: Q2 = Respondent AND Q3 = Yes

For Caregiver Groups: Q2 = Child AND Q4 = Yes AND Q4 = Very or somewhat involved

SCREEN OUT ALL OTHERS

INVITATION TO PARTICIPATE:

Adults: I would like to invite you to attend a focus group discussion for people with asthma. The focus group will be sponsored by the Oregon Department of Health. The focus group will last about two hours and you would be compensated with $60 and free parking as a thank you for your attendance. A light meal will also be served. Would you be interested in participating in one of these group discussions?

Portland, Oregon
Wednesday, December 6th at 6:00 PM
BN Research at 1220 SW Morrison

Eugene, Oregon
Thursday, December 7th at 6:00 PM
Hilton Hotel and Conference Center

No → May I ask why you are not interested in participating in the session?

Caregivers: I would like to invite you to attend a focus group discussion for caregivers of children with asthma. The focus group will be sponsored by the Oregon Department of Health. The focus group will last about two hours and you would be compensated $60 as a thank you for your attendance. A light meal will also be served. Would you be interested in participating in one of these group discussions?

Portland, Oregon
Wednesday, December 6th at 8:00 PM
BN Research at 1220 SW Morrison

Eugene, Oregon
Thursday, December 7th at 8:00 PM
Hilton Hotel and Conference Center

No → May I ask why you are not interested in participating in the session?

Qualify as both an Adult patient and as a Caregiver: I would like to invite you to attend a focus group discussion. The focus group will be sponsored by the Oregon Department of Health. The focus group will last about two hours and you would be compensated $60 as a thank you for your attendance. A light meal will also be served. Would you be interested in participating in one of these group discussions?

For Adults

Portland, Oregon

Wednesday, December 6th at 6:00 PM

BN Research at 1220 SW Morrison

Eugene, Oregon

Thursday, December 7th at 6:00 PM

Hilton Hotel and Conference Center

For Caregivers:

Portland, Oregon

Wednesday, December 6th at 8:00 PM

BN Research at 1220 SW Morrison

Eugene, Oregon

Thursday, December 7th at 8:00 PM

Hilton Hotel and Conference Center

No → May I ask why you are not interested in participating in the session?

Thank you for agreeing to participate. We will be mailing you a letter and calling you the day before the discussion to confirm the time and location. Would you please give your:

NAME:

ADDRESS:

PHONE:

(home)

(work)

(cell)

Thank you for your time. We look forward to seeing you on [DATE}. If you have any questions about the focus group, please feel free to call SRBI at the following toll-free-number: 1-888-772-4269. We look forward to seeing you at the group discussion and appreciate your willingness to take part in this important research study.

Appendix 2: Focus Group Confirmation E-mail

Dear :

Thank you for agreeing to participate in the group discussion to be sponsored by the Oregon Department of Health on _____, _____ beginning at _____ P.M.. The session will be held at ____ _____. Directions to the facility are enclosed.

This should be an interesting discussion which will provide valuable insight to the Oregon Department of Health about the experiences of adults and caregivers, and we appreciate your willingness to participate. We will be paying $60 as a "thank you" for your participation. We will also serve a light snack prior to the session, so please plan to come a little early. Please plan to stay for the entire group discussion.

Again, thank you for agreeing to take part in this important group discussion and we look forward to meeting you.

Sincerely,

Carla Jackson
Vice President

Enclosure

Appendix 3: Focus Group Telephone Reminder

Telephone Confirmation for Asthma Focus Groups

Name_____

Home phone _____

Work phone _____

Cell phone_____

Hello, this is _____ from SRBI Research. May I please speak with _____.
(REPEAT IF NEEDED)

I am calling to confirm that you will be attending the Asthma Focus Group for the Oregon Department of Health at (Facility) on (Day) (Date) at (6:00 or 8:00) PM.

1 Yes, confirms
2 No, will not be there ☐ We're sorry that you won't be able to make it.

And just to confirm, we wanted to make sure that you have been diagnosed with, and still have, asthma?

1 Yes ☐ Did you receive the directions we sent you?)
  1 Yes
  2 No ☐ ASK IF THEY NEED DIRECTIONS. IF SO, PLEASE READ DIRECTIONS.

Thank you, we look forward to seeing you there and have a great evening.

2 No ☐ This focus group is for people who have been diagnosed with, and still have, asthma. From the online survey you completed a few weeks ago, you qualified to attend the focus group, but this focus group will not be of interest to someone who does not have asthma. Can we put you on our list to be contacted about focus groups on other topics to be held in the your area?
  1 Yes
  2 No

  Thank you for your cooperation and have a great evening.

Appendix 4: Focus Group Moderator's Guides

Moderator's Guide
Focus Groups with People with Asthma

Introduction (5 minutes)

Hello, my name is _____. I am a focus group moderator for SRBI Research, and we have been asked to assist the Oregon Department of Human Services. During the course of our discussion, we will talk about some of the ways asthma affects your life and some of the things you do to control it. Your input will provide valuable information for the Oregon Asthma Program. This is an important topic, and we thank you in advance for sharing your experiences with us.

How many of you have been in a focus group before? (Ask for a show of hands.) For those of you who haven't, and as a refresher for those of you who have, let me review a couple of ground rules for our session this evening.

- There are no right or wrong answers in a session like this. Please feel free to tell me what you feel about the questions I will be asking.
- Everyone's opinion is important and we need everyone to participate in the discussion.
- We will be here no longer than two hours. I will be watching our time and directing our discussion. I am not planning on a formal break, but if you need to stand up and stretch or leave to use the restroom, please do so quietly, and come back as quickly as possible.
- We are audio- and videotaping this session, so that I don't have to take notes. This is one of four meetings like this that we will be holding on this topic.
- Since we are audio-taping, I need for you to speak one-at-a-time, loudly and clearly. Please avoid side conversations.
- Portland: You will notice a one-way mirror behind me. We have some colleagues behind the mirror who are interested in hearing your comments first-hand.
- Eugene: The videotaping is also feeding into an adjoining room where we have some colleagues that are interested in hearing your comments first-hand.

I have a lot of material to cover with you this evening. It may be necessary at some point for me to interrupt the conversation and move on to another topic. If I have to do this, please bear with me.

Topics

- Warmup (10 minutes)
  - To begin, would you please tell me your first name and how long ago you were first diagnosed with asthma. (Go around the table to each respondent).
  - What was your asthma like when you were first diagnosed?
  - What is your asthma like now?
  - If asthma were an animal, what animal would it be? (Ask for an answer from each respondent.)

- How serious is asthma (5 minutes)
  - What do you think about this statement: "asthma cannot be cured but it can be controlled"?
  - How serious is asthma as a disease? What about asthma compared to heart disease or diabetes? How is asthma different from heart disease or diabetes? How is asthma similar?

- Asthma control and management (40 minutes)
  - Have you had an asthma attack in the past year? How did you feel? What did you do about it?
  - Have you had any asthma symptoms without having a full-blown attack in the past year? How did you feel? What did you do about it?
  - What causes you to have (worse) asthma symptoms? What do you do to avoid these things? How does this affect your daily life or your activities?
  - Do you change any of your plans or activities because of your asthma? (Probe for sports and recreation, normal physical activity, choice of jobs or careers, social activities)
  - Have you had times in the past year of a week or more when you weren't having asthma symptoms? What were you doing? Were you:
    - Taking asthma medications?
    - Limiting your activities?
    - Something else?
  - Have you ever received an asthma action plan (short description here) from your doctor/provider?
    If yes, how did the asthma action plan help you manage your asthma?
  - Are there any barriers to doing the things you know you can do to prevent asthma symptoms and attacks? (e.g., can't quit smoking, can't afford visits to provider, can't afford or won't take daily meds, won't get rid of pets, etc.)

- How many medications do you take for your asthma?
  - How often do you take your asthma medications?
  - What do you take the medications for? Are they to stop asthma problems when they happen? Prevent asthma symptoms? (Trying to get at whether they understand controller vs. rescue med)
  - How do you feel about taking your asthma medications?

- Interactions with health care system and doctor/provider (15 minutes)
  - When do you decide to see a health care provider for your asthma?
  - Where do you go when you see a health care provider for asthma? (i.e., clinic, ED) Who do you see? (i.e., doctor, nurse, PA, NP, naturopath, other)
  - How do you feel about talking with your health care provider about asthma?
  - Are there any barriers that affect whether you go in for asthma care or get your prescriptions? (money, transportation, time off work, etc.)
  - When you go in for asthma care, do you get any information on how to manage your asthma? What kind of information does the provider give you? Info on:
    - Medications?
    - Triggers?
    - When to seek care?

- Asthma education (10 minutes)
  - Where do you get information on asthma? (e.g., provider, family, friends, co-workers, religious or community leaders) How valuable are these sources of information to you?
  - What information on asthma have you looked for?
  - How do you like to receive information on asthma? (e.g., internet, doctor, brochure, telephone counseling)

- Community support (10 minutes)
  - What kinds of things do people in your family/people you live with do to help you with your asthma?
  - What kinds of things does your workplace do to make the workplace safe for people with asthma?

- Smoking and secondhand smoke (10 minutes)
  - How does cigarette smoke affect your asthma?
  - Are you around cigarette smoke at home? Work? Other places (probe for whether indoors or outdoors)?
  - How do you feel about being around cigarette smoke?

Moderator's Guide
Focus Groups with Caregivers of Children with Asthma

Introduction (5 minutes)

Hello, my name is _____. I am a focus group moderator for SRBI Research, and we have been asked to assist the Oregon Department of Human Services. During the course of our discussion, we will talk about some of the ways asthma affects your child's life and how you help them control it, and also how your child's asthma affects your life. Your input will provide valuable information for the Oregon Asthma Program. This is an important topic, and we thank you in advance for sharing your experiences with us.

How many of you have been in a focus group before? (Ask for a show of hands.) For those of you who haven't, and as a refresher for those of you who have, let me review a couple of ground rules for our session this evening.

- There are no right or wrong answers in a session like this. Please feel free to tell me what you feel about the questions I will be asking.
- Everyone's opinion is important and we need everyone to participate in the discussion.
- We will be here no longer than two hours. I will be watching our time and directing our discussion. I am not planning on a formal break, but if you need to stand up and stretch or leave to use the restroom, please do so quietly, and come back as quickly as possible.
- We are audio- and videotaping this session, so that I don't have to take notes. This is one of four meetings like this that we will be holding on this topic.
- Since we are audio-taping, I need for you to speak one-at-a-time, loudly and clearly. Please avoid side conversations.
- Portland: You will notice a one-way mirror behind me. We have some colleagues behind the mirror who are interested in hearing your comments first-hand.
- Eugene: The videotaping is also feeding into an adjoining room where we have some colleagues that are interested in hearing your comments first-hand.

I have a lot of material to cover with you this evening. It may be necessary at some point for me to interrupt the conversation and move on to another topic. If I have to do this, please bear with me.

Topics

- Warmup (10 minutes)
  - To begin, would you please tell me your first name and how old your child was when s/he was first diagnosed with asthma. (Go around the table).
  - What was your child's asthma like when s/he was first diagnosed? What is it like now?
  - How do you think asthma makes your child feel?
  - If you had to choose one word to describe your child's asthma, what would it be?

- How serious is asthma? (5 minutes)
  - What do you think about this statement: "asthma cannot be cured but it can be controlled"?
  - How serious is asthma as a disease?
  - What about asthma compared to heart disease or diabetes? How is asthma different from heart disease or diabetes? How is asthma similar?

- Asthma control and management (40 minutes)
  - Has your child had an asthma attack in the past year? How did they feel? What did you and your child do about it?
  - Has your child had any asthma symptoms without having a full-blown attack in the past year? How did they feel? What did you and your child do about it?
  - What causes your child to have (worse) asthma symptoms? What do you and your child do to avoid these things? How does this affect his/her daily life or activities?
  - Are your child's plans or activities changed because of his/her asthma? (e.g., sports, school, normal physical activity, social activities)
  - Have there been times in the past year of a week or more when your child wasn't having asthma symptoms? What was s/he doing? Was s/he:
    - Taking asthma medications?
    - Limiting his/her activities?
    - Something else?
  - Has your child ever received an asthma action plan from his/her doctor?
    - If yes, how did the plan help you manage your child's asthma?
  - Are there any barriers to doing the things you know you can do to prevent asthma symptoms and attacks in your child? (e.g., can't afford visits to provider, can't afford or won't take daily meds, won't get rid of pets, etc.)

- How many medications does your child take for asthma?
  - How often does s/he take asthma medications?
  - What does s/he take the medications for? Are they to stop asthma problems when they happen? Prevent asthma symptoms?
  - How does your child feel about taking asthma medications? How do you feel about them taking asthma medications?

- Interactions with health care system and doctor/provider (15 minutes)
  - When do you decide to take your child to see a health care provider for asthma?
  - Where do you take your child to see a health care provider for asthma? (clinic, ED?) What kind of provider do you see? (i.e., doctor, nurse, PA, NP, etc.)
  - Are there any barriers that affect whether your child goes in for asthma care or gets asthma prescriptions? (money, transportation, time off work, etc.)
  - When your child goes in for asthma care, do you get any information on how to manage his/her asthma? What kind of information does the provider give?
    - Medications?
    - Triggers?
    - When to seek care?
  - How is your access to health care (clinics, hospitals) for your child's asthma? What makes it easy or difficult?
  - Are there are any barriers to getting good health care for your child's asthma?

- Asthma education (10 minutes)
  - Where do you get information on asthma for your child? (e.g., provider, family, friends, co-workers, religious or community leaders) How valuable are these sources of information to you?
  - What information on asthma have you looked for?
  - How do you like to receive information on asthma? (e.g., internet, doctor, brochure, telephone counseling)

- Community support (10 minutes)
  - What kinds of things do people in your family/people you live with do to help your child with her/his asthma? What do they do that make it more difficult to deal with her/his asthma?
  - What kinds of things does your child's school do to make the school safe for children with asthma?

- Smoking and secondhand smoke (10 minutes)
  - How does cigarette smoke affect your child's asthma?
  - Does your child smoke?
  - Does anybody smoke at home inside the house? (could probe primary vs. secondary residence if joint custody) At the house but outside? Is your child regularly exposed to cigarette smoke in other places? Where?
  - How do you feel about your child being around cigarette smoke?

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