



ALLIES AGAINST ASTHMA ASTHMA CORE CAREGIVER SURVEY

Instrument Description

The Asthma Core Caregiver Survey can be used to assess individual-level asthma-related outcomes. This instrument is a compilation of previously existing surveys designed to collect self-report data about asthma management, exposures to community events and programs, and outcomes. It was designed to measure individual outcomes between baseline and follow-up periods within an intervention and control/comparison group. It measures the following:

- Quality of Life: The Paediatric Asthma Quality of Life Questionnaire was used to measure quality of life. (To obtain this questionnaire and additional information about its use, please go to <http://www.qoltech.co.uk/PaedAsthma.htm>)
- Asthma Symptoms
- Exposure to Asthma-Related Community Events and Programs
- Parent Asthma Management Strategies
- Hospitalizations and Emergency Department visits (self-report)

The English version and a Spanish translation are included in this document.

Development and Conditions of Use

Adapted by Allies Against Asthma, 2003.

For use and/or adaptations of this document, please credit Allies Against Asthma and the applicable references below.

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Quality of Life

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Parent Asthma Management Strategies

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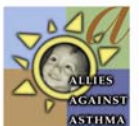
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ALLIES AGAINST ASTHMA ASTHMA CORE CAREGIVER SURVEY

Date of administration: ____/____/____

Site ID# _____

Respondent ID# _____

Administration Method:
(check one)

____ Self-administered

____ Interviewer-administered

If interviewer-administered:

Interviewer ID: _____

How interviewed? ____phone ____face-to-face

Language:

____ English

____ Spanish

____ Other _____

Paediatric Asthma Caregiver's Quality of Life Questionnaire

This section, two pages long, is not included in this document due to copyright restrictions; to obtain this questionnaire and additional information about its use, please go to

<http://www.qoltech.co.uk/PaedAsthma.htm>

Asthma Symptoms

These next four questions ask about how asthma affects you and [CHILD] each day. The questions ask about asthma symptoms during two different time periods: in the last 14 days, and over the last 12 months.

S1. During the daytime in the last 14 days, how many days did [CHILD] have asthma symptoms such as wheezing, shortness of breath, tightness in the chest, or cough? ____Days

S1.1 How about in the last 12 months? ____Days

Begin with a PAUSE, if no answer restate the question.

Avoid ranges: if given a range, i.e. 2 to 5 days a month, ask, “would that be closer to 2 or closer to 5? Is that every month?”

If respondent says it varies during the year ask “at the worst time how many days a month? For how many months? And the rest of the year, how many days a month?”

If respondent says most of the time, or all of the time etc. restate the response “do you mean a few days a week? How many?” “Do you mean every day of the year?”

INTERVIEWER: Calculate and enter responses adjusted for 12 months.

S2. During the nighttime in the last 14 nights, how many nights did [CHILD] wake up because of asthma symptoms such as wheezing, shortness of breath, tightness in the chest, or cough?
____Nights

S2.1 How about in the last 12 months? ____Nights

Use same probes as above replacing term “days” with “nights.”

These next two questions ask about hospitalizations and emergency visits over the past 12 months.

S3. During the past 12 months (that is since _____), did [child] have to stay overnight in the hospital because of asthma?

S4. Not counting hospitalizations, during the past 12 months, (that is, since _____), did [child] go to an emergency room because of asthma?

Items on Exposure to Community Events and Programs Related to Asthma

Next are some questions about your community.

E1. Have you heard of (insert coalition name, program or other organization as appropriate)?

YES ☐

NO ☐

DON'T KNOW ☐

If NO or DON'T KNOW: Go to #3

If YES, ask:

E2. How many times have you participated in activities or received help from (insert coalition name, program or other organization as appropriate)?

*****Probe if per week, month, year*****

1 - ___ ___/week

2 - ___ ___/month

3 - ___ ___/year

NEVER ☐

DON'T KNOW ☐

E3. How often do you hear someone in your neighborhood talking about asthma?

VERY OFTEN ☐

SOMETIMES ☐

SELDOM ☐

NEVER ☐

DON'T KNOW ☐

E4. Have you or your child talked with a doctor or nurse about your child's asthma in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E5. Has anyone visited your home to talk with you about your child's asthma in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E6. Has anyone called you on the phone to talk with you about your child's asthma in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E7. Have you or your child attended a class on asthma in your child's school in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E8. Have you or your child attended a class on asthma at any other place, like a health clinic, neighborhood center, or church in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E9. Have you or your child participated in some other activity for people with asthma such as a health fair, asthma camp, or neighborhood event in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E10. Have you heard a presentation on asthma in a church or some other community organization in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E11. Have you received hand-outs or fliers or manuals on asthma in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E12. Have you noticed posters or billboards or other announcements in your neighborhood about asthma in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

E13. (Optional) Have you been to an asthma support group in the last 6 months?

YES ☐

NO ☐

DON'T KNOW ☐

Parent Asthma Management Strategies (long version)

Now I am going to ask some questions about things **YOU** may have done to manage **[child's]** asthma at home during the **past 12 months**. Some parents find some of these things helpful and others feel that they are not helpful. For the past 12 months, please tell me whether you did these things to manage **[child's]** asthma

All the time, Fairly often, Not too often or Never.....

During the past 12 months....	All the time	Fairly often	Not too often	Never
a. Did you give [child] asthma prescription medicine when s/he was having symptoms	[4]	[3]	[2]	[1]
b. Did you find ways to keep yourself and [child] calm	[4]	[3]	[2]	[1]
c. Did you have [child] rest or play quietly	[4]	[3]	[2]	[1]
d. Did you take [child] away from what caused symptoms when possible	[4]	[3]	[2]	[1]
e. Did you observe [child] to see if symptoms got better or worse	[4]	[3]	[2]	[1]
f. Did you ask someone for advice or help	[4]	[3]	[2]	[1]
g. Did you use a peak flow meter to try to predict [child's] asthma attacks	[4]	[3]	[2]	[1]
h. Did you watch [child] closely when symptoms began, in order to determine how serious they were	[4]	[3]	[2]	[1]
i. Did you watch closely after giving [child] medicine to see if it was working to reduce or stop symptoms	[4]	[3]	[2]	[1]
j. Did you try to identify things that might be triggering [child's] symptoms	[4]	[3]	[2]	[1]
k. Did you look for early warning signs of an asthma attack	[4]	[3]	[2]	[1]
l. Did you decide on your own whether or not the medicine was working or needed to be changed	[4]	[3]	[2]	[1]

m. Did you use some system or method for deciding when to change the type or dose of medicine according to the changes in [child's] asthma symptoms	[4]	[3]	[2]	[1]
n. Did you determine if the changes you made in [child's] environment, for example, bedroom furnishings, household pets, or air quality had any effect on [child's] symptoms	[4]	[3]	[2]	[1]
o. Did you give [child] asthma medicines before s/he came in contact with something that might cause asthma symptoms to begin	[4]	[3]	[2]	[1]

Parent Asthma Management Strategies (short version)

I'd like to ask you about things you may have done to manage (child's name) at home during the past 12 months. Some parents find these things helpful, others find they are not helpful.

For each item, please tell me how often you did these things: all the time, fairly often, not too often, never.

How often did you:	All the time	Fairly Often	Not too often	Never
1. Give (child's name) asthma prescription medicine when he/she was having symptoms.	4	3	2	1
2. Find ways to keep yourself and (child's name) calm when he/she was having symptoms.	4	3	2	1
3. Have (child's name) rest or play quietly when he/she was having symptoms.	4	3	2	1
4. Take (child's name) away from what caused the symptoms.	4	3	2	1
5. Ask someone for help or advice about managing (child's name)'s asthma.	4	3	2	1

6. Give (child's name) asthma medicines before he/she had contact with something that might cause wheezing or coughing, for example, before entering a smoky restaurant or before he/she played sports.	4	3	2	1
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* Clark, N.M., Gong, M, Kaciroti, N. A model of self-regulation for control of chronic disease. *Health Education & Behavior* 28(6):769-782, 2000.

Demographics

Child

D1. What is your child's sex? ☐ Male ☐ Female

D2. What is your child's age and date of birth?

Age (in years)

Date of birth:

Month

Day

Year

D3. Is your child Spanish/Hispanic/Latino?

Mark (X) in the "NO" box if not Spanish/Hispanic/Latino.

☐ No, not Spanish/Hispanic/Latino

☐ Yes, Mexican, Mexican American, Chicano

☐ Yes, Puerto Rican

☐ Yes, Cuban

☐ Yes, other Spanish, Hispanic, Latino

(print group) _____

D4. What is the child's race?

Mark (X) one or more races to indicate what race the caregiver considers him or her to be.

☐ White

☐ Black or African American

☐ American Indian or Alaskan Native

☐ Asian Indian

☐ Chinese

☐ Filipino

☐ Japanese

☐ Korean

☐ Vietnamese

☐ Other Asian (print race below)

☐ Native Hawaiian

☐ Guamanian or Chamorro

☐ Samoan

☐ Other Pacific Islander (print race below)

☐ Other race (print race below)

(print race) _____

D5. Is your child currently covered by health insurance? ☐ Yes ☐ No

If yes, what insurance? _____

Is that through Medicaid or CHIP (or whatever name appropriate for site)?_____

Primary Caregiver

D6. What is your zip code of residence?_____

D7. What is your sex? ___ Male ___ Female

D8. What is your age and date of birth?

___ Age (in years)

Date of birth:

Month

Day

Year

D9. What is your relationship to [**child**]?

___ Mother ___ Father ___ Grandmother ___ Grandfather ___ Aunt

___ Uncle

___ Other: (specify)_____

D10. Are you Spanish/Hispanic/Latino?

Mark (X) in the “NO” box if not Spanish/Hispanic/Latino.

___ No, not Spanish/Hispanic/Latino

___ Yes, Mexican, Mexican American, Chicano

___ Yes, Puerto Rican

___ Yes, Cuban

___ Yes, other Spanish, Hispanic, Latino

(print group)_____

D11. What is your race?

Mark (X) one or more races to indicate which race the caregiver consider herself or himself to be.

___ White

___ Black or African American

___ American Indian or Alaskan Native

___ Asian Indian

___ Chinese

___ Filipino

___ Japanese

___ Korean

___ Vietnamese

___ Other Asian (print race below)

___ Native Hawaiian

- ___ Guamanian or Chamorro
- ___ Samoan
- ___ Other Pacific Islander (print race below)
- ___ Other race (print race below)
- (print race) _____

D12. What is the highest level of school you have COMPLETED?

Mark (X) only ONCE.

If currently enrolled, mark the previous grade or highest grade completed.

Interviewer: Do not read responses. Check appropriate box and probe if necessary.

- ___ No schooling completed
- ___ Nursery school to 4th grade
- ___ 5th grade or 6th grade
- ___ 7th grade or 8th grade
- ___ 9th grade
- ___ 10th grade
- ___ 11th grade
- ___ 12th grade—**NO DIPLOMA**
- ___ **HIGH SCHOOL GRADUATE**—high school
- ___ DIPLOMA or the equivalent (for example: GED)
- ___ Some technical/vocational school
- ___ Completed technical/vocational school
- ___ Some college credit, but less than 1 year
- ___ 1 or more years of college, no degree
- ___ Associate's degree (for example: AA, AS)
- ___ Bachelor's degree (for example: BA, AB, BS)
- ___ Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- ___ Professional degree (for example: MD, DDS, DVM, LLB, JD)
- ___ Doctorate degree (for example: PhD, EdD)
- ___ Other (please describe, including country where education took place) _____

D13. What was your total family income before taxes last year? (Optional)

Or

D14. Which category best describes your total family income before taxes last year? (***For interviewer-administered: “Please stop me when I get to the category that best describes your total income.”***)

- ☐ Less than \$5000
- ☐ \$5001-\$10,000
- ☐ \$10,001-\$15,000
- ☐ \$15,001-\$20,000
- ☐ \$20,001-\$30,000
- ☐ \$30,001-\$40,000
- ☐ \$40,001-\$50,000
- ☐ \$50,001-\$60,000
- ☐ \$60,001-\$70,000
- ☐ \$70,001-\$80,000
- ☐ \$80,001 and above

ALIANZA CONTRA EL ASMA

ENCUESTA PARA EL ENCARGADO O GUARDIÁN PRINCIPAL DE ASMA

Fecha de administración: ____/____/____

ID. # del Sitio: ____

ID. # del entrevistado: ____

Método de administración:
(marque uno)

____ Auto-administrado

____ Administrado por el entrevistador

Si fue administrado por el entrevistador:

ID. del entrevistador: ____

¿Cómo entrevistó? ____ Teléfono ____ Cara a cara

Idioma:

____ Inglés

____ Español

____ Otro _____

Cuestionario de la Calidad de Vida de la Persona Encargada del Cuidado del Niño con Asma

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Síntomas de asma

Las siguientes cuatro preguntas son acerca de cómo es que el asma los afecta a usted y a [nombre del niño/a] cada día. Las preguntas se refieren a los síntomas del asma durante dos períodos de tiempo distintos: durante los últimos 14 días y durante los últimos 12 meses.

S1. Durante el día en los últimos 14 días, ¿cuántos días tuvo [nombre del niño/a] silbidos (pitos) al respirar, falta de aire, opresión en el pecho o tos?

S1.1 ¿Y durante los últimos 12 meses? ____ Días

Empiece con una PAUSA, si no hay respuesta, repita la pregunta.

Evite períodos de tiempo: por ejemplo si le contesta de 2 a 5 días al mes, pregunte “eso sería más cerca a 2 ó a 5? Y eso es ¿cada mes?”

Si el entrevistado responde que varía durante el año pregunte, “durante la peor época ¿cuántos días al mes? ¿Cuántos meses? Y durante el resto del año ¿cuántos días al mes?”

Si el entrevistado responde la mayor parte del tiempo o todo el tiempo, etc. repita la respuesta diciendo “¿Usted quiere decir unos pocos días a la semana? ¿Cuántos días?” “¿Quiere decir todos los días del año?”

ENTREVISTADOR: Calcule y escriba las respuestas ajustándolas a 12 meses.

S2. Durante la noche en las últimas 14 noches, ¿cuántas noches se despertó [nombre del niño/a] por el asma, con silbidos (pitos) al respirar, falta de aire, opresión en el pecho o tos?

S2.1 ¿Y durante los últimos 12 meses? ____ Noches

Use las mismas preguntas que arriba, sustituyendo “días” con “noches.”

Las próximas dos preguntas son acerca de hospitalizaciones y idas a la sala de emergencia durante los últimos 12 meses.

S3. Durante los últimos 12 meses (eso es desde _____), ¿[nombre del niño/a] tuvo que pasar la noche en el hospital por el asma?

Sin contar las hospitalizaciones durante los últimos 12 meses, (eso es desde _____), ¿[nombre del niño/a] ha tenido que ir a la sala de emergencia por el asma?

Preguntas sobre la exposición a eventos y programas de la comunidad relacionados con el asma

Ahora le haré algunas preguntas acerca de su comunidad.

E1) ¿Ha oído acerca de (diga el nombre de la coalición, programa u otra organización que corresponda)?

SÍ
NO
NO SABE

Si responde NO o NO SABE: Vaya al #3

Si responde SÍ, pregunte:

E2) ¿Cuántas veces ha participado en las actividades o recibido ayuda de (diga el nombre de la coalición, programa u otra organización que corresponda)?

****Insista en aclarar si es a la semana, al mes, al año****

1 - ____ / a la semana
2 - ____ / al mes
3 - ____ / al año
NUNCA
NO SABE

E3) ¿Con qué frecuencia escucha a alguien en su comunidad hablar acerca del asma?

MUY SEGUIDO/ FRECUENTEMENTE
ALGUNAS VECES
RARAS VECES
NUNCA
NO SABE

E4) Durante los últimos seis meses, ¿usted o su niño con asma han hablado con un doctor o una enfermera acerca del asma de su niño?

SÍ
NO
NO SABE

E5) Durante los últimos seis meses, ¿los ha visitado alguien en su casa para hablar acerca del asma de su niño?

SÍ
NO
NO SABE

E6) Durante los últimos seis meses, ¿los ha llamado alguien por teléfono para hablar acerca del asma de su niño?

SÍ
NO
NO SABE

E7) Durante los últimos seis meses, ¿usted o su hijo han asistido a una clase acerca del asma en la escuela de su hijo?

SÍ
NO
NO SABE

E8) Durante los últimos seis meses, ¿usted o su hijo han asistido a una clase acerca del asma en algún otro lugar como una clínica, el centro de su comunidad o iglesia?

SÍ
NO
NO SABE

E9) Durante los últimos seis meses, ¿usted o su hijo han participado en alguna otra actividad para personas con asma tal como una feria de salud, un campamento para niños con asma o un evento en su comunidad?

SÍ
NO
NO SABE

E10) Durante los últimos seis meses, ha asistido a una presentación acerca del asma en una iglesia u otra organización en su comunidad?

SÍ
NO
NO SABE

E11) Durante los últimos seis meses, ¿ha recibido impresos, folletos informativos o manuales acerca del asma?

SÍ
NO
NO SABE

E12) Durante los últimos seis meses, ¿ha visto carteles, letreros o anuncios acerca del asma en su comunidad?

SÍ
NO
NO SABE

E13) (Opcional) Durante los últimos seis meses, ¿ha asistido a un grupo de apoyo de asma?

SÍ
NO
NO SABE

Demografía

Niño/a

D1. ¿Cuál es el sexo de su niño/a? ____ Masculino ____ Femenino

D2. ¿Cuál es la edad de su niño/a y su fecha de nacimiento?

____ Edad (en años)

Fecha de Nacimiento:

Mes

Día

Año

D3. ¿Qué es su niño/a, español/a, hispano/a, latino/a?

Sí no es español/a, hispano/a o latino/a, ponga una "X" en la caja "NO".

____ No, no es español/hispano/latino

____ Sí, mexicano, mexicano-americano, chicano

____ Sí, puertorriqueño

____ Sí, cubano

____ Sí, otro grupo español, hispano o latino

Escriba el grupo en letra de molde _____

D4. ¿Cuál es la raza del niño/a?

Ponga una o más "X" para indicar la raza a la que pertenece el/la niño/a, según el/la encargado/a del cuidado del niño/a.

____ Blanca

____ Negra, africana americana

____ India americana o nativa de Alaska

____ India asiática

____ China

____ Filipina

____ Japonesa

____ Coreana

____ Vietnamita

____ Otra asiática (*Escriba abajo la raza en letra de molde*)

____ Hawaiano nativo

____ Guam o Chamorro

____ Samoano

____ Otra de las islas del Pacífico (*Escriba abajo la raza en letra de molde*)

____ Alguna otra raza (*Escriba abajo la raza en letra de molde*)

D5. ¿Actualmente, tiene su niño/a seguro médico? ____ Sí ____ No

Si tiene, ¿qué seguro tiene? _____

¿El seguro es por medio de Medicaid o CHIP (o cualquier nombre apropiado al lugar)?

Persona encargada del cuidado del niño

D6. ¿Cuál es el código postal del área donde vive? _____

D7. ¿Cuál es su sexo? ____ Masculino ____ Femenino

D8. ¿Cuántos años tiene usted y cuál es su fecha de nacimiento?

____ Edad (en años)

Fecha de Nacimiento:

Mes

Día

Año

D9. ¿Cuál es su relación con [niño/a]? ____Madre ____Padre ____Abuela ____Abuelo ____ Tío/a
____ Otro: (especifique) _____

D10. ¿Es usted español/a, hispano/a, latino/a?

Sí no es español/a, hispano/a o latino/a, ponga una "X" en la caja "NO".

____ No, no es español/hispano/latino

____ Sí, mexicano, mexicano-americano, chicano

____ Sí, puertorriqueño

____ Sí, cubano

____ Sí, otro grupo español, hispano, latino

Escriba el grupo en letra de molde _____

D11. ¿Cuál es su raza?

Ponga una o más "X" para indicar la raza a la que él/ella considera que pertenece.

____ Blanca

____ Negra, africana americana

____ India americana o nativa de Alaska

____ India asiática

____ China

____ Filipina

____ Japonesa

____ Coreana

____ Vietnamita

____ Otra asiática (*Escriba abajo la raza en letra de molde*)

____ Hawaiano nativo

____ Guam o Chamorro

____ Samoano

____ Otra de las islas del Pacífico (*Escriba abajo la raza en letra de molde*)

____ Alguna otra raza (*Escriba abajo la raza en letra de molde*) _____

D12. ¿Cuál es el nivel más alto de educación que Ud. ha terminado?

Ponga UNA SOLA “X”.

Si Ud. está estudiando, por favor marque el nivel anterior al actual o el nivel más alto que haya completado.

Entrevistador: No lea las respuestas. Marque la caja apropiada y tantee si es necesario.

- ☐ No ha completado ningún grado
- ☐ Guardería infantil (nursery school) a 4º grado
- ☐ 5º ó 6º grado
- ☐ 7º u 8º grado
- ☐ 9º grado
- ☐ 10º grado
- ☐ 11º grado
- ☐ 12º grado—**SIN DIPLOMA**
- ☐ **GRADUADO/A DE ESCUELA SECUNDARIA—**
- ☐ DIPLOMA de escuela secundaria o su equivalente (por ejemplo: GED)
- ☐ Alguna escuela técnica/vocacional
- ☐ Terminó escuela técnica/vocacional
- ☐ Algunos créditos universitarios, pero menos de 1 año
- ☐ 1 año o más de universidad, sin título
- ☐ Título de asociado universitario (por ejemplo: AA, AS)
- ☐ Título de bachiller universitario (por ejemplo: BA, AB, BS)
- ☐ Título de maestría (por ejemplo: MA, MS, MEng, MEd, MSW, MBA)
- ☐ Título profesional (por ejemplo: MD, DDS, DVM, LLB, JD)
- ☐ Título de doctorado (por ejemplo: Ph.D, Ed.D)
- ☐ Otro (por favor describa; incluya el país donde estudió:

D13. Antes de pagar impuestos ¿cuál fue el ingreso de su familia el año pasado?
(Opcional) _____

O

D14. ¿Qué categoría describe mejor el ingreso total de su familia, el año pasado, antes de pagar impuestos? (**Entrevistador: “Por favor párame cuando llegue a la categoría que describe mejor sus ingresos totales.”**)

- ☐ Menos de \$5,000
- ☐ \$5,001-\$10,000
- ☐ \$10,000-\$15,000
- ☐ \$15,001-\$20,000
- ☐ \$20,001-\$30,000
- ☐ \$30,001-\$40,000
- ☐ \$40,001-\$50,000
- ☐ \$50,001-\$60,000
- ☐ \$60,001-\$70,000
- ☐ \$70,001-\$80,000
- ☐ \$80,000 o más



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