

Supplemental Online Content

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This supplemental material has been provided by the authors to give readers additional information about their work.

eMethods. AD Flare Definition Survey

Start of Block: Flare Informed Consent

flare_consent Welcome! Please read about the survey before you participate.

Study Purpose

The National Eczema Association (NEA) is committed to amplifying the true lived experience of eczema. When it comes to atopic dermatitis (AD), “flare” is a term used for many purposes, generally to describe worsening of disease or a disease event, yet there is no one definition used and no definition that has been created with significant input from patients themselves. So, we are conducting a study to get closer to a definition of AD flare from the patient perspective. NEA gathered together a diverse group of patients to help determine the most important concepts to include in a patient definition of flare. The result was 15 statements that patients said are important for the definition. **With this survey, we are asking specifically if you—as an atopic dermatitis patient—agree with the statements that are important to include in a definition of atopic dermatitis flare.** In addition to this main question, we are collecting other information about your AD experience so we can understand what could be associated with differences in how patients define an AD flare.

What’s involved? You will take a 10-15 minute online survey.

Eligibility

- You can participate in this survey if you meet all the below criteria:
- You are a U.S. resident.
- You are 18 years or older.
- You can speak, read, and understand English language.
- You have been diagnosed by a healthcare provider with Atopic Dermatitis (a type of eczema).

Compensation

You will not be compensated for completing the survey. However, you can enter a drawing to win **one of twenty \$25 Amazon gift cards** upon completion of the survey.

Confidentiality

This study is conducted by the National Eczema Association (NEA). Your participation in this survey is strictly confidential. NEA will not ask for information that could identify you, such as your name, birthday, or medical records. No personally identifiable information (information that, when taken together, could possibly identify you) will be collected and linked to the information you provide. If you provide personally identifiable information during the course of the study, NEA will handle this information confidentially and redact it from data records. We collect demographic (age, race/ethnicity, gender) and socio-economic status (location, education, income, insurance) information that will be used for general statistical analyses.

How we will use your data

In subsequent research reports, publications, or presentations, data will be presented in summary form so that no individual can be identified by demographic statistics or other identifying information. We plan to communicate a summary of our findings to you and the public on our website.

Participation in this study is voluntary

You are not required to participate. Should you decide to end your participation, simply exit your web browser which will close the survey.

Questions?

If you have any questions or concerns about this survey, please contact Isabelle Thibau at research@nationaleczema.org. Please print or [download a copy](#) of this informed consent to keep for your records.

- I have read the above information and I AGREE to continue (1)
- I have read the above information and I DO NOT AGREE to continue (0)
-

End of Block: Flare Informed Consent

Start of Block: Bot

Honeypot Have you been diagnosed with AD?

- Yes (1)
 - No (2)
-

ReCaptcha Before we begin, tell us about you:

Bot Just to be sure, write the answer to 2+2.

End of Block: Bot

Start of Block: Eligibility

flare_eligibility_01 Do you reside in the U.S. or its territories?

- Yes (1)
 - No (0)
-

flare_eligibility_02 Are you 18 years of age or older?

- Yes (1)
 - No (0)
-

flare_eligibility_03 Can you speak, read, and understand the English language?

- Yes (1)
 - No (0)
-

flare_eligibility_04 Have you been diagnosed with atopic dermatitis by a healthcare provider?

- Yes (1)
 - No (0)
-

flare_eligibility_05 Please indicate your **primary connection to atopic dermatitis**. Only adult patients are eligible to take the survey.

- I am an adult (18 years or older) with atopic dermatitis (1)
- I am a parent/primary caregiver for a child aged 0-17 who has atopic dermatitis (2)
- Other (neither adult with atopic dermatitis nor parent/caregiver of a minor with atopic dermatitis) (3)

End of Block: Eligibility

Start of Block: Demographics

flare_demo_01 What is your gender?

- Male (1)
- Female (2)
- Non-binary (3)
- Other (4)
- Prefer not to answer (5)

flare_demo_02 What is your Race?

- White (1)
- Black or African American (2)
- Asian or Asian American (3)
- Native American or Alaskan Native (4)
- Native Hawaiian or Pacific Islander (5)
- Multiracial (Please Specify) (6) _____
- Other (Please Specify) (7) _____
- I don't know/prefer not to Answer (8)

flare_demo_03 Are you of Hispanic/Latino origin?

- Yes (1)
 - No (0)
-

flare_demo_04 What is your age?

- Younger than 18 years old (1)
- 18 years old (18)
- 19 years old (19)
- 20 years old (20)
- 21 years old (21)
- 22 years old (22)
- 23 years old (23)
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- 87 years old (87)
- 88 years old (88)
- 89 years old (89)
- 90 years old or older (90)

flare_demo_05 At approximately what age were you diagnosed with atopic dermatitis?

- I have not been diagnosed with AD (101)
- Unsure, some time in childhood (102)
- Unsure, some time in adulthood (103)
- Under 1 year old (0)
- 1 year old (1)
- 2 years old (2)
- 3 years old (3)
- 4 years old (4)
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- 6 years old (6)
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- 88 years old (88)
- 89 years old (89)
- 90 years old or older (90)

End of Block: Demographics

Start of Block: Existing Flare Definition

flare_define_text Below are 3 definitions of atopic dermatitis flare being used by clinicians and clinical trial investigators. For each definition, please tell us if the definition resonates with you (meaning, do you think it reflects your experience and understanding of what an atopic dermatitis flare is?).

flare_define_01 Definition 1:

Acute, clinically significant worsening of signs and symptoms of atopic dermatitis requiring therapeutic

intervention or requiring a physician consultation or application of prescription medication.

Does this definition resonate with you?

Yes (1)

No (0)

flare_define_01a Please elaborate on why this does/does not resonate with you.

flare_define_02 Definition 2:

**A clinically meaningful worsening in EASI (eczema area and severity index, a scale of 0 to 72 points).
Defined as an EASI score increase of greater than or equal to 6.6 points from baseline.**

Does this definition resonate with you?

Yes (1)

No (0)

flare_define_02a Please elaborate on why this does/does not resonate with you.

flare_define_03 Definition 3:

**Your symptoms become worse, new symptoms develop, or a symptom is experienced at a new location.
Common signs and symptoms include itching, skin pain, redness, and dryness.**

Does this definition resonate with you?

Yes (1)

No (0)

flare_define_03a Please elaborate on why this does/does not resonate with you.

End of Block: Existing Flare Definition

Start of Block: Flare Statement Rankings

flare_agreement Below are 15 statements identified by other atopic dermatitis patients as important to include in the definition of an atopic dermatitis flare. You may agree or disagree that these statements are important to include in a definition of atopic dermatitis flare. The aim is to see if any of these statements will reach consensus from the larger atopic dermatitis community (meaning, will the atopic dermatitis community come to agreement on what is important for a definition of flare?). In order for a statement to reach consensus, 70% or more of respondents must choose “strongly agree” or “agree” with fewer than 15% choosing “disagree” or “strongly disagree.”

For each statement, please choose your level of agreement/disagreement for whether it is critically important

to include in a definition of atopic dermatitis flare.

Note these definitions:

Sign: objective evidence of disease, visible, something the clinician can observe without directly asking you, such as inflamed skin, scratch marks, oozing. Common signs include redness and dryness.

Symptom: subjective evidence of disease, something the clinician can only learn about by asking you, such as pain, itch, sleep quality, mental health. Common symptoms include itching, skin pain.

	strongly disagree (1)	disagree (2)	undecided (3)	agree (4)	strongly agree (5)
An atopic dermatitis flare is acute worsening of <u>symptoms</u> of AD. (18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is an "eruption" on some area of my body. (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is a change in physical health associated with AD that interrupts my day to day. (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is a worsening of itching associated with AD. (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when my <u>signs</u> go from being background noise to being in the foreground. (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when my <u>symptoms</u> go from being background noise to being in the foreground. (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when my <u>symptoms</u> take significantly more of my attention than normal. (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

An atopic dermatitis flare is when I start thinking about my <u>signs</u> constantly. (25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when I start thinking about my <u>symptoms</u> constantly. (26)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when I lose my sense of control over my disease management. (27)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when <u>symptoms</u> impact my quality of life. (28)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when <u>symptoms</u> affect my daily activities. (29)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is when my condition is unacceptable to me. (30)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An atopic dermatitis flare is a change in my condition that causes me to make decisions about daily life activities that are out of the norm. (31)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

An atopic dermatitis flare is a worsening of physical <u>symptoms</u> associated with AD. (32)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Display This Question:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = agree

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = strongly agree

flare_rankings The following are the statements you agreed are critical to include in a definition of atopic dermatitis flare. Please **drag and drop** the statements in order of importance according to you, with 1 being the most important.

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is acute worsening of <u>symptoms</u> of AD. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is acute worsening of <u>symptoms</u> of AD. [strongly agree]

_____ An atopic dermatitis flare is acute worsening of symptoms of AD. (1)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is an "eruption" on some area of my body. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is an "eruption" on some area of my body. [strongly agree]

_____ An atopic dermatitis flare is an "eruption" on some area of my body. (2)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a change in physical health associated with AD that interrupts my day to day. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a change in physical health associated with AD that interrupts my day to day. [strongly agree]

_____ An atopic dermatitis flare is a change in physical health associated with AD that interrupts my day to day.

(3)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a worsening of itching associated with AD. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a worsening of itching associated with AD. [strongly agree]

_____ An atopic dermatitis flare is a worsening of itching associated with AD. (4)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>signs</u> go from being background noise to being in the foreground. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>signs</u> go from being background noise to being in the foreground. [strongly agree]

_____ An atopic dermatitis flare is when my signs go from being background noise to being in the foreground. (5)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>symptoms</u> go from being background noise to being in the foreground. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>symptoms</u> go from being background noise to being in the foreground. [strongly agree]

_____ An atopic dermatitis flare is when my symptoms go from being background noise to being in the foreground. (6)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>symptoms</u> take significantly more of my attention than normal. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my <u>symptoms</u> take significantly more of my attention than normal. [strongly agree]

_____ An atopic dermatitis flare is when my symptoms take significantly more of my attention than normal. (7)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I start thinking about my <u>signs</u> constantly. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I start thinking about my <u>signs</u> constantly. [strongly agree]

_____ An atopic dermatitis flare is when I start thinking about my signs constantly. (8)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I start thinking about my <u>symptoms</u> constantly. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I start thinking about my <u>symptoms</u> constantly. [strongly agree]

_____ An atopic dermatitis flare is when I start thinking about my symptoms constantly. (9)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I lose my sense of control over my disease management. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when I lose my sense of control over my disease management. [strongly agree]

_____ An atopic dermatitis flare is when I lose my sense of control over my disease management. (10)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when <u>symptoms</u> impact my quality of life. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when <u>symptoms</u> impact my quality of life. [strongly agree]

_____ An atopic dermatitis flare is when symptoms impact my quality of life. (11)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when <u>symptoms</u> affect my daily activities. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when <u>symptoms</u> affect my daily activities. [strongly agree]

_____ An atopic dermatitis flare is when symptoms affect my daily activities. (12)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my condition is unacceptable to me. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is when my condition is unacceptable to me. [strongly agree]

_____ An atopic dermatitis flare is when my condition is unacceptable to me. (13)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a change in my condition that causes me to make decisions about daily life activities that are out of the norm. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a change in my condition that causes me to make decisions about daily life activities that are out of the norm. [strongly agree]

_____ An atopic dermatitis flare is a change in my condition that causes me to make decisions about daily life activities that are out of the norm. (14)

Display This Choice:

If Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a worsening of physical <u>symptoms</u> associated with AD. [agree]

Or Below are 15 statements identified by other atopic dermatitis patients as important to include in... = An atopic dermatitis flare is a worsening of physical <u>symptoms</u> associated with AD. [strongly agree]

_____ An atopic dermatitis flare is a worsening of physical symptoms associated with AD. (15)

flare_statement_miss Is there any concept you feel is critically important to a definition of atopic dermatitis flare that was not covered in the list of 15?

End of Block: Flare Statement Rankings

Start of Block: Disease History

flare_history_01 Do you and your primary eczema healthcare provider agree on what an atopic dermatitis flare is?

- Yes (1)
 - No (0)
 - Unsure (2)
-

flare_history_02 Has your definition of an atopic dermatitis flare changed over time?

- Yes (1)
 - No (0)
-

Display This Question:

If Has your definition of an atopic dermatitis flare changed over time? = Yes

flare_history_03 Why has your definition of flare changed over time?

- My disease has changed over time (1)
 - I have grown to understand my atopic dermatitis better (2)
 - I have learned more about the science behind atopic dermatitis (3)
 - Talking with other atopic dermatitis patients about their experiences has changed my views of what a flare is (4)
 - Talking with healthcare providers about their understanding of flares has changed my views of what a flare is (5)
 - Other (please specify) (6) _____
-

flare_history_04 Would you say you are “in an atopic dermatitis flare” or “flaring” right now?

- Yes (1)
 - No (0)
-

Display This Question:

If Would you say you are “in an atopic dermatitis flare” or “flaring” right now? = No
flare_history_05 When did you last experience an atopic dermatitis flare?

- Within the last week (1)
- Within the last 6 months (2)
- Within the last 1 year (3)
- 1 year to within 3 years ago (4)
- 3 years to within 5 years ago (5)
- More than 5 years ago (6)

Display This Question:

If When did you last experience an atopic dermatitis flare? = Within the last week
Or When did you last experience an atopic dermatitis flare? = Within the last 6 months
Or When did you last experience an atopic dermatitis flare? = Within the last 1 year
Or Would you say you are “in an atopic dermatitis flare” or “flaring” right now? = Yes
flare_history_06 How many flares have you had in the **past 12 months**?

flare_history_07 How would you want to or expect to use a patient-centered definition of flare? Select all that apply.

- For myself to monitor changes in my condition (1)
- For myself as a way to note down adverse events with therapy (6)
- To explain my condition to family or friends (2)
- With a doctor to explain what my flares are/how they behave (3)
- With a doctor to monitor changes in my condition (4)
- With a doctor to talk about health outcomes I’m most interested in (5)
- Don’t know/unsure (7)
- I don’t think a definition would be useful for me (8)
- Other (please specify) (9) _____

End of Block: Disease History

Start of Block: RECAP

flare_recap_text The next set of questions ask about how your atopic dermatitis (AD) has been OVER THE LAST WEEK.

flare_recap_01 Over the last week, **how has your AD been?**

- Very good (1)
 - Good (2)
 - Ok (3)
 - Bad (4)
 - Very bad (5)
-

flare_recap_02 Over the last week, on how many days has your **skin been itchy** because of your AD?

- No days (0)
 - 1-2 days (1)
 - 3-4 days (2)
 - 5-6 days (3)
 - Every day (4)
-

flare_recap_03 Over the last week, on how many days has your **skin been intensely itchy** because of your AD?

- No days (0)
 - 1-2 days (1)
 - 3-4 days (2)
 - 5-6 days (3)
 - Every day (4)
-

flare_recap_04 Over the last week, how much has your **sleep been disturbed** because of your AD?

- Not at all (0)
 - A little bit (1)
 - Quite a bit (2)
 - A huge amount (3)
 - Completely (4)
-

flare_recap_05 Over the last week, how much has your AD been **getting in the way of day-to-day activities**?

- Not at all (0)
 - A little bit (1)
 - Quite a bit (2)
 - A huge amount (3)
 - Completely (4)
-

flare_recap_06 Over the last week, on how many days has your AD **affected how you have been feeling**?

- No days (1)
 - 1-2 days (2)
 - 3-4 days (3)
 - 5-6 days (4)
 - Every day (5)
-

flare_recap_07 Over the last week, **how acceptable** has your AD been to you?

- Completely acceptable (1)
- Mostly acceptable (2)
- Quite acceptable (3)
- Not very acceptable (4)
- Not at all acceptable (5)

End of Block: RECAP

Start of Block: Severity

flare_severity_01 How would you rate your overall atopic dermatitis severity **over the past month**?

- Clear (1)
- Mild (2)
- Moderate (3)
- Severe (4)

flare_severity_02 Is the severity rating you chose in the previous question your **typical severity**?

- Yes (1)
- No (0)

Display This Question:

If Is the severity rating you chose in the previous question your typical severity? = No

flare_severity_03 What is your typical severity?

- Clear (1)
- Mild (2)
- Moderate (3)
- Severe (4)

flare_severity_04 When your atopic dermatitis was **at its worst**, what was the severity?

- Clear (1)
 - Mild (2)
 - Moderate (3)
 - Severe (4)
-

flare_severity_05 How would you describe your general knowledge of atopic dermatitis? (meaning: your understanding of what the condition is, what the potential causes are, how it affects your health, etc.)

- Excellent (1)
 - Good (2)
 - Average (3)
 - Poor (4)
 - Terrible (5)
-

End of Block: Severity

Start of Block: Economic Factors

Q62 Finally, the following are some background questions. As mentioned earlier, all your answers will be kept strictly confidential and will be only used for general statistical analyses.

flare_economics_01 In which U.S. state or territory is your household located?

- Alabama (1)
- Alaska (2)
- Arizona (3)
- Arkansas (4)
- California (5)
- Colorado (6)
- Connecticut (7)
- Delaware (8)
- Florida (9)
- Georgia (10)
- Hawaii (11)
- Idaho (12)
- Illinois (13)
- Indiana (14)
- Iowa (15)
- Kansas (16)
- Kentucky (17)
- Louisiana (18)
- Maine (19)
- Maryland (20)
- Massachusetts (21)
- Michigan (22)
- Minnesota (23)
- Mississippi (24)

- Missouri (25)
- Montana (26)
- Nebraska (27)
- Nevada (28)
- New Hampshire (29)
- New Jersey (30)
- New Mexico (31)
- New York (32)
- North Carolina (33)
- North Dakota (34)
- Ohio (35)
- Oklahoma (36)
- Oregon (37)
- Pennsylvania (38)
- Rhode Island (39)
- South Carolina (40)
- South Dakota (41)
- Tennessee (42)
- Texas (43)
- Utah (44)
- Vermont (45)
- Virginia (46)
- Washington (47)
- West Virginia (48)
- Wisconsin (49)

- Wyoming (50)
 - District of Columbia (D.C.) (51)
 - Puerto Rico (52)
 - U.S. Virgin Islands (53)
 - Pacific Territories (including Guam, American Samoa, etc.) (54)
-

flare_economics_02 What is your ZIP code?

flare_economics_03 What is your highest level of education?

- Less than high school (1)
 - Completed some high school (2)
 - High school graduate (3)
 - Technical post-secondary (4)
 - Completed some college (5)
 - Four-year college degree (6)
 - Master's Degree/Doctorate (7)
-

flare_economics_04 Which of the following categories best describes your 2023 household income before taxes?

- \$24,999 or less (1)
 - \$25,000 to \$49,999 (2)
 - \$50,000 to \$74,999 (3)
 - \$75,000 to \$99,999 (4)
 - \$100,000 to \$124,999 (5)
 - \$125,000 to \$149,999 (6)
 - \$150,000 or more (7)
-

flare_economics_text Please click the “next” arrow to end the survey and follow instructions on the next page to enter to win one of twenty \$25 Amazon e-gift cards.

End of Block: Economic Factors

eTable 1. List of 98 Statements, Where All Statements Begin With “An Atopic Dermatitis Flare Is...”

1	Acute worsening of signs of AD.
2	Acute worsening of symptoms of AD.
3	An increase in intensity of signs that comes on rapidly.
4	An increase in intensity of symptoms that comes on rapidly.
5	An increase in intensity of signs that are short in duration.
6	An increase in intensity of symptoms that are short in duration.
7	An increase in intensity of signs that are of recent onset.
8	An increase in intensity of symptoms that are of recent onset.
9	Clinically significant worsening of signs of AD. Clinically significant means the change is apparent enough for the healthcare provider to visually see.
10	Clinically significant worsening of symptoms of AD. Clinically significant means the change is apparent enough for the healthcare provider to visually see.
11	Worsening of signs of AD that requires therapeutic intervention.
12	Worsening of signs of AD that requires a physician consultation.
13	Worsening of signs of AD that requires use of a prescription medication.
14	Worsening of symptoms of AD that requires therapeutic intervention.
15	Worsening of symptoms of AD that requires a physician consultation.
16	Worsening of symptoms of AD that requires use of a prescription medication.
17	At minimum, a 1-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on area of involvement & intensity of lesions that is assessed by the clinician.
18	At minimum, a 2-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on area of involvement & intensity of lesions that is assessed by the clinician.
19	At minimum, a 3-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on area of involvement & intensity of lesions that is assessed by the clinician.
20	At minimum, a 1-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on my perception of intensity of AD signs.
21	At minimum, a 2-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on my perception of intensity of AD signs.
22	At minimum, a 3-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on my perception of intensity of AD signs.
23	At minimum, a 1-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on intensity of AD symptoms.
24	At minimum, a 2-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on intensity of AD symptoms.
25	At minimum, a 3-point increase from my baseline (aka my “normal”) on a severity scale from 0 (clear) to 10 (highest severity) using a scale based on intensity of AD symptoms.
26	A negative change in my overall health.

27	A negative change in my skin's condition.
28	When my baseline (aka my "normal" state of AD) worsens to any degree.
29	A change in physical health associated with AD that interrupts my day-to-day more than normal.
30	A change in mental health associated with AD that interrupts my day-to-day more than normal.
31	An "eruption" in some area of my body define.
32	A worsening of my baseline that must last at least 1 hour.
33	A worsening of my baseline that must last at least a day.
34	A worsening of my baseline that is distinct from my normal disease fluctuations (ups and downs).
35	A worsening of my baseline that can be part of my normal disease fluctuations (ups and downs).
36	Started when I feel something is "off."
37	No longer a flare when my skin is clear.
38	No longer a flare if my skin condition goes back to my baseline.
39	No longer a flare if my overall health goes back to my baseline.
40	No longer a flare even if my skin is not back to the way it was before the flare.
41	No longer a flare if my new AD condition becomes my "new normal".
42	A worsening that always resolves.
43	A worsening that doesn't always resolve.
44	A worsening of itching associated with AD.
45	A worsening of skin tingling associated with AD.
46	A worsening of skin heat associated with AD.
47	A worsening of physical symptoms associated with AD.
48	A feeling of itch.
49	A change in the skin texture. (how skin feels)
50	A change in the skin integrity. (how skin behaves)
51	A visual change in baseline (aka my normal) skin appearance.
52	A noticeable change in skin. (any difference in skin)
53	A worsening of skin on a visible part of my body.
54	A worsening of skin on a non-visible part of my body (on a part of the body that can be hidden). For example, a part of the body that can be hidden by clothes or that I can't see like my back).
55	No longer a flare when there are no active skin lesions.
56	Increased scratching behavior (even if there is no itch).
57	Potentially caused by compulsive scratching if it leads to a change in skin.
58	Started when I experience heat/warmth of the skin.
59	Started when I experience itch.
60	A change in my AD that can induce temporary heightened feelings of isolation.
61	A change in my AD that can induce temporary heightened feelings of anxiety.
62	A change in my AD that can induce temporary heightened feelings of depression.
63	An increase in negative emotions associated with AD. (common negative emotions are sadness, fear, distraction)
64	An increase in poor mental health associated with AD. (common poor mental symptoms are anxiety, suicidal thoughts, feeling low energy).
65	A worsening of signs associated with AD that are more distracting than normal.

66	A worsening of symptoms associated with AD that are more distracting than normal.
67	A worsening of signs associated with AD that are more concerning to me than normal.
68	A worsening of symptoms associated with AD that are more concerning to me than normal.
69	A worsening of signs that cause heightened concern with body image.
70	A worsening of symptoms that cause heightened concern with body image.
71	When my signs go from being background noise to being in the foreground.
72	When my symptoms go from being background noise to being in the foreground.
73	When my symptoms take significantly more of my attention than “normal.”
74	No longer a flare when my signs go from being in the foreground to being background noise.
75	No longer a flare when my symptoms go from being in the foreground to being background noise.
76	When I start thinking about my signs constantly (for example, an inflamed patch of skin that I can no longer ignore)
77	When I start thinking about my symptoms constantly (for example, an itch that I can no longer ignore)
78	No longer a flare when I can get a good night’s sleep.
79	When I lose my sense of control over my disease management.
80	No longer a flare when I can resume “cruise control” over my disease management (when my disease management takes little effort to do/goes back to being routine).
81	No longer a flare when I can focus on things other than what is happening to my body.
82	When signs impact my quality of life.
83	When symptoms impact my quality of life.
84	When signs affect my daily activities.
85	When symptoms affect my daily activities.
86	A disease state where I identify as having a disability.
87	When I get more bothered by my signs.
88	When I get more bothered by my symptoms.
89	When I have trouble falling asleep because of my signs.
90	When I have trouble falling asleep because of my symptoms.
91	When I have trouble staying asleep because of my signs.
92	When I have trouble staying asleep because of my symptoms.
93	When my condition is unacceptable to me.
94	A change in my condition that causes me to make decisions about daily life activities that are out of the norm.
95	Change in signs/symptoms where I am unsure of the cause.
96	Disease activity where I am consumed with trying to find the cause.
97	A worsening that requires physician intervention for a newly diagnosed patient.
98	A worsening that could potentially be self-treated for an experienced patient (dependent on experience and resources at hand).

eTable 2. Demographic Characteristics of Participants in the Modified eDelphi Exercise

Total participants	28
Age (years)	
18-24	9
25-34	9
35-44	7
45-54	2
55-64	1
65+	0
Gender	
Male	8
Female	20
Race	
White	8
Asian or Asian American	10
Black or African American	5
Native Hawaiian or Pacific Islander	1
Native American or Alaskan Native	1
Multiracial	1
Some other race or ethnicity	1
I don't know/prefer not to answer	1
Hispanic/Latino ethnicity	
Yes	4
No	24
Age at diagnosis	
0-10	23
11-18	1
19-44	2

45 or older	1
Not sure	1
Eczema Severity	
Clear	2
Mild	13
Moderate	10
Severe	3
Number of flares in past 12 months	
1-5	11
6-10	6
11 or more	9
Not sure	2

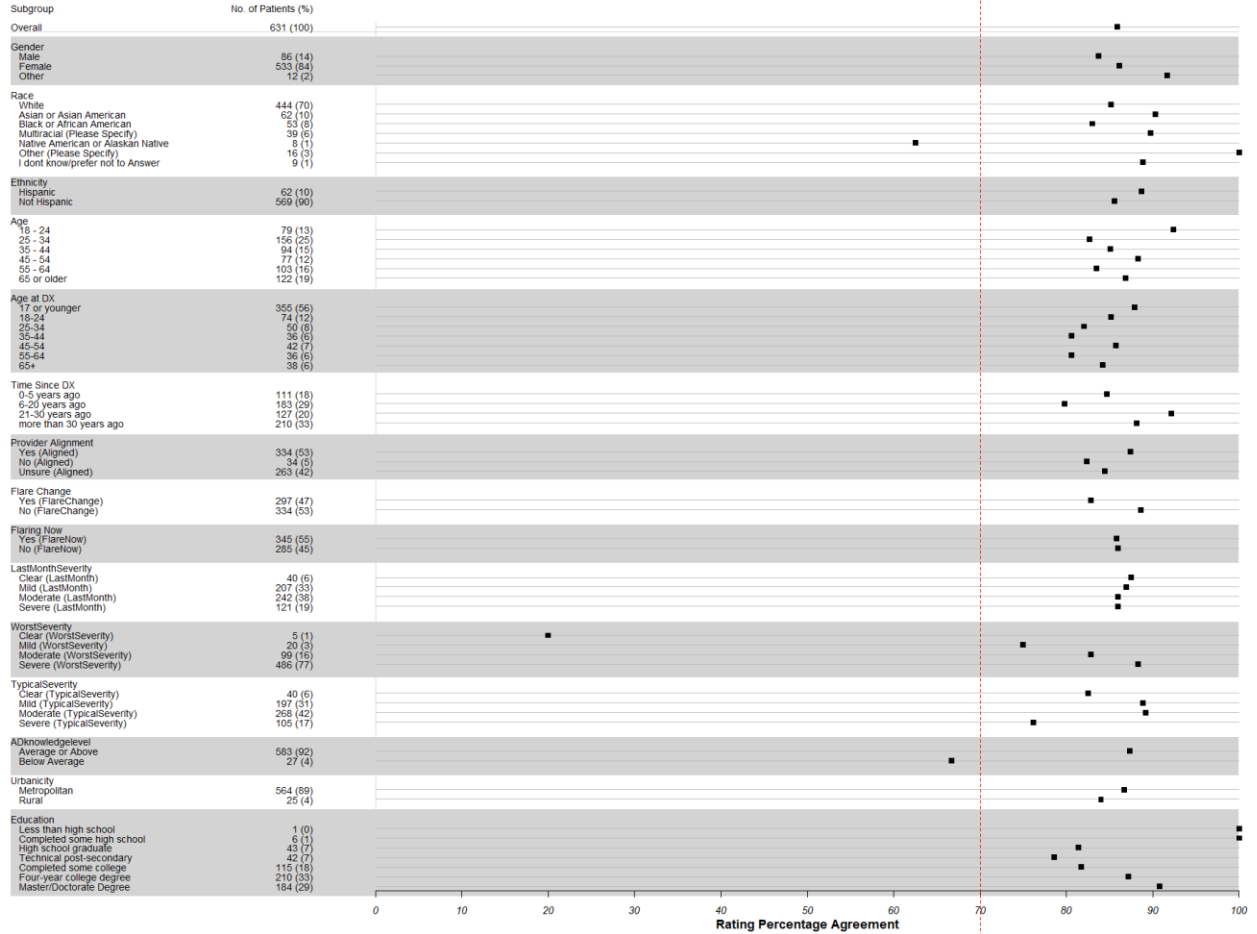
eTable 3. Fifteen Statements Identified by the Modified eDelphi Consensus Activities as Critically Important to Include in a Definition of Flare: Mean Rating and Ranking From the Focus Group

Statement, ordered by Focus Group mean ranking. All statements begin with “An atopic dermatitis flare is…”	Focus Group mean rating score (n=28, mean ± SD) ^a	Focus Group mean ranking score (n=26, mean ± SD) ^b
1. when my symptoms go from being background noise to being in the foreground.	7.48 (1.50)	4.5 (2.93)
2. when my symptoms take significantly more of my attention than normal.	7.54 (1.55)	4.7 (2.30)
3. a worsening of physical symptoms associated with AD.	7.18 (1.96)	6.4 (4.02)
4. when my signs go from being background noise to being in the foreground.	7.04 (1.88)	6.5 (3.30)
5. acute worsening of symptoms of AD.	7.54 (1.67)	6.9 (3.40)
6. a change in my condition that causes me to make decisions about daily life activities that are out of the norm.	7.68 (1.83)	7.7 (3.99)
7. when I lose my sense of control over my disease management.	7.57 (1.67)	7.9 (3.86)
8. when symptoms affect my daily activities.	7.61 (1.93)	8.2 (3.00)
9. a change in physical health associated with AD that interrupts my day to day.	7.25 (1.43)	8.2 (3.41)
10. when symptoms impact my quality of life.	7.32 (1.96)	8.5 (3.39)
11. when I start thinking about my symptoms constantly.	7.43 (1.71)	8.5 (3.25)
12. a worsening of itching associated with AD.	7.14 (1.78)	9.7 (3.83)
13. an ‘eruption’ on some area of my body.	6.88 (1.54)	9.9 (3.63)
14. when my condition is unacceptable to me.	7.25 (1.73)	11.0 (3.51)
15. when I start thinking about my signs constantly.	7.00 (2.13)	11.4 (2.57)

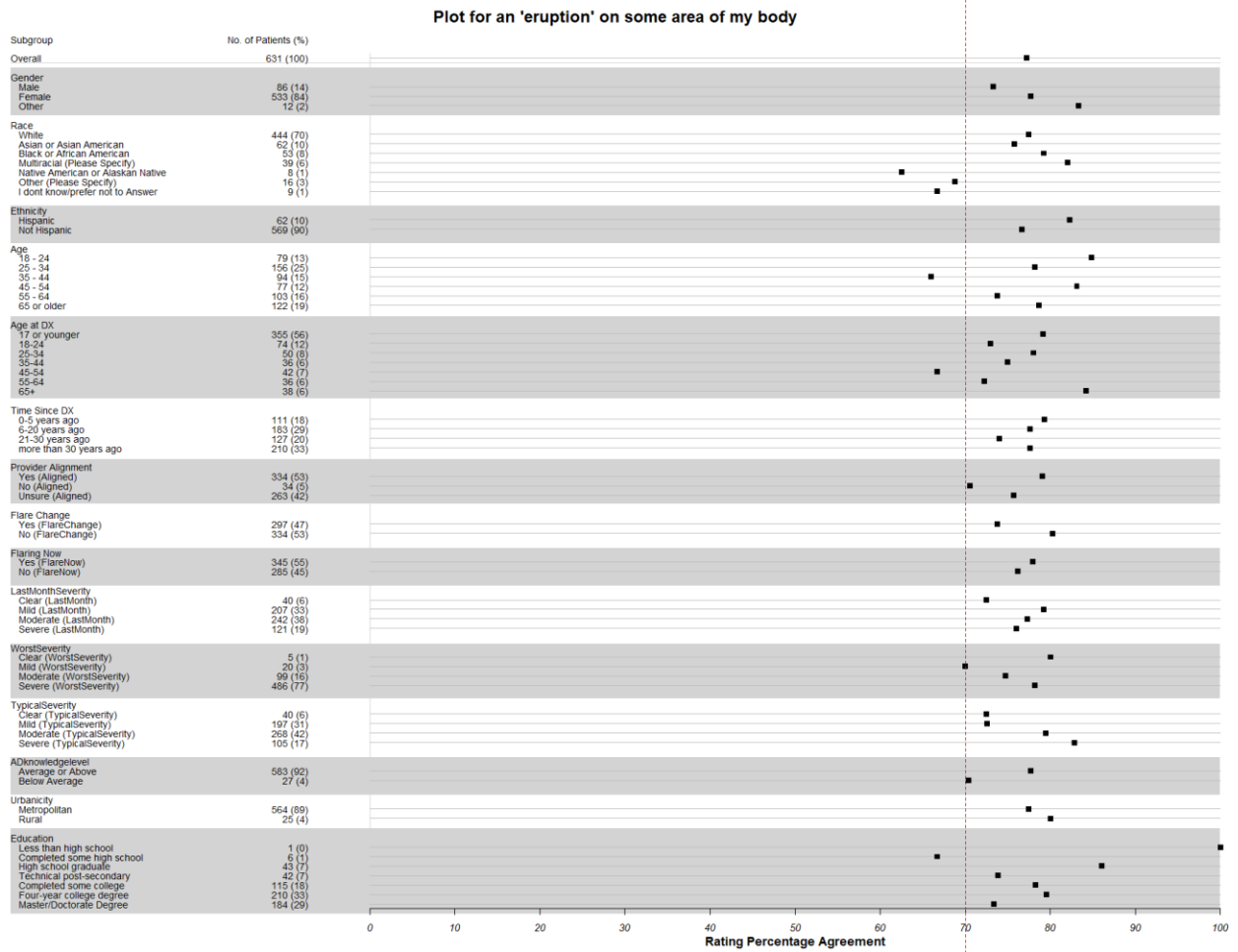
^a Based on 1-3 (not important), 4-6 (important but not critical), 7-9 (critical). ^b Lower scores signify higher ranking position (more important than other statements).

eFigure 1. Acute Worsening of Symptoms of AD

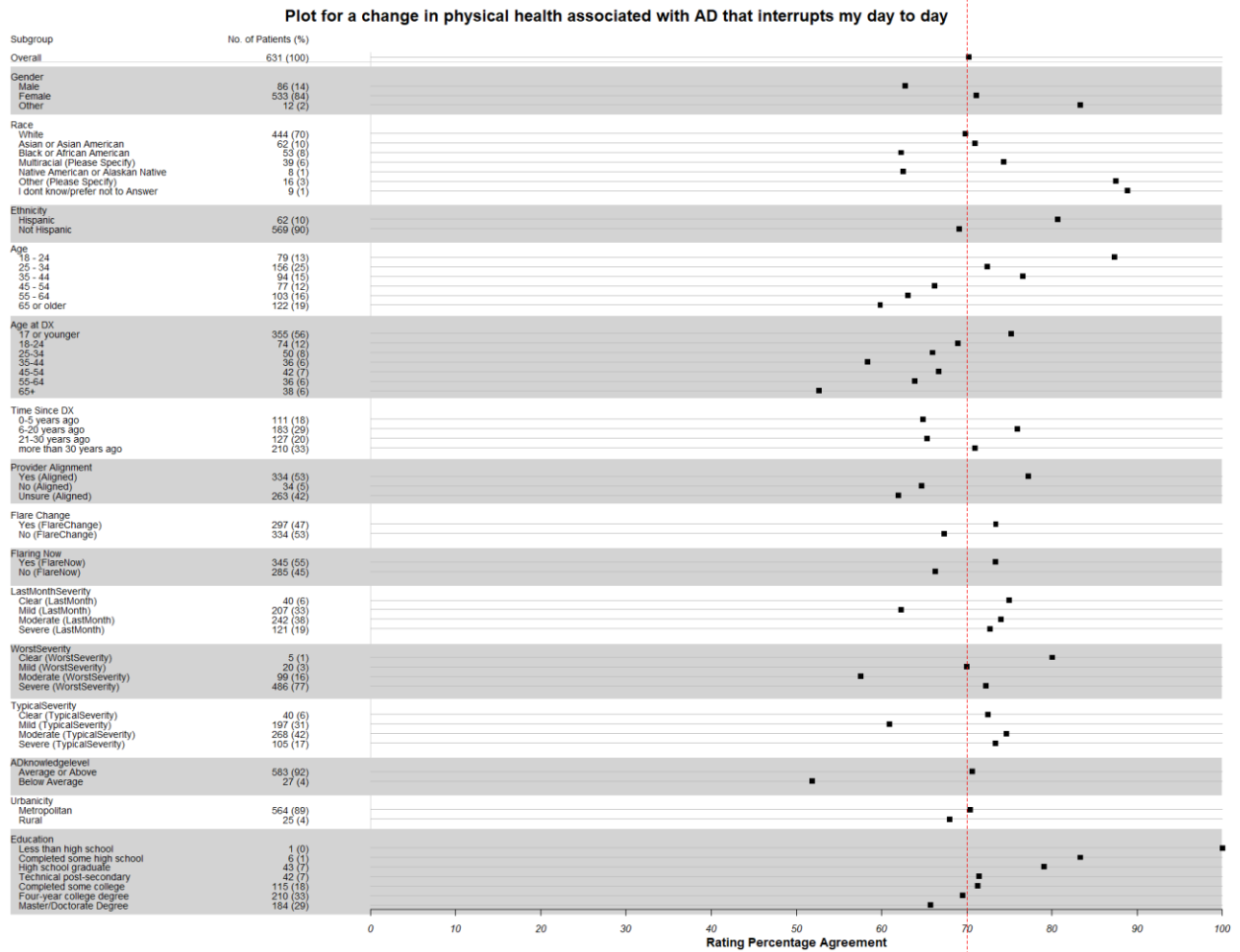
Plot for acute worsening of symptoms of AD



eFigure 2. An Eruption on Some Area of My Body

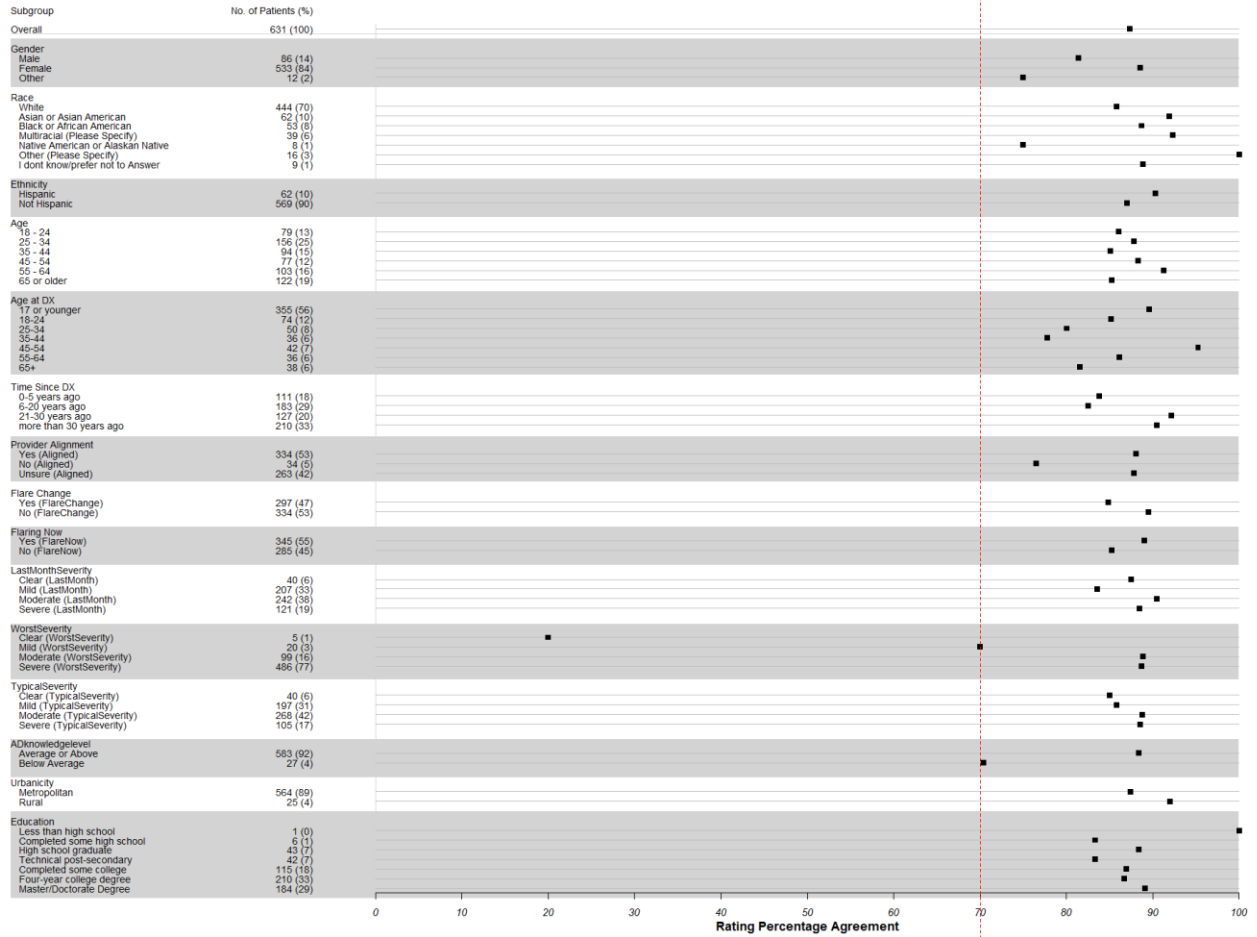


eFigure 3. A Change in Physical Health Associated With AD That Interrupts My Day to Day

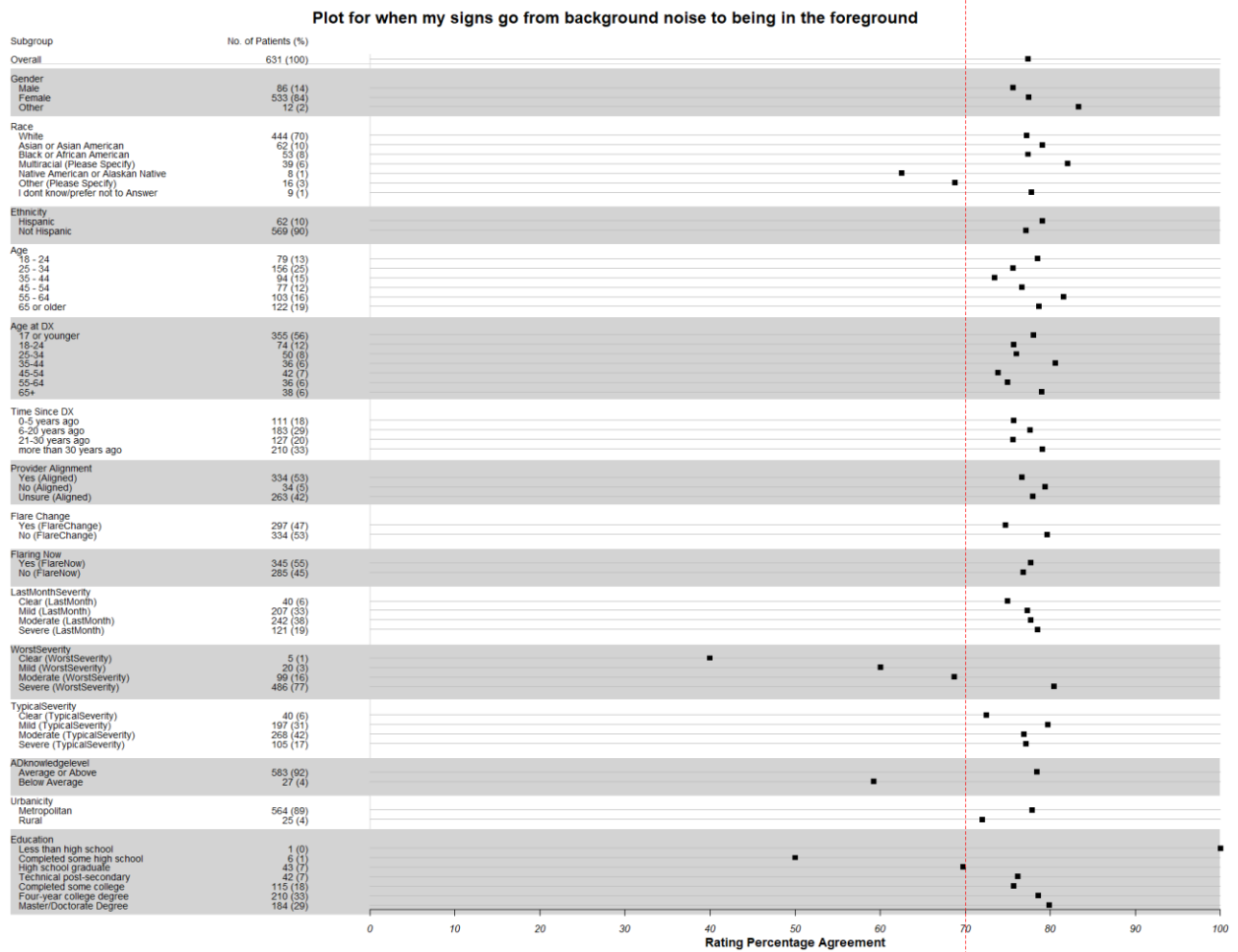


eFigure 4. A Worsening of Itching Associated With AD

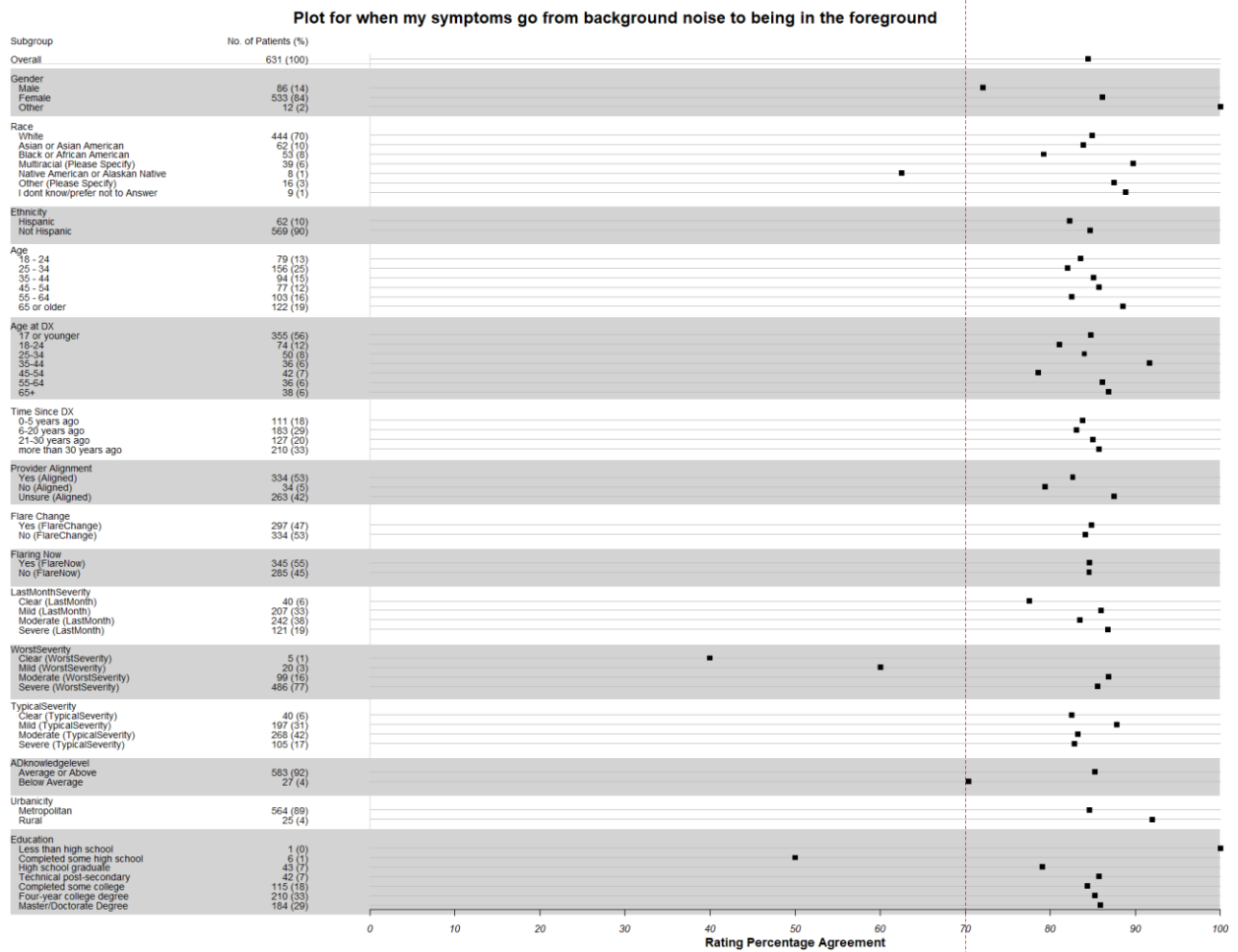
Plot for a worsening of itching associated with AD



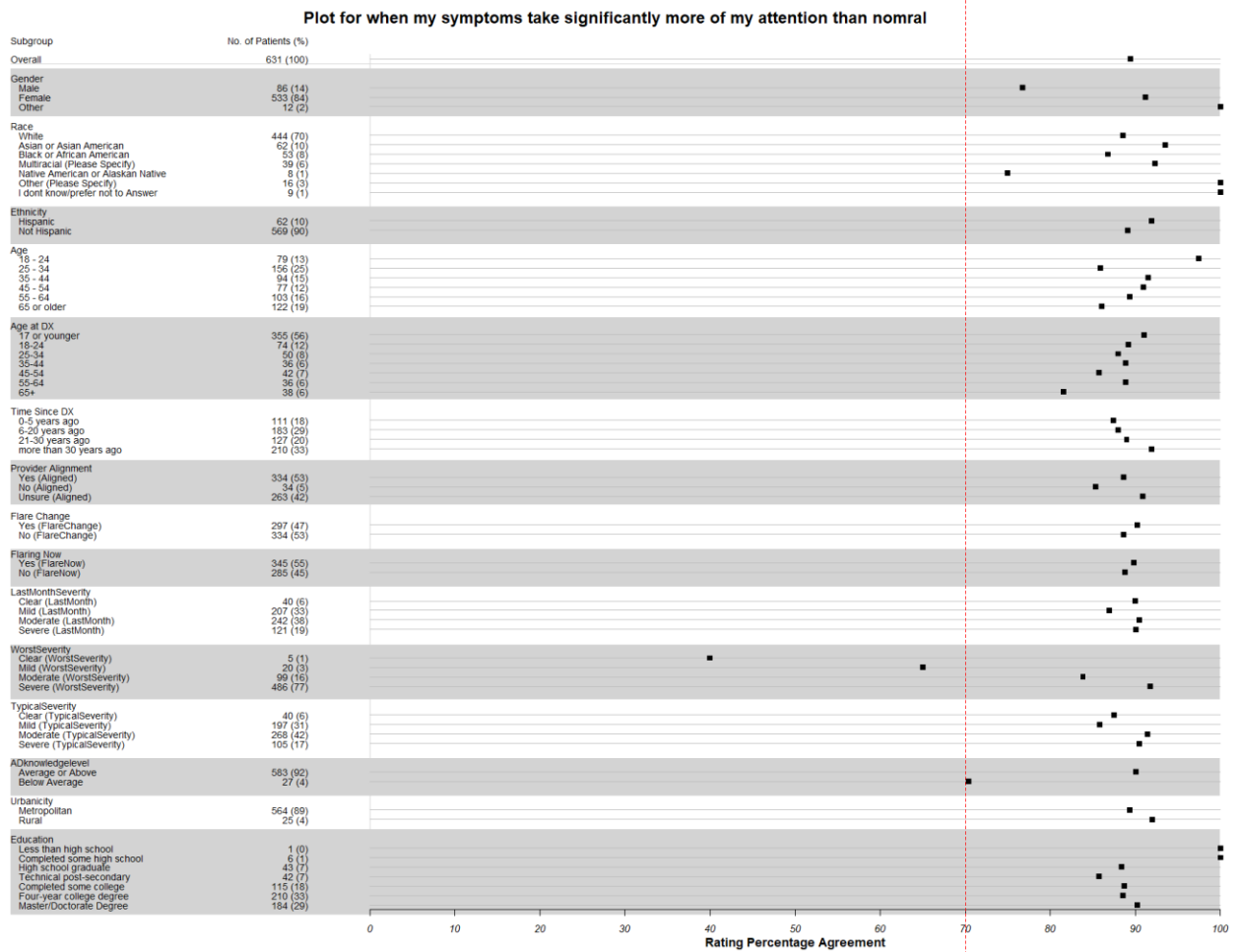
eFigure 5. When My Signs Go From Being Background Noise to Being in the Foreground



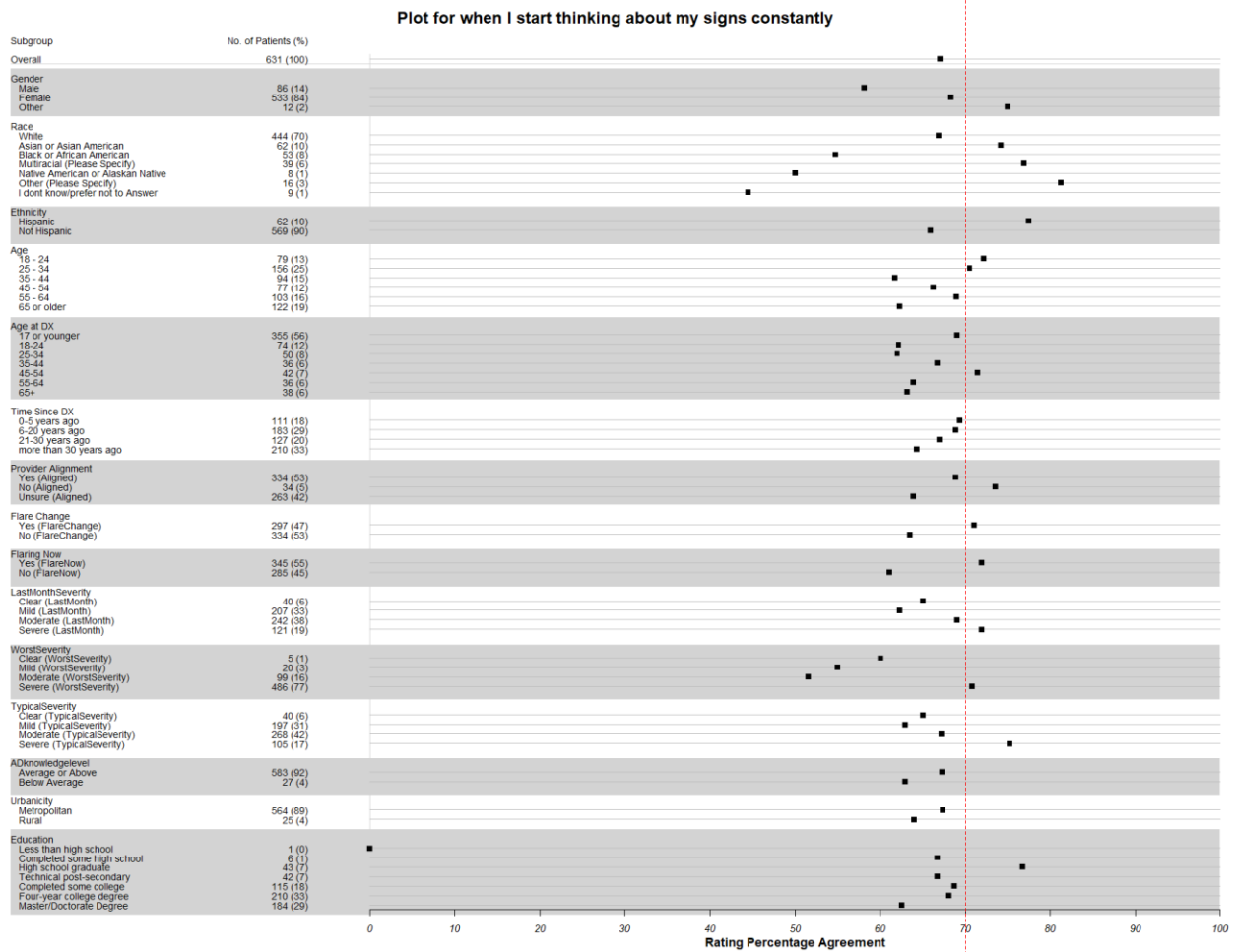
eFigure 6. When My Symptoms Go From Being Background Noise to Being in the Foreground



eFigure 7. When My Symptoms Take Significantly More of My Attention Than Normal

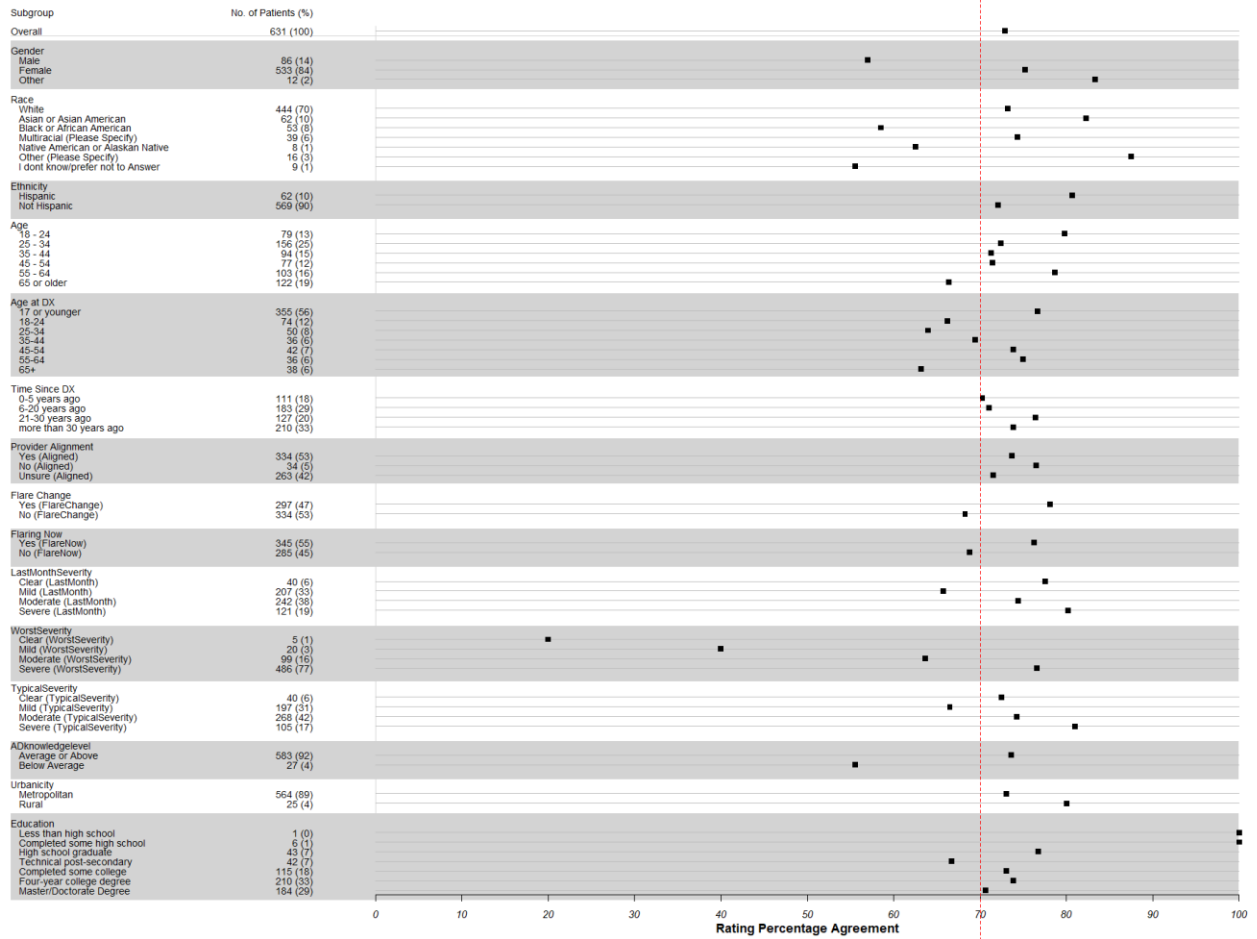


eFigure 8. (Did Not Meet Consensus) When I start Thinking About My Signs Constantly

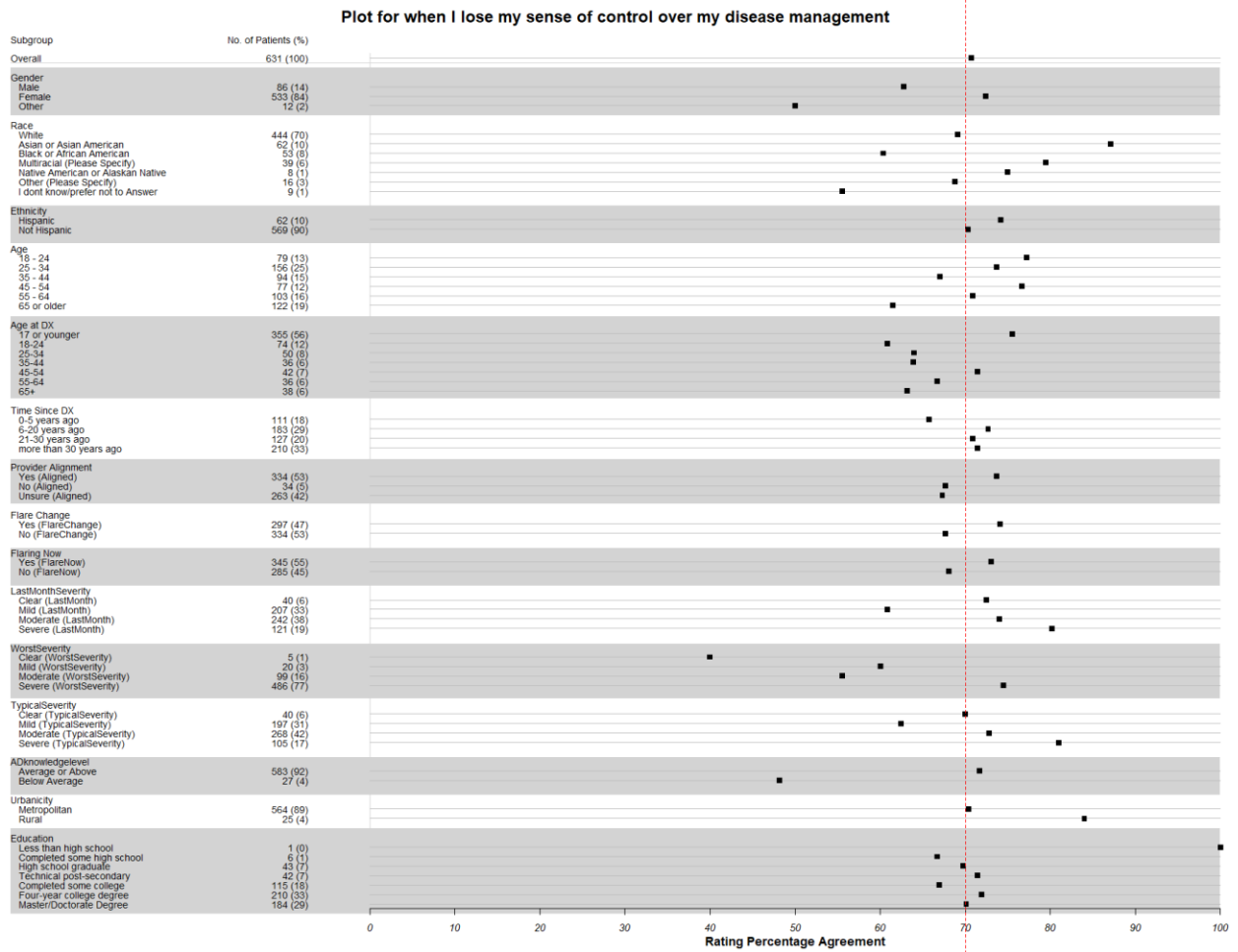


eFigure 9. When I Start Thinking About My Symptoms Constantly

Plot for when I start thinking about my symptoms constantly

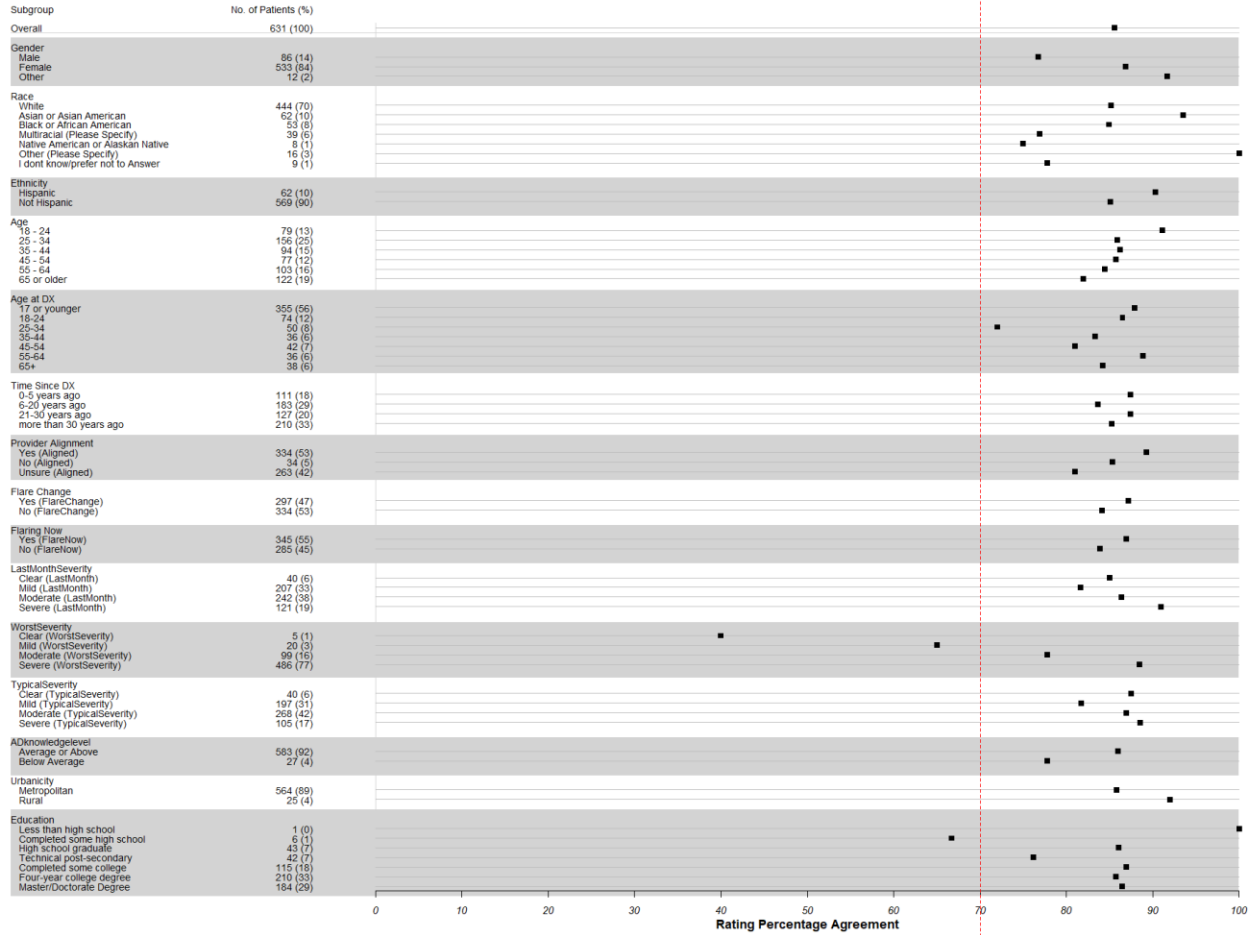


eFigure 10. When I lose My Sense of Control Over My Disease Management



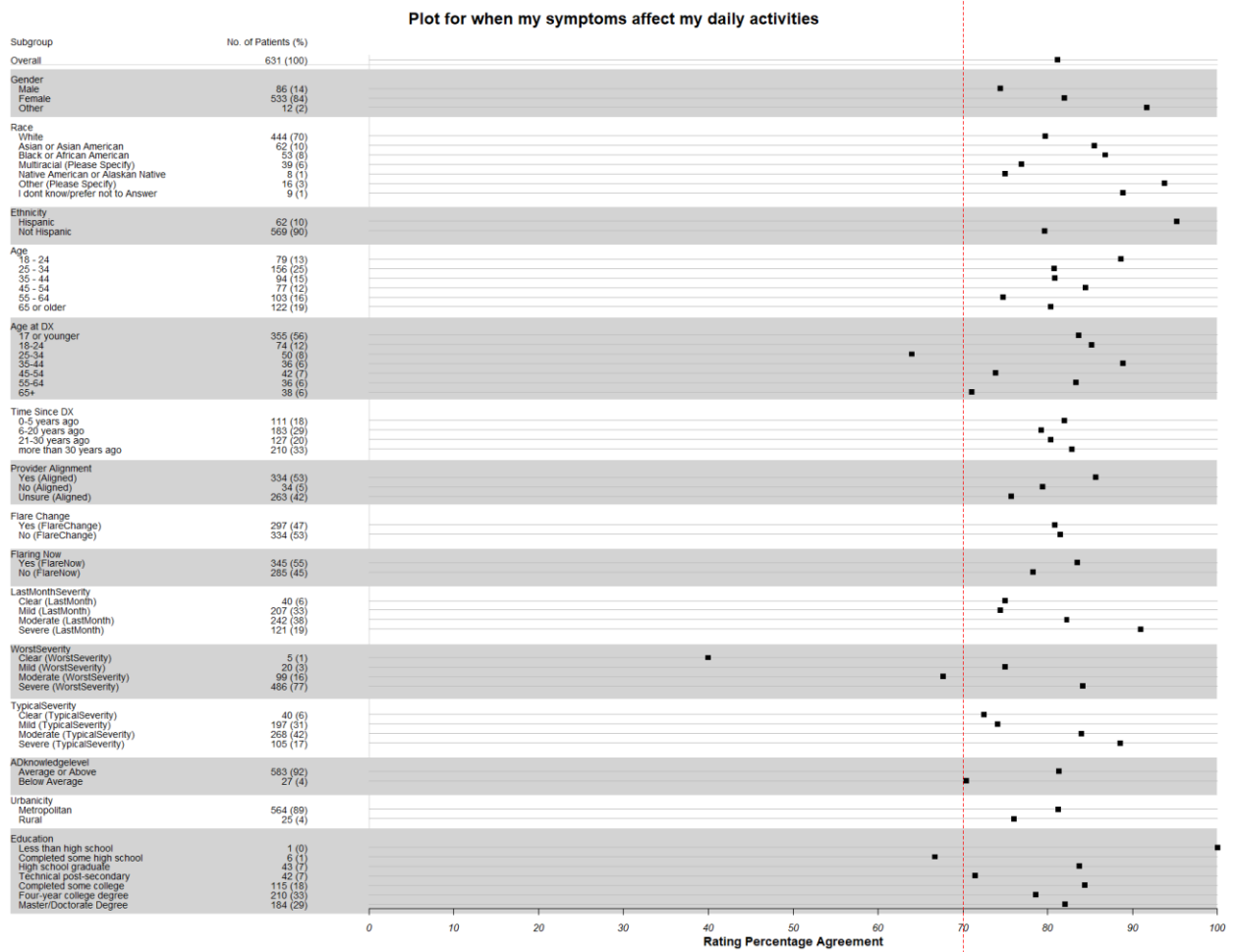
eFigure 11. When Symptoms Affect My Quality of Life

Plot for when my symptoms impact my quality of life

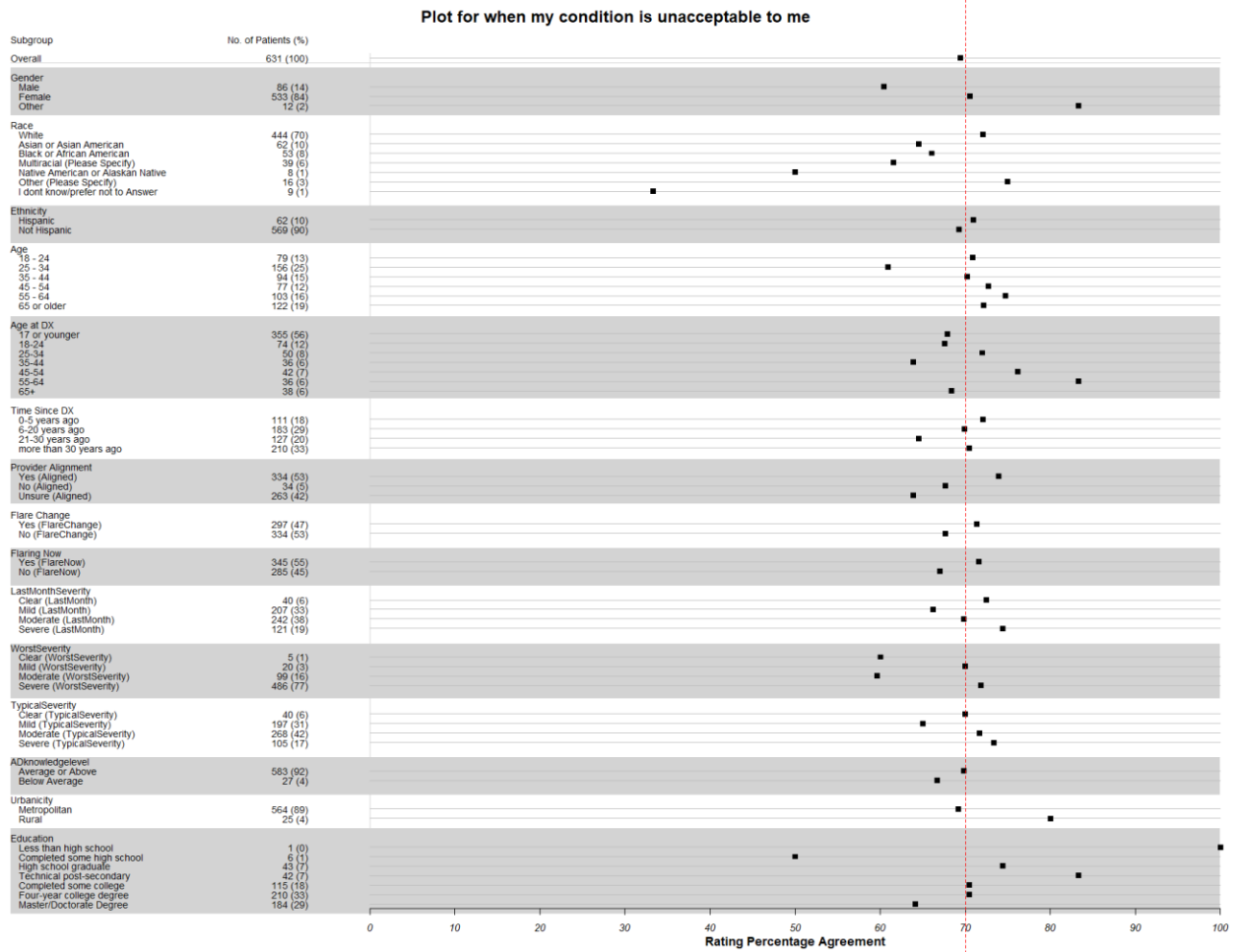


eFigure 12. When Symptoms Affect my Daily Activities

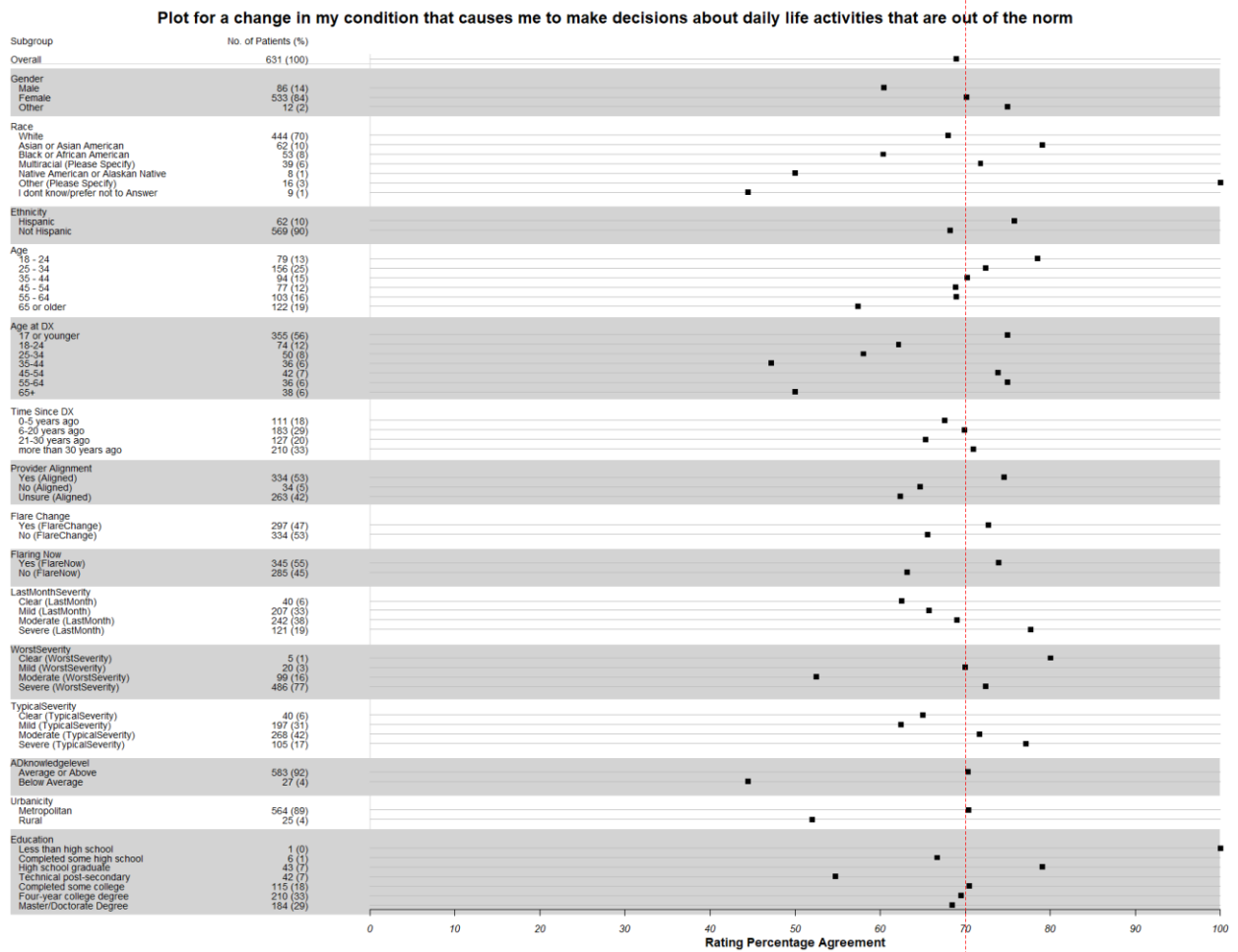
Plot for when my symptoms affect my daily activities



eFigure 13. (Did Not Meet Consensus) When my Condition Is Unacceptable to Me



eFigure 14. (Did Not Meet Consensus) a Change in My Condition That Causes Me to Make Decisions About Daily Life Activities That Are Out of the Norm



eFigure 15. A Worsening of Physical Symptoms Associated With AD

