

# **Summary of results**

### Section 1: Introduction and methodology

- Atopic dermatitis (AD) is an inflammatory skin condition associated with other atopic manifestations such as asthma, rhinitis and food allergy.
- It presents in varying degrees of severity from a mild disease treated with over-the-counter products to severe disease requiring treatment with systemic immunosuppressive agents.
- Common symptoms of AD include itchiness, red to brownish-grey patches on the skin, small, raised bumps, which may leak fluid and crust over when scratched, and/or thickened, cracked, dry, scaly skin.
- Onset of AD occurs most commonly in infants and children, however it can occur at any age with clinical features varying with age of onset.
- Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.
- In this PEEK study, 100 people diagnosed with AD throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in AD is therefore the largest mixed methodology study worldwide conducted in last five years and the only study that focuses on an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

### Section 2: Demographics and study population characteristics

- One hundred participants from Australia were included in the study.
- Participants reported a current Patient Oriented Eczema Measure (POEM) score to determine severity of disease. 11 were mild (11.00%), 26 Moderate (26.00%), 41 severe (41.00%) and 22 very severe (22.00%).
- Participants came from NSW (45.00%), Queensland (17.00%), Victoria (13.00%), Western Australia (11.00%), South Australia (5.00%), Australian Capital Territory (4.00%), Tasmania (4.00%) and the Northern Territory (1.00%); from major cities (59.00%) and regional/rural (41.00%).
- Eighty-eight females (88.00%) and 12 males (12.00%) were included in this study.
- Subgroup analysis were included throughout the study. The subgroups were disease severity - mild (11.00%), moderate (26.00%), severe (41.00%) and very severe (22.00%); those with comorbid anxiety and depression (39.00%) and those without (61.00%); by location- Major city (59.00%) or Regional/Remote (41.00%); and by education status - those with a university degree (58.00%) and those with high school or trade (42.00%).
- The baseline health SF36 scores for the entire cohort were very good for physical functioning and role limitations due to physical health; the scores for role limitations due to emotional problems, emotional well-being, social functioning and pain were good; and the scores for energy/fatigue, general health and health change were moderate.
- Participants with very severe disease scored worse than all other groups for the physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and had worse scores than those with moderate or severe disease for energy/fatigue. There were no differences between disease severity groups for role limitations due to emotional problems or for health change scores.
- Participants with comorbid depression and anxiety scored worse on the physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health SF36 scales compared to those that did not have comorbid depression and anxiety. There were no differences between these groups for energy/fatigue, role limitations due to physical health, and health change scores.
- Participants that had a university degree had better outcomes compared to those with high school or trade

for the social functioning, pain and general health SF36 scales.

- No differences in SF36 subscales were observed for those that lived in major cities compared to those that live in regional/rural areas.

### Section 3: Experience of symptoms and diagnosis

#### Symptoms at diagnosis

- The most common symptoms leading to diagnosis were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%) that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.
- There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).
- There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history (n=24, 24.00%).
- There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.
- 64 participants (64.00%) noted that they had no support at diagnosis, (n=21; 21.00%) reported having some support, but not enough and (n=15, 15.00) reported having enough support.
- There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

#### Genetic/biomarker tests

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.
- Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%) indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

#### Knowledge of condition and prognosis

- In relation to how much participants knew about their condition at diagnosis, the main theme was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). 18 participants (18.00%) described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they knew.
- There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).
- Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better. 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation.
- There were two sub-group variations. Participants with mild AD reported their prognosis as being something

they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

### Section 4: Experience of health professional communication

#### Conversations about treatments

- Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream.
- There was one sub-group variation. Participants with very severe AD described feeling as though there were no or limited treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

#### Decision-making

- Participants were asked who was involved in decisions made about treatment and care. Participants clinician and 5 The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.
- There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).
- Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment would take to administer and this was noted by 34 (34.00%) of participants. There were 31 participants (31.00%) that described considering the severity of side effects, 30 participants (30.00%) spoke about understanding the evidence behind the treatment option, cost was another consideration that was noted by 27 participants (27.00%) and there also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health.
- There were three sub-group variations. Participants with mild AD reported considering the severity of side effects less frequently than the general cohort (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).
- Participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and 24 participants described taking more of an active role or interest in their condition in adulthood.
- There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

### Section 5: Experience of treatment and service provision

#### Treatments experienced

- The most common treatments reported by nearly all participants were corticosteroid creams (n=94, 94.00%). This was followed by non-prescription creams that control itching (n=61, 61.00%), antihistamines (n=61, 61.00%) and wet dressings (n=47, 47.00%). Antibiotics and calamine lotion were both reported by 40 participants (40.00%).
- Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Mean quality of life scores ranged from 2.40 to 3.62, that is, all quality of life scores were within the 'life was distressing' to 'Life was a little distressing' range. The treatments that scored the least impact on quality of life were non-prescription creams that control itching and inflammation (average score 3.62), antihistamines (average score 3.33), creams to repair cracked skin (average score 3.31), stress reduction treatments (average score 3.21) and corticosteroid creams (average score 3.03). The treatments that had the greatest impact on quality of life were antibiotics (average score 2.40), diluted bleach baths (average score 2.42) and relaxation or behaviour modification (average score 2.42).
- Participants were asked to rate how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored between a range of 1.53 to 3.86, that is ineffective to moderately effective. The most effective treatments were oral or injectable corticosteroids (average score 3.86), corticosteroid creams (average score 3.42), and wet dressings (average score 3.13). The least effective treatments were calamine lotion (average score 1.53), stress reduction techniques (average score 2.21) and diluted bleach baths (average score 2.29).
- In relation to side effects that participants felt they could cope with, the main theme was that there were no significant side effects of treatment noted, but the eczema itself needed to be managed (n=47, 47.00%). There were 13 participants (13.00%) that described being able to cope with all side effects, 12 participants (12.00%) that described being able to cope with dryness and/or scarring and/or bruising, 10 participants (10.00%) that described being able to cope with dryness and/or scarring and/or bruising, and 10 participants (10.00%) that described being able to cope with the thinning of skin. There were a further 11 participants (11.00%) that did not describe any side effects that they could cope with, rather they only described side effects that were difficult.
- In relation to sub-group variations, participants with mild AD reported no significant side effects more frequently than the general cohort (63.64% compared to 47.00% in the general cohort) while participants with very severe AD reported this less frequently (31.82% compared to 47.00% in the general cohort). There were also no participants with mild AD that reported only having difficult side effects.
- For the participants that did speak about difficult side effects, there was a broad range of difficult side effects noted by participants including coping with the impact on mental health, skin dryness, cracking, bruising and thinning, and the long-term impact of treatment, however no themes were coded more than ten times. The most common theme overall was difficulty coping with the impact on mental health (n=7, 7.00%).
- While we acknowledge that there were few significant themes identified in relation to difficult side effects, it is important to note that there were six participants (6.00%) that also noted the difficulties in managing long term side effects of treatment as this is also aligned with the psychological stress associated with AD.

#### Adherence to medication

- The main theme noted by 23 participants (23.00%) was that they would stick to a treatment for as long as it was working for them. In relation to a specific time frame in which participants would adhere to a treatment, the main time frame was about a month (n=19, 19.00%) followed by a week or less (n=16, 16.00%) and two to three months (n=16, 16.00%).
- There was one sub-group variation where participants with mild AD reported sticking to a treatment for as long as it worked more frequently than the general cohort (36.36% compared to 20.00% in the general cohort).

- Participants were asked what needed to change for them to feel as though a treatment was working. The key theme noted by over half of the cohort was needing to have a reduction in itchiness (n=53, 53.00%). Participants describes this as a key symptom that causes discomfort and the importance of ameliorating this. The next most common theme was that the AD needed to disappear in general (n=33, 33.00%) and there were three additional, common themes including needing to see a reduction in rash, redness or inflammation (n=26, 26.00%), needing to feel more comfortable in general (n=19, 19.00%) and a reduction on skin dryness, flakiness or skin cracking (n=18, 18.00%).
- There was one sub-group variation where there were no participants that had mild AD who reported needing the AD to disappear in general (compared to 33.00% in the general cohort).

### Complementary therapies

- The main theme was that participants considered using various creams and gentle soaps as complementary therapies (n=36, 36.00%). This was followed by dietary changes that were also considered to be complementary therapies. There were 27 participants (27.00%) that described accessing naturopaths or homeopaths and 24 participants (24.00%) that described accessing Chinese medicine and acupuncture.
- There were a number of sub-group variations. Participants with mild AD reported using creams and gentle soaps more frequently than the general cohort (81.82% compared to 36.00% in the general cohort), while participants with moderate AD reported this less frequently (19.23% compared to 36.00% in the general cohort). In relation to dietary changes, participants with mild AD reported this less frequently (9.09% compared to 35.00% in the general cohort) and participants with severe AD reported this more frequently (51.22% compared to 36.00% in the general cohort). With the exception of using creams and gentle washes, participants with mild AD reported overall less use of complementary treatments over all themes.

### Service provision and affordability

- The majority of patients had private healthcare insurance (n=75, 75%), and half of the participants were treated mostly as a public patient (n=50, 50%). Of those that were treated for atopic dermatitis in hospital, most were treated in a public hospital (n=39, 6.94%)
- Approximately half of the participants have never missed medical appointments due to cost (n=52, 52.00%), and have never been unable to afford prescription medications (n=49, 49.50%), however, approximately half of the participants have missed appointments or been unable to pay for medications at some point. The majority of participants have never had trouble paying for basic needs due to their diagnosis with atopic dermatitis (n=62, 62.00%).

## Section 6: Information and communication

### Access to information

- The majority of participants (n=75, 75.00%) described the internet as their main source of information. There was a large gap between this main theme and the next most common theme of accessing information through their treating clinician which was noted by 25 participants (25.00%).
- There were a number of sub-group variations. Participants with very severe AD described accessing information through their treating clinician less frequently than the general cohort (9.09% compared to 25.00% in the general cohort), while those with moderate AD accessed information this way more frequently (42.31% compared to 25.00% in the general cohort). There were also no participants with very severe AD that did not seek information about their condition, compared to 12.00% in the general cohort.

### Information that was helpful

- 21 participants (21.00%) felt that was that no information or little information was particularly helpful. This primarily referred to participants feeling as though there were no concrete answers or that information did not offer anything beyond what they already knew. There were 14 participants that described information about diet as being a useful topic and 14 participants (14.00%) that described information about other people's experience as helpful. There were 13 participants (13.00%) that described the internet being a



useful source of information. Some of the specific topics that participants described as being useful, in addition to diet, were information about treatments (n=10, 10.00%) and information about allergies and triggers (n=9, 9.00%).

- In relation to sub-group variations, participants with mild AD described dietary information as being helpful more frequently than participants in the general cohort (36.36% compared to 14.00% in the general cohort) and however overall, this group reported the various types of information as being useful, less frequently than the general cohort.

### Information that was not helpful

- The main theme in this section was that there was not information that was not helpful (n=28, 28.00%). There were 15 participants (15.00%) that described being confident in deciding whether or not information was credible in relation to determining if it was useful. The next most common theme was that information based on the experience of others was not helpful (n=13, 13.00%). Information provided by general practitioners or specialists was described as not being helpful by 11 participants (11.00%). The final theme in this section was in relation to a lack of new information (n=10, 10.00%).
- There were two sub-group variations. Participants with mild AD reported no information as being unhelpful more frequently than the general cohort (54.55% compared to 28.00% in the general cohort) and also reported receiving conflicting information more frequently than the general cohort (18.18% compared to 4.00% in the general cohort).

### Timing of information

- The two most common themes were being most receptive to information when AD becomes worse (during flares) (n=22, 22.00%) and the same number of people had no particular time in which they could absorb information better. The next most common theme was that participants were most receptive to information when they were well and not too busy (n=17, 17.00%). Participants described that the time during flares and when life is busy, is too distracting to take in information.
- Participants with mild AD reported having a preference for information during flares, more frequently than the general cohort (45.45% compared to 22.00% in the general cohort). This sub-group also reported having no preference in relation to timing of information less frequently (9.09% compared to 22.00% in the general cohort) and receiving information at times when they are not too busy, less frequently (9.09% compared to 22.00% in the general cohort). Participants with moderate AD reported a preference for receiving information at times when they are not too busy, more frequently (30.77% compared to 17.00% in the general population and participants with very severe AD reported this less frequently (4.55% compared to 17.00% in the general population).

### Health professional communication

- The main theme described by close to half of all participants (n=48, 48.00%) was that they felt their AD was dismissed by health professionals in general. The next most common theme was that communication was overall positive (n=32, 32.00%). There were also 15 participants that spoke about health professionals not understanding AD and therefore, not always providing accurate information.
- In relation to sub-group variations, participants with mild AD and moderate AD reported overall positive communication (holistic) more frequently than the general cohort (45.45% and 46.15% compared to 32.00% in the general cohort) while participants with severe and very severe AD reported this less frequently (26.83% and 16.16% compared to 32.00% in the general cohort).

### Respect shown to patients

- The majority of participants (n=51, 51.00%) reported that they had been treated with respect. There were 35 participants (35.00%) that reported that they were treated with respect however, they also felt that they were often dismissed and/or that their AD was not being taken seriously
- In relation to sub-group variations, participants with mild AD reported being treated respectfully more frequently (72.73%) while participants with very severe AD reported this less frequently (31.82%) than the general cohort (51.00%). Participants with mild AD reported not being heard or feeling like there was a lack

of knowledge about AD, less frequently (18.18%) while participants with very severe AD reported this more frequently (45.45%) than the general cohort (35.00%). Participants with very severe AD also reported not being treated respectfully more frequently than the general cohort (22.73% compared to 11.00% in the general cohort).

### Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 sub scales; knowledge, treatment, symptoms and coping. A higher score denotes a better outcome.

- Overall, the participants scored in the top quintile for, adherence to treatment, and management of symptoms, indicating very good outcomes; the overall median score for knowledge, and mean score for coping and total score were all in the second highest quintile indicating outcomes.
- Participants with very severe disease scored lower compared to all other groups in the PIH coping and PIH total score.
- There were no differences observed in PIH subscales by comorbid depression and anxiety, location and education status.

### Information given by healthcare professionals and searched for independently.

- Information about treatment options (77.00%), disease management (41.00%) and dietary information (27.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (3.00%) and psychological support (2.86%) were given least often.
- Information about treatment options (74.00%), disease cause (58.00%), and disease management (57.00%) were most often searched for independently by participants, and clinical trials (14.00%) and how to interpret test results (16.00%) were least searched for.

### Most trusted information sources

- Across all participants, information from the not for profit or charitable organisations was most trusted followed by participants' hospital or clinic, then government, and then pharmaceutical companies. This order of trusted information source was the same for all of the subgroups (disease severity, comorbid depression and anxiety, location and education) with the exception of those with moderate disease. Those with moderate disease most trusted information from government.

## Section 7: Experience of care and support

### Coordination of care

- Overall the entire cohort had a mean communication score of 38.06, total score of 64.06, a median score of 5.00 for care co-ordination and 6.00 for care received; these scores fall in the middle of the scale. The median score for navigation was 26.00, this falls in the second highest quintiles indicating good navigation.
- The care coordination navigation scores and total scores were better for those with moderate disease compared to those with either severe or very severe; and the care coordination communication scores were better for those with moderate disease compared to those with very severe disease.
- There was a significant difference between those that live in metropolitan areas compared with those that live in regional/rural areas for care coordination. Those that live in regional/rural areas had a higher score.
- There were no significant differences in care coordination between the comorbid depression and anxiety subgroups or the education status subgroups.

### Care and support

- Participants were asked what care and support they had received throughout their experience. The majority of participants described care and support coming from family and friends (n=76; 76.00%), and this was the most common theme followed by care and support accessed from the hospital or clinical setting (n=27;



27.00%). There were also 16 (16.00%) participants that described feeling as though they did not need additional support, however, participants that had severe AD were stated this less frequently (9.09% compared to 16.00% in the general cohort). This was also stated less frequently by participants that had a high school/trade education (7.14 compared to 16.00% in the general cohort).

### Section 8: Experience of quality of life

#### Quality of life

- In the questionnaire, participants were asked to indicate which symptoms they had experienced and then rate their quality of life while experiencing those symptoms. The most common symptom experienced by nearly all participants (n=93, 93.00%) was raw, sensitive, swollen skin from scratching followed by thickened, cracked, dry scaly skin (n=89, 89.00%), itching which is uncomfortable but reasonably controlled (n=88, 88.00%), small, raised bumps, which may leak fluid and crust (n=87, 87.00%) and red to brownish-grey patches (n=82, 82.00%).
- Across all symptoms experienced, the average number of symptoms that participants experienced increased with severity of AD. The average number of symptoms experienced by the total cohort was 6.52, for mild AD it was 4, for moderate AD it was 6.12 for severe AD it was 7 and for very severe AD it was 7.36 symptoms per participant.
- As a follow-up question, participants were asked to rate their quality of life while experiencing symptoms on a scale of 1 to 7 where 1 is life was very distressing and 7 is life was good. All symptom mean scores were within the 'life was very distressing' to 'life was a little distressing' range. The symptom that scored the poorest quality of life was sores that may become infected by bacteria or viruses (1.91), followed by itching which is severe and not controlled (2.00), regular sleep disturbance (2.35), and raw, sensitive, swollen skin from scratching (2.62). The symptoms that scored the highest in relation to quality of life were itching, which is uncomfortable but reasonably controlled (3.53) and red to brownish-grey patches (3.04).
- In the structured interview, participants were asked how their condition affect their quality of life. The most common theme noted by close to half of all participants (n=43, 43.00%) was that AD caused a significant impact in relation to self-esteem and confidence. Participants also spoke about this leading to social isolation. This was followed by an impact on relationships with family and friends (n=31, 32.00%). There were 28 participants (28.00%) that noted that there was a significant impact in relation to not being able to work and 24 participants (24.00%) that described not being able to do everyday activities. Other themes that emerged included participants feeling as though quality of life was good now, but not when they were younger (n=24, 24.00%) and the impact of itchiness on quality of sleep (n=22, 22.00%).
- There were three sub-group variations. Participants with mild AD reported the impact on self-esteem and confidence less frequently than the general cohort (9.09% compared to 43.00%). They also did not describe the impact on relationships at all (0.00% compared to 32.00% in the general cohort) and this sub-group described the impact on being able to work less frequently (9.09% compared to 28.00% in the general cohort).
- The theme of impact on sleep was further explored with a prompted question that asked whether AD affected their sleep and the implications of this. There were 41 participants (41.00%) that described AD having an impact on sleep and this primarily referred to itchiness. The next most common theme (n=28, 28.00%) was restlessness and agitation throughout the night to manage their AD. There were 19 participants (19.00%) that described heat affecting their AD and therefore their sleep and 14 participants (14.00%) described not being able to function properly following poor sleep.

#### Regular activities to maintain health

- Participants were asked what they considered to be some of the things that they needed to do regularly to maintain their health? There were 87 participants (87.00%) that described a daily routine of applying creams (moisturisers, QV cream, steroid cream), this was followed by needing to avoid some types of food (dairy, gluten etc.) or change their diet (n=24, 24.00%), needing to preventing skin from drying (n=17, 17.00%), needing to avoid getting too hot/cold to control eczema (n=16, 16.00%), and taking medicine as part of daily routine (n=15, 15.00%).
- There were a number of sub-group variations. Participants with mild AD reported having a daily routine of

moisturizers less frequently than the general cohort (63.64% compared to 87.00% in the general cohort). Participant with moderate AD reported needing to avoid certain foods less frequently than the general cohort (11.54% compared to 24.00% in the general cohort) while participants with severe AD reported this more frequently (36.59% compared to 24.00% in the general cohort).

- As a follow-up question, participants were asked what their usual routine was for showering and getting ready in the morning. In answering this question, some participants spoke about the time required, which was anywhere between 20 minutes to over one hour, while other participants spoke about the routine that they needed to adhere to in order to get ready each day. Another key theme described by 10 participants (10.00%) was that AD had a significant impact on relationships in relation to self-esteem and confidence/being embarrassed.

### Impact on relationships

- Participants were asked whether their condition has had an impact on personal relationships with family and friends. There was a reasonably even response with 53 participants (53.00%) describing no impact, or limited impact while they were managing flares, and 47 participants (47.00%) stating that there was a significant impact. Where there was an impact, the most common challenge described (n=16, 16.00%) was a significant impact on relationships with their family member, specifically intimacy with their partner. The next most common theme was a significant impact on quality of life in relation to becoming isolated/not being able to go out and be social (n=12, 12.00%).
- There were two sub-group variations. Participants with mild AD reporting having no impact on their relationships less frequently than the general cohort (81.81% compared to 53.00% in the general cohort). They also described having a significant impact on relationships less frequently (18.18% compared to the general cohort).
- As a follow-up question, participants were asked whether they felt their condition had resulted in any additional burden on their family. Half of all participants (n=50, 50.00%) described not needing any additional assistance. These participants spoke about being independent and being able to manage their condition themselves. There were 16 participants (16.00%) that described AD being a burden on their family and this was primarily in relation to needing additional assistance or the additional financial burden to their family. Another theme that emerged was that participants felt as though AD was not a burden now, but that it was when they were younger (n=12, 12.00%). There were also an additional 10 participants that specifically spoke about needing and appreciating the assistance and care that was provided to them by their mother (10.00%).
- There were a number of sub-group variations. Participants with moderate AD reported not needing any additional assistance more frequently than the general cohort (65.38% compared to 50.00% in the general cohort). Participants with mild AD reported not needing assistance now, but needing assistance in earlier life, more frequently than the general cohort (36.36% compared to 12.00%).

### Anxiety and fear of progression

- The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, with a higher score denoting increased anxiety. Overall the entire cohort had a median total score of 28.00, which is a score in the second lowest quintile indicating a small amount of fear.
- Those with very severe disease had a greater fear of progression compared with those with mild, moderate or severe disease.
- Those with comorbid depression and anxiety had a greater fear of progression compared to those without.

## Section 9: Expectations of future treatment, care and support, information and communication

### Expectations of future treatment

- When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single them (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options. There were two similar themes in relation

to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.

- There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health.
- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were severe and uncontrolled itching and raw sensitive swollen skin from scratching, the least important sleep disturbance and sores that may become infected.
- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making.
- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government.

### Expectation of future information provision

- Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious. There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think there were any advancements in treatments, there was little point in offering more information. Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

### Expectation of future healthcare professional communication

- In relation to what participants would like to see improved in relation to the way that health professionals communicate with patients, the most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

### Expectation of future care and support

- Participants were asked whether there was anything they would like to see in relation to the way the care and support they receive. There were two main themes identified including recommendations to develop opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

### Messages

- Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long. There were 34 participants that whose message was to treat the condition holistically, including emotional

## Summary of results

support, having a care plan and being told about treatment options. An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition. The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%).

### Section 10: Advice to other patients and families

#### Summary

- Participants were asked what advice they would give to other people who are newly diagnosed with AD and their families. There were two key themes including to find what works best for you and this was noted by 26 participants (26.00%). The next most common theme was in a similar vein where participants spoke about various individual products that had worked for them, demonstrating the individual nature of the condition (n=24, 24.00%). Other themes included to pay attention to your diet, as many people found this to be helpful (n=18, 18.00%), do as much of your own research as possible (n=11, 11.00%) and to use gentle body washes and moisturizers - be diligent with moisturizing (n=11, 11.00%).

Table i: Sub-group variations

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Baseline health				Poorer scores for physical functioning, role limitations due to physical health, emotional well-being, social functioning, pain, and general health SF36 scales, and fatigue	Poorer scores for physical functioning, role limitations due to emotional problems, emotional well-being, social functioning, pain and general health			Better scores for social functioning, pain and general health	
Symptoms that led to diagnosis	Red to brownish-grey patches	Red to brownish-grey patches							Allergies that led to diagnosis
Diagnostic tests	Skin examination only								
Support at diagnosis	No support at diagnosis	Enough support at diagnosis							
Knowledge of disease at diagnosis				Knew about AD through other family members					
Description of prognosis	AD is something they will have for their lifetime			AD is under control					
Discussions about treatments				No or limited treatment options					
Decisions about treatment	An individual process								

## Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Considerations when making decisions about treatment	Severity of side effects Treatment effectiveness								Treatment effectiveness
Changes in approach to decision making	More informed over time								
Side effects	No significant side effects No difficult side effects			No significant side effects					
Adherence to medication	As long as it works AD needs to disappear								
Complementary therapies	Creams and gentle soaps Use of comp. therapies in general	Creams and gentle soaps	Dietary changes						
Access to information		Through their treating clinician		Through their treating clinician  Did not seek information at all					
Helpful information	Information about diet								
Unhelpful information	No information is unhelpful Conflicting information								
Timing of information	During flares No preference When busy/not distracted	When busy/not distracted		When busy/not distracted					



## Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Trusted information			Information from government						
Partners in Health				Lower coping and total score		Higher care coordination score			
Health professional communication	Positive and holistic	Positive and holistic	Positive and holistic	Positive and holistic					
Care coordination		Better navigation and communication						Received better care	
Respect	Treated respectfully Not being heard			Treated respectfully Not being heard	Not treated respectfully				
Care and support				No additional support needed					No additional support needed
Average no. symptoms experienced	4	6.12	7	7.36					
Quality of life	Impact on self- esteem Impact on relationships Impact on being able to work Itch affecting sleep No impact on sleep								
Everyday activities to maintain health	Daily routine of moisturizers	Avoid certain foods		Avoid certain foods					
Impact on relationships	No burden on relationships Significant burden on relationships								

## Summary

	Mild AD	Moderate AD	Severe AD	Very severe AD	Depression/ Anxiety	Regional/ Rural	Metropolitan	University educated	High school/ Trade educated
Burden on family	No assistance now, but would have in earlier years	No additional assistance needed							
Fear of Progression				Greater fear of progression	Greater fear of progression				

Key

Less frequently

More frequently