



## Factors related to eczema clinical trial participation among adult patients and caregivers

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### ABSTRACT

**Background:** Eczema can be difficult to treat due to its chronic, heterogeneous nature. Effective long-term treatments for adults and children are needed. Little is known about what considerations influence eczema patient and caregiver decision-making regarding clinical trial participation (CTP). This study identifies factors that adult patients and caregivers consider important for CTP and determines if differences exist between these groups.

**Methods:** A 46-question survey was administered May 1–June 6, 2020, to adults and caregivers of children with eczema. Respondents were asked to rate the importance of a series of factors when considering CTP; adults and caregivers were compared.

**Results:** Out of 31 total factors queried, eleven factors differed significantly in importance ratings between adults (n = 470) and caregivers (n = 134). The route of therapy (p = 0.030), side effects (p = 0.014), washout period (p = 0.028), receiving a placebo (p = 0.027), rescue therapy option (p = 0.033), access to test drug after trial (p = 0.027), sticking with the clinical trial regimen (p = 0.025), fit with work/school (p = 0.005), impact on overall health (p = 0.008), and satisfaction with current treatment (p = 0.033) were all more likely to be rated as important by caregivers than by adult patients. Only altruism was rated more highly by adult patients than caregivers (p = 0.027).

**Conclusions:** Caregivers are more likely than adults to attribute high importance to factors that may affect their child's eczema or well-being when considering CTP. Patient-centered CTP education materials and decision aids may support patients and caregivers in CTP decision-making.

### 1. Introduction

Eczema is an inflammatory skin disease that can occur throughout the lifespan [1]. It is heterogenous and individualistic in nature, with waxing and waning signs and symptoms, making it difficult to treat with a singular, universal approach. Atopic dermatitis (AD), the most common form of eczema, affects 13% of children and 7% of adults in the United States [2–4]. Patients with eczema experience a multidimensional burden of disease that negatively affects their quality of life.

There are several topical and immunosuppressive systemic therapies traditionally prescribed to treat AD. However newer more targeted treatment options are currently being investigated, with several recently FDA-approved. Over the past 15 years there has been an unprecedented increase in eczema clinical trials (CTs)<sup>1</sup>; in 2021, [clinicaltrials.gov](http://clinicaltrials.gov)

reported over 90 active eczema CTs, a 3-fold increase in the number of eczema CTs since 2008 ([ClinicalTrials.gov](http://ClinicalTrials.gov)). Yet despite this progress in the expansion of novel therapeutic options for eczema patients and the number of CTs, eczema clinical trial participation (CTP)<sup>2</sup> has remained low [5,6].

A long-standing challenge in the conduct of CTs worldwide is the small number of people willing to participate [7,8]. While little is known about motivators and barriers for eczema CTs specifically, a recent study indicated that there are many factors that can hinder CTP consideration for adult patients including a lack of knowledge about CTs and CT terminology, decreased confidence in where to find information on CTs, the possibility of receiving a placebo, time constraints and general concerns about the consent process [7,9]. Additionally, drivers for eczema CTP among adult patients may include the benefit to other eczema patients

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<sup>1</sup> CT: Clinical trial.

<sup>2</sup> CTP: Clinical trial participation.

(altruism), or dissatisfaction with current therapy [10,11]. Previous research has also demonstrated further determinants contributing to parental willingness for their child to participate in a CT. Top contributing factors for patients—both pediatric and adult—and caregivers, have been identified as: recruitment strategies, perceived risk, the disease severity of the child, feeling the study's objectives were important, logistical inconveniences and caregiver CT knowledge and understanding [11–14].

Successful implementation of CTs—and subsequent advanced treatment options for patients—is rooted in understanding factors that influence patient and caregiver decisions around CTP [7]. As therapeutic innovation continues in this disease space, participation in eczema CTs is pivotal to advancing patient care, addressing unmet needs, and better aligning new treatment options with patient-desired outcomes and preferences. Little is known about the factors eczema patients consider important for CTP, and information is especially scarce from the perspective of caregivers. Understanding the factors that influence a caregiver's consent to their child's participation in CTs may inform future practices in CT research. The aims of this study are to 1) identify and rate the factors that adult patients and caregivers consider important for CTP and 2) to determine to what extent children are involved in the decision-making process for CTP.

## 2. Methods

### 2.1. Study design and population

A 46-question online survey was administered from May 1 to June 6, 2020, to adult eczema patients and adult caregivers of pediatric eczema patients ( $\geq 18$  years) who were US or US territory residents. Eczema was defined as one or more of the following self-reported diagnoses: atopic dermatitis, allergic/irritant contact dermatitis, dyshidrotic eczema, hand eczema, neurodermatitis, nummular eczema, seborrheic dermatitis, and/or stasis dermatitis. Patient volunteers supported National Eczema Association (NEA)<sup>3</sup> staff in the development of the survey. Patients pilot tested the survey instrument and provided feedback on both content and literacy level. Feedback was incorporated prior to survey implementation. Survey availability was communicated to NEA members via the NEA website, email, and social media. Potential participants were directed to online screening for eligibility and informed consent. Participants who completed the survey were entered into a drawing to win one of ten \$50 e-gift cards. This study was identified as exempt by the WCG institutional review board.

The survey collected information on respondent demographics, understanding of and experience with CTs, and factors related to preferences for, or likelihood to consider CTP in the future. Only eczema patients and caregivers who had considered CTP in the past (without attempting), had attempted CTP but ultimately did not participate, or who had successfully participated in one or more CTs were included in this study. Respondents were asked to rate the importance of a series of factors (shown to respondents in the domains of general, therapy, financial, convenience, social, and personal) when considering CTP (options: “Not important at all”, “Of little importance”, “Of medium importance”, “Of high importance”). The lowest two categories were combined to achieve an adequate analysis sample size.

Caregivers of children ages 6–17 were asked two additional questions regarding their children's involvement in the CT process, specifically: “Who would be the ultimate decider of whether or not your child participates in an eczema clinical trial?” (options: “I am the ultimate decider”, “My child and I must both agree on the decision”, “My child is the ultimate decider”, or “I have never thought about it before/I don't know”) and “How engaged is your child in the clinical trial decision-making?” (5 options ranging from not engaged at all, to engaged to a

very great extent).

### 2.2. Statistical analysis

Descriptive statistics were used to summarize respondent characteristics and survey responses (means and standard deviations for continuous variables; frequencies and percentages for categorical variables). Comparisons for categorical variables were performed using chi-square tests, while for continuous variables the Student's t-test was used.

Comparisons for importance ratings between adult patients and caregivers were made using the Cochran-Armitage Test for Trend. The Benjamini-Hochberg method was used to decrease the false discovery rate, and the adjusted p-value is reported. Analysis was done using R: A Language and Environment for Statistical Computing [15]. Significance was set at  $P < 0.05$ .

## 3. Results

A total of 1016 respondents participated in the survey. Of those, 412 either did not indicate their previous CT experience or had never considered CTP and were not asked to rate the importance factors. Analysis was therefore based on 604 respondents (77.8% adult patients and 22.2% caregivers of children). Table 1 shows the characteristics of the study population. Caregivers were more likely to be female ( $p < 0.001$ ), non-White ( $p = 0.004$ ), and Hispanic (0.010). There was no difference between the groups in understanding of CTs or in patient-reported disease severity.

Table 2 shows the factors related to CTP consideration, and the proportion of respondents that ranked them as important. Fig. 1 shows the top three factors most frequently rated as being highly important for CT consideration by adults and caregivers. The factor with the largest proportion of high importance ratings for caregivers was “Having in-depth details on the purpose of the clinical trial and test drug” while for adults it was “Having trust in the clinical trial doctor(s)/site”. Fig. 2 shows the four factors with the largest proportion of high importance ratings for all respondents by current self-reported eczema severity. Those reporting severe eczema were more likely to rate the potential for better care as highly important compared to those with mild eczema (74.6% vs 87.2%, chi-square;  $p = 0.003$ ), and there was a trend for those with severe eczema to rate having in-depth details on the CT more highly than those with mild eczema (77.1% vs. 84.4%, chi-square;  $p = 0.082$ ).

Caregivers and patients were similar in their perceptions of which factors had no or little importance for CTP consideration. For both groups, the factor most frequently rated as having little or no importance was “Approval from family or friends to participate in a trial” (76.2% of adults and 68.6% of caregivers), followed by “Trial impact on family planning/pregnancy” (73.0% of adults and 68.6% of caregivers), and “Having a supportive community outside the clinical trial” (58.3% of adults and 47.8% of caregivers).

There were eleven factors that differed significantly in importance ratings between caregivers and adult patients. In terms of general and therapy factors, consideration of the route of therapy ( $p = 0.030$ ), possible side effects ( $p = 0.014$ ), a washout period ( $p = 0.028$ ), possibility of receiving a placebo ( $p = 0.027$ ), having a rescue therapy option ( $p = 0.033$ ), and access to a test drug after the trial ( $p = 0.027$ ) were all more likely to be rated as important by caregivers than by adult patients. While caregivers were more likely to rate learning/sticking with the CT regimen as important ( $p = 0.025$ ), no other financial or convenience factors differed between the groups. Caregivers also were more likely to attribute high importance to overall fit with work/school trajectory ( $p = 0.005$ ), potential impact on overall health ( $p = 0.008$ ), and on satisfaction with current treatment ( $p = 0.033$ ). The only factor that adult patients were more likely to rate as important than caregivers was “Knowing that I would contribute to research that will ultimately help find better treatment for myself and others who suffer from eczema” ( $p$

<sup>3</sup> NEA: National Eczema Association.

**Table 1**  
Characteristics of the study population.

	All (n = 604)	Adult Patients (n = 470)	Caregivers (n = 134)	P-value
Respondent age (Years; mean ± SD)	46.1 ± 16.8	47.9 ± 18.4	40.4 ± 8.5	<0.001
Respondent gender [% (n)]				<0.001
Male	17.9% (108)	20.8% (98)	7.5% (10)	
Female	81.3% (491)	78.1% (367)	92.5% (124)	
Other	0.8% (5)	1.1% (5)	0.0% (0)	
Respondent race [% (n)]				0.004
White	69.9% (422)	72.3% (340)	61.2% (82)	
Black or African American	10.1% (61)	7.6% (36)	18.6% (25)	
American Indian/Alaskan Native/Native Hawaiian or Pacific Islander	1.3% (8)	1.1% (5)	2.2% (3)	
Asian or Asian American	9.3% (56)	9.6% (45)	8.2% (11)	
Multiracial/Other/I don't know/prefer not to answer	9.4% (57)	9.4% (44)	9.7% (13)	
Ethnicity [% (n)]				0.010
Hispanic	10.4% (63)	8.7% (41)	16.4% (22)	
Non-Hispanic	89.6% (541)	91.3% (429)	83.6% (112)	
Respondent rating of general understanding of how a CT is conducted [% (n)]				0.603
Excellent/Good	69.5% (420)	63.6% (299)	60.4% (81)	
Average	35.1% (212)	28.5% (134)	32.8% (44)	
Poor/Terrible	9.3% (56)	7.9% (37)	6.7% (9)	
Patient eczema severity [% (n)] (Worst of all diagnoses over the past month)				0.063
Clear	4.8% (29)	5.1% (24)	3.7% (5)	
Mild	23.8% (144)	25.9% (122)	16.4% (22)	
Moderate	41.7% (252)	41.3% (194)	43.3% (58)	
Severe	29.6% (179)	27.7% (130)	36.6% (49)	

= 0.027).

Child involvement and engagement with CT decision making were evaluated for the 83 caregivers of children ages 6–17. Parents reported being the ultimate decider more often for children ages 6–11 than those ages 12–17 (Fig. 3).

#### 4. Discussion

This study suggests the factors eczema patients and caregivers consider most and least important when considering CTP are largely the same. Caregivers, however, are more likely to attribute higher importance to factors that may affect the well-being of their child, such as the impact on overall health, possibility of a washout period, or the option to have a rescue therapy. Only altruism is rated more highly by adults than caregivers. Caregivers of children ages 6 to 11 are more likely to report being the sole decider of whether or not their child participates in a CT and that their child is not at all engaged in the decision-making process, compared to caregivers of children ages 12–17. These findings play a critical role in understanding the reasons why adult eczema patients and

caregivers of children with eczema do or do not participate in clinical trials and the factors that are most important to them when considering CTP.

Caregivers rated “washout period” and “rescue therapy” both as high importance factors when considering CTP for their child. Previous work found that more than half of the study participants reported a below-average understanding of these terms and that health literacy, overall, played a significant role in CTP [9]. Specifically, a greater understanding of clinical trial terminology and the overall CT process was associated with increased likelihood of caregiver support of their child’s CTP [9]. Findings in this study corroborate that increased understanding of both younger patients and caregivers of the purpose of the clinical trial, promotes elevated confidence in decision-making related to potential risks they/their child may face, and overall CTP.

Adult patients rated altruism as an important factor when considering CTP. Individuals have shown to be more motivated to participate in clinical trials when they feel that the outcomes of the trial, and the knowledge gained from CTP, would result in benefits to both them and their community [16]. In the case of eczema, as many are often diagnosed in childhood, the lifelong nature of this chronic disease and the shared lived experiences of the eczema community may foster this sentiment [6]. Altruism may motivate individuals to consider CTP, however, researchers must consider this factor as it relates to CTP in practice. Recognizing this idea of ‘conditional altruism’ could have implications on CT recruitment, communication, and methodology. Researchers should be intentional in CT recruitment planning, addressing both the individual and societal benefits of the trial, to promote more informed trial participation [16,17].

Previous work conducted by Grinich et al., 2022, has identified patterns of awareness and understanding and key factors associated with CTP of adult patients in the eczema community [9]. The previous study found that age, satisfaction with current therapy, confidence in ability to find information on eczema CTs, and increased knowledge of CT-related terms, were correlated with an increase in CT awareness [9]. Interestingly, in the current study, patients with more severe eczema placed higher importance on the potential for receiving better care but tended to care less about the details of the CT or drug being tested. Educating the general public about the need and purpose of CTs (i.e., that they are experiments, not care options) and the manner in which they are conducted may ultimately lead to increased confidence, trust, and overall CTP. Special attention may need to be given to those with more severe disease to ensure they are not inflating the benefits of CTP.

Although certain factors were attributed as being of higher importance when it comes to eczema CTP, multiple considerations were found to be significant when considering CTP. Our results suggest that much like the heterogeneous nature of eczema, eczema CTP is a complex decision where factors are multidimensional and span several categories. Emphasis on any single factor alone will be unable to facilitate the successful recruitment, enrollment, and retention of participants in eczema CTs. Factors associated with CTP facilitators and barriers among eczema patients and patients with other chronic diseases, particularly among oncology, are analogous. Health literacy, not having a complete understanding of the CT and drug development process, fear of the unknown, including adverse events and potential drug side effects, and older age are well-established inhibitors to CTP [13,18–20]. Likewise, altruism and access to a new/better treatment increased the likelihood of CTP among both the eczema and oncology communities [18,19,21]. These findings suggest that drivers and barriers to eczema CTP are comparable with other chronic diseases and should not require a unique approach for eczema CT recruitment and retention.

Understanding the factors affecting caregivers’ attitudes, knowledge, and willingness of clinical trial participation (CTP) for their child(ren) is advantageous to the creation of family-centered care and the advancement of clinical research. In this study, over half of caregivers reported they and their child must both agree on the decision to participate in CTs, nonetheless, 35% said they were the ultimate decider. Similar to

**Table 2**  
Factors important to consider for CTP.

Factors [% (n)]	Adult (n = 470)	Caregiver (n = 134)	P-value	Adj. P-value (Benjamini-Hochberg)
<b>GENERAL FACTORS</b>				
Having in-depth details on the purpose of the clinical trial and test drug			0.139	0.205
Not important at all/Of little importance	3.4% (16)	3.7% (5)		
Medium importance	19.1% (90)	11.2% (15)		
High importance	77.4% (364)	95.1% (114)		
Having trust in the clinical trial doctor(s)/site			0.712	0.735
Not important at all/Of little importance	1.5% (7)	3.7% (5)		
Medium importance	13.4% (63)	10.4% (14)		
High importance	85.1% (400)	85.8% (115)		
Understanding when/how I can still work with my current doctor			0.112	0.193
Not important at all/Of little importance	18.9% (89)	13.4% (18)		
Medium importance	28.5% (134)	27.6% (37)		
High importance	52.6% (247)	58.9% (79)		
Route of therapy administration (pill vs. needle vs. topical)			0.009	0.030
Not important at all/Of little importance	16.0% (75)	11.2% (15)		
Medium importance	23.6% (111)	14.2% (19)		
High importance	60.4% (284)	74.6% (100)		
Transparency (i.e., understanding of how my clinical trial data will be used)			0.025	0.055
Not important at all/Of little importance	12.8% (60)	7.5% (10)		
Medium importance	27.0% (127)	22.4% (30)		
High importance	60.2% (283)	70.1% (94)		
<b>THERAPY FACTORS</b>				
Potential side effects of the test drug			0.001	0.014
Not important at all/Of little importance	3.4% (16)	1.5% (2)		
Medium importance	15.1% (71)	4.5% (6)		
High importance	81.5% (383)	94.0% (126)		
Washout period (i.e., having to stop my current therapy)			0.007	0.028
Not important at all/Of little importance	25.5% (120)	18.6% (25)		
Medium importance	32.8% (154)	25.4% (34)		
High importance	41.7% (196)	56.0% (75)		
Potential to receive better eczema care than currently receiving			0.176	0.248
Not important at all/Of little importance	2.3% (11)	1.5% (2)		
Medium importance	16.1% (76)	11.9% (16)		
High importance	81.5% (383)	86.5% (116)		
Possibility of receiving a placebo (inactive treatment)			0.005	0.027
Not important at all/Of little importance	24.7% (116)	14.9% (20)		
Medium importance	35.7% (168)	33.6% (45)		
High importance	39.6% (186)	51.5% (69)		
Having Rescue Therapy option (i.e., ability to receive treatment when new or unexpected eczema flare occurs)			0.012	0.033
Not important at all/Of little importance	5.1% (24)	5.2% (7)		
Medium importance	27.0% (127)	12.7% (17)		
High importance	67.9% (319)	82.1% (110)		
Potential access to study test drug at completion of trial			0.006	0.027
Not important at all/Of little importance	7.0% (33)	3.7% (5)		
Medium importance	32.1% (151)	22.4% (30)		
High importance	60.9% (286)	73.9% (99)		
<b>FINANCIAL FACTORS</b>				
Coverage/acceptance of clinical trial by my current insurance if not covered by the trial			0.413	0.512
Not important at all/Of little importance	6.2% (29)	6.7% (9)		
Medium importance	21.7% (102)	25.4% (34)		
High importance	72.1% (339)	67.9% (91)		
Potential financial impacts (i.e., missing work/school, or incurring unreimbursed OOP costs)			0.657	0.727
Not important at all/Of little importance	14.7% (69)	13.4% (18)		
Medium importance	25.3% (119)	24.6% (33)		
High importance	60.0% (282)	61.9% (83)		
Ability to be compensated or reimbursed for participation (including daycare)			0.469	0.538
Not important at all/Of little importance	27.4% (129)	33.6% (45)		
Medium importance	32.6% (153)	26.1% (35)		
High importance	40.0% (188)	40.3% (54)		
<b>CONVENIENCE FACTORS</b>				
Distance of clinical trial site to my home			0.704	0.736
Not important at all/Of little importance	5.7% (27)	7.5% (10)		
Medium importance	31.1% (146)	25.4% (34)		
High importance	63.2% (297)	67.1% (90)		
Duration/length of the trial			0.022	0.052
Not important at all/Of little importance	18.1% (85)	15.7% (21)		
Medium importance	43.0% (202)	31.3% (42)		
High importance	38.9% (183)	53.0% (71)		
Number of required study visits, procedures, or follow-up items			0.032	0.067
Not important at all/Of little importance	14.9% (70)	11.9% (16)		
Medium importance	38.9% (183)	30.0% (40)		
High importance	46.2% (217)	58.2% (78)		

(continued on next page)

Table 2 (continued)

Factors [% (n)]	Adult (n = 470)	Caregiver (n = 134)	P-value	Adj. P-value (Benjamini-Hochberg)
Ability to complete some study requirements from home instead of in the clinic (e.g., wearable devices, online surveys, etc.)			0.065	0.119
Not important at all/Of little importance	22.1% (104)	17.9% (24)		
Medium importance	37.7% (177)	27.6% (37)		
High importance	40.2% (189)	52.2% (70)		
Ease/difficulty in learning and sticking with the trial treatment regimen			0.003	0.025
Not important at all/Of little importance	19.8% (93)	11.2% (15)		
Medium importance	37.2% (175)	32.8% (44)		
High importance	43.0% (202)	56.0% (75)		
Overall fit with work/life schedule			0.742	0.742
Not important at all/Of little importance	14.7% (69)	11.2% (15)		
Medium importance	30.4% (143)	35.1% (47)		
High importance	54.9% (258)	53.7% (72)		
<b>SOCIAL FACTORS</b>				
Approval from family or friends to participate in a trial			0.136	0.205
Not important at all/Of little importance	73.0% (343)	68.6% (92)		
Medium importance	16.4% (77)	14.9% (20)		
High importance	10.6% (50)	16.4% (22)		
Having a supportive community outside the clinical trial			0.046	0.089
Not important at all/Of little importance	58.3% (274)	47.8% (64)		
Medium importance	23.4% (110)	29.1% (39)		
High importance	18.3% (86)	23.1% (31)		
My trusted doctor's recommendation to participate			0.019	0.050
Not important at all/Of little importance	27.2% (128)	19.4% (26)		
Medium importance	34.0% (160)	31.3% (42)		
High importance	38.7% (182)	49.3% (66)		
Any doctor's recommendation to participate			0.468	0.538
Not important at all/Of little importance	38.1% (179)	36.6% (49)		
Medium importance	40.4% (190)	38.0% (51)		
High importance	21.5% (101)	25.4% (34)		
Knowing that I would contribute to research that will ultimately help find better treatment for myself and others who suffer from eczema			0.005	0.027
Not important at all/Of little importance	5.5% (26)	9.7% (13)		
Medium importance	23.2% (109)	31.3% (42)		
High importance	71.3% (335)	59.0% (79)		
<b>PERSONAL FACTORS</b>				
Overall fit with your career/school trajectory			<0.001	0.005
Not important at all/Of little importance	37.4% (176)	20.1% (27)		
Medium importance	29.8% (140)	33.6% (45)		
High importance	32.8% (154)	46.3% (62)		
Trial impact on family planning/pregnancy			0.212	0.278
Not important at all/Of little importance	76.2% (358)	68.6% (92)		
Medium importance	8.3% (39)	14.2% (19)		
High importance	15.5% (73)	17.2% (23)		
Overall fit with family obligations (such as caring for a family member, marriage status changes, ability to participate in family functions)			0.216	0.278
Not important at all/Of little importance	50.9% (239)	42.5% (57)		
Medium importance	24.0% (113)	30.6% (41)		
High importance	25.1% (118)	26.9% (36)		
Potential impact on overall health (such as on a condition other than eczema)			<0.001	0.008
Not important at all/Of little importance	12.1% (57)	6.7% (9)		
Medium importance	23.4% (110)	11.2% (15)		
High importance	64.5% (303)	82.1% (110)		
Level of satisfaction with current treatment approaches			0.011	0.033
Not important at all/Of little importance	18.3% (86)	9.7% (13)		
Medium importance	37.0% (174)	35.8% (48)		
High importance	44.7% (210)	54.5% (73)		
Having support from the clinical trials site to help navigate the process and manage all the "moving parts"			0.123	0.201
Not important at all/Of little importance	8.9% (42)	7.5% (10)		
Medium importance	36.0% (169)	29.1% (39)		
High importance	55.1% (259)	63.4% (85)		

adults with eczema, the decision-making process for child CTP is a complex experience that involves many dimensions. Snethen et al. described three prominent dimensions of the CTP decision-making process: the parent's goals, the child's involvement, and the parent perspective in regard to their role in the decision-making process [22]. Informative decision making could explain the discrepancy between child engagement in the decision-making process and caregivers being the ultimate decider. In informative decision making, parents have open dialogue with their child about CTP. They include their child in

discussion about the CT and disease treatment opportunities, however, parents still make the final decision on CTP [22]. Additional factors that influence the involvement of the child in the decision-making process are; disease severity of the child, pre-existing family dynamics, and basic knowledge of clinical trial research [13,22]. Understanding the gaps in parent's knowledge of pediatric drug development and of what CTP entails may lead to the development of clinical studies that are specifically designed to address the needs and priorities of parents. This, in turn, can lead to increased child CTP [23].

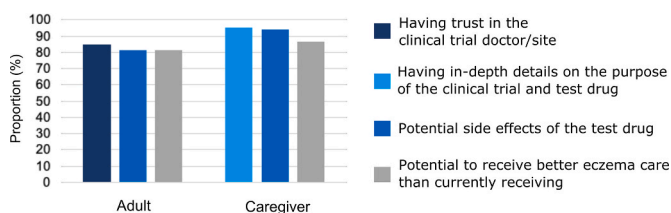


Fig. 1. Factors most frequently rated as highly important for CT consideration by adults and caregivers.

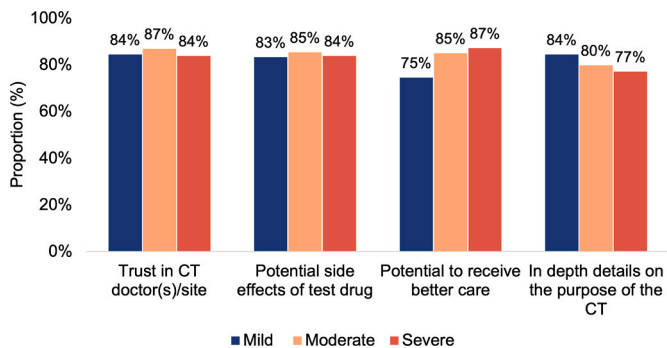


Fig. 2. Factors related to adult and caregiver CTP consideration with the largest proportion of high importance ratings, separated by current eczema self-reported severity.

Strengths of this study included a holistic view of the eczema patient experience with CTP through the inclusion of a large, diverse sample size of patients and caregivers with all types of eczema, ranging in severity. The inclusion of patient-reported data is also a strength of this study as it provides a snapshot of the personal experiences and considerations of

eczema patients with CTs that cannot always be ascertained through observational studies. Limitations of this study included the selection of participants being limited to NEA community members and the potential recall bias that arises from self-reported, retrospective responses to survey questions. Another limitation to this study was the omission of participants who responded that they had never considered participating in a CT, as they were not asked factor-based questions. Respondents included in these study results had either actual CTP or considered CTP with or without actual attempt.

5. Conclusions

This study reveals insights into the factors that are important for eczema patients and caregivers to appraise when considering CTP. Eczema patients and caregivers place similar value on factors that contribute to consideration of CTP, however, caregivers may more carefully consider factors that affect the well-being of their child. These findings suggest the need for researchers to improve the quality and type of information they share to patients and caregivers about CTP, especially in regard to the risk: benefit relationship. Clinical trial information that is patient-centered has the opportunity to increase the understanding of patients and caregivers about CTs, allowing space for improved shared decision making within families prior to CT recruitment.

CRedit author statement

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Research data

Survey respondents were assured raw data would remain confidential and would not be shared.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: This study was sponsored by the National Eczema Association (NEA). Wendy Smith Begolka is an employee of the NEA; received advisory board honoraria from Pfizer and Incyte.

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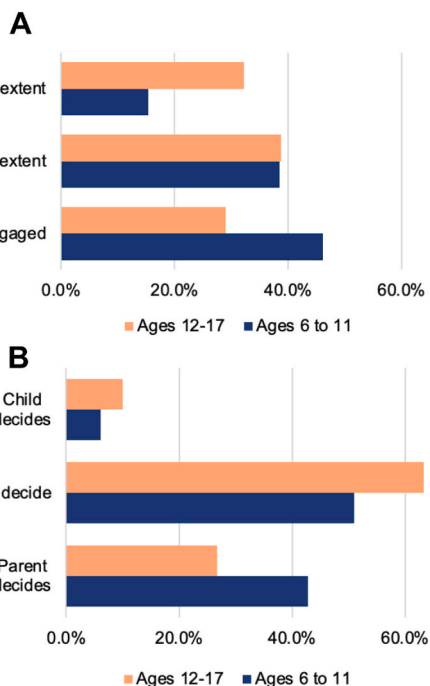


Fig. 3. Panel A shows caregivers' evaluation of how engaged their child is in the clinical trial decision-making process. Younger children (ages 6 to 11) were less likely to be engaged. Panel B shows caregivers' perspective on who is the ultimate decider of whether or not their child participates in a clinical trial. Caregivers were more likely to be the sole decider for younger children.

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