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A report for the Australia Alopecia Areata Foundation Inc.

Associations between physical activity, quality of life and mental health in patients with Alopecia Areata: *The Physical Activity, quality of Life and Mental health (PALM) pilot study*.

Prepared by:

Ms Yamuna Rajoo[a]

Dr Jason Wong[a,b]

Dr Isaac Selva Raja[a]

[a]School of Health and Biomedical Science, [b]School of Education

RMIT University, Melbourne Australia

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ACKNOWLEDGEMENT

INTRODUCTION

Alopecia Areata (AA) is an autoimmune condition that is characterized by the appearance of patches of non-scarring hair loss.[1] In the general population, the prevalence was estimated at 0.1-0.2% with a lifetime risk of 1.7%.[2,3] Both genetic predisposition and environmental factors such as psychological stress levels play a role in its development.[1, 4]

Alopecia Areata is categorized into three different forms according to distinctive clinical patterns of hair loss. Patchy alopecia is a small round or patchy bald lesion usually on the scalp, that can progress to total loss of scalp hair only which is known as alopecia totalis. Alopecia universalis is characterized by total loss of all body hair. [4]

Although the physical effects of AA are only cosmetic, one possibly debilitating characteristic of this condition is that it is associated with depression and anxiety disorders as well as decreased quality of life (QoL). [1,5] Patients diagnosed with AA often consider their hair loss to be a serious problem, subsequently leading to distress and negatively impacting their QoL. Over half of patients with AA experience poor health-related quality of life. [6]

Physical activity (PA) is one intervention that has positive effects on mental health [7,8] and QoL.[9] However, the associations between physical activity, mental health and QoL in AA patients have not been investigated previously. The aim of this pilot study is to examine the associations of physical activity (PA), mental health and QoL among Australian AA patients. It is important to understand these associations so that interventions to improve mental health and QoL in AA patients can be developed.

METHODS

The Physical Activity, quality of Life and Mental health (PALM) study

Participants and study design

The pilot study was conducted in Australia and a cross-sectional approach was used to provide quantitative data on associations between physical activity, quality of life and mental health in participants who have been diagnosed with Alopecia Areata (AA).

Recruitment

A total of 83 participants were recruited through the Australia Alopecia Areata Foundation Inc (AAAF) network and social media page (i.e. Facebook), word of mouth and via collaborators' private practices. All the participants were diagnosed by a dermatologist or clinician with at least one type of AA. The study protocols were approved by the Human Research Ethics Committee of RMIT (Royal Melbourne Institute of Technology) University, Australia in accordance with the National Health and Medical Research Council's guidelines (Approval reference: 59/14[19131] (Appendix B). Participants were given detailed information about the study aims, objectives and procedures. Informed consent was implied by the completion and return of the anonymous questionnaire. Participation was voluntary and participants could withdraw from the study at any time.

PALM Measures/Questionnaire (Appendix A)

The self-administered PALM questionnaire was devised in 2015 and captures data about demographic characteristics (age, self-rated health status, education levels and annual income), AA status, severity and relapse, and lifestyle behaviours (e.g. smoking status). Socio demographic data and characteristics of the disease such as duration, onset and treatments in the recent period were recorded.

Anthropometric assessment

Self-reported height (m) and weight (kg) were used to calculate body mass index (BMI; kg/m^2) and participants were classified as underweight (<18.50 kg/m^2), normal ($18.50 - 24.99$ kg/m^2), overweight (≥25.00 kg/m^2) and obese (≥30.00 kg/m^2) according to the World Health Organization's protocol. [10]

Physical Activity Assessment-The International Physical Activity Questionnaire (IPAQ)

The International Physical Activity Questionnaire (IPAQ) was used to capture physical activity participation and sitting time. The IPAQ has demonstrated reliability and validity against other self-report PA instruments (Spearman's ρ 0.8, 0.3 respectively). [11] Total moderate to vigorous physical activity (MVPA) in min/day was calculated by combining the activity score of both moderate and vigorous intensity activity for each work and recreational activity domain. Responses were converted to Metabolic Equivalent Task minutes per week (MET-min/week) according to the IPAQ scoring protocol. Participants were further classified into three categories (low, moderate, or high) according to their total PA per week (MET-min/week) based on the IPAQ guidelines with the following criteria:

• High: A person meeting any of the following criteria is classified in this category: (1) Vigorous-intensity activity on at least three days achieving a minimum of 1500 MET-min/week or seven or more days of any combination of walking, moderate-or (2) vigorous-intensity activities achieving a minimum of 3000 MET-min/week

• Moderate: A person not meeting the criteria for the 'high' category, but meeting any of the following criteria is classified in this category: (1) Three or more days of vigorous-intensity activity of at least 20 minutes per day or five or more days of moderate-intensity activity or (2) walking for at least 30 minutes per day or five or more days of any combination of

walking, moderate-or vigorous-intensity activities achieving a minimum of 600 MET-min/week.

• Low: A person not meeting any of the above-mentioned criteria.[6]

Total PA time in MET-min/week was then used to categorized participants as 'meeting' or 'not meeting' guidelines, based on the criterion of achieving at least 600 MET-minutes/week (150 minutes) or more of at least moderate-intensity PA per week. [12]

Alopecia Areata – Quality of Life Index (AA-QLI)

The impact of AA on QoL was evaluated with a recently developed AA specific questionnaire. The Alopecia Areata – Quality of Life Index (AA-QLI) has been validated with the Dermatology Life Quality Index (DLQI) and shown to provide more comprehensive insights about psychological distress among AA patients specifically. [13] The results of quality life index have been presented on a scale varying between 0 and 84; A score 0 represents the best QoL, while a score of 84 represents the poorest QoL outcomes. The AA-QLI consists of questions covering three areas of daily life: (i) subjective symptoms; (ii) relationship; and (iii) objective signs.

The Depression and Anxiety Stress Scale (DASS21) questionnaire

Mental health status of the participants was assessed using the Depression and Anxiety Stress Scale (DASS 21) questionnaire. The DASS21 questionnaire measures three subsets of mental health: Depression (DASS21-D), Anxiety (DASS21-A), and Stress (DASS21-S). The essential function of the DASS 21 is to assess the severity of the core symptoms of Depression, Anxiety and Stress. Each subset comprises of 7 items with responses to reflect severity scales: did not apply to me at all, applied to me to, applied to me to a considerable degree and applied to me very much. To yield equivalent scores with the full DASS 42

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questionnaire, the total score of each scale was multiplied by two, and scores ranged from 0 to 42. [14]

Statistical analyses

Statistical analyses were carried out using the SPSS software (Statistical Package for the Social Sciences) program for windows version 24 (SPSS Inc., Chicago, IL). Descriptive statistics were expressed as means (± SD), frequencies and percentages. Variables were expressed as categorical data and were examined using chi square test between participants meeting and not meeting PA guidelines. Logistic regression was performed to examine the association between PA, QoL and mental health. A p value < 0.05 was taken to indicate statistical significance.

RESULTS

Socio demographic

A total of 83 participants with a mean age of 41 ± 13.24 years participated in this study from various backgrounds. Almost half of the participants had normal BMI range (49.2%; 95%CI=36.1%-62.3%). The proportion of participants who obtained at least bachelor degree, graduate diploma or postgraduate degree was 45.9% (95%CI=33.1%-59.2%). 75.4% (95%CI=62.7%-85.5%) of the participants originated from Australia while the rest came from New Zealand, USA, Canada, and non-English speaking countries such as Europe, Middle East and Asia. 49.3% (95%CI=37.4%-61.3%) of participants reported their self-rated health as fair and good while the remaining reported very good and excellent health status as shown in Table 1.

Table 1. Demographic and socio demographic characteristics of Alopecia Areata (AA) patients (N=83)

Characteristics of participants	N = 83	Percentage (%)
Age (years)		
18-24	7	11.5
25-44	29	47.5
45-64	22	36.1
>64	3	4.9
BMI (Body Mass Index; kg/m^2)		
Underweight (<18.50)	11	18.0
Normal (18.50 - 24.99)	30	49.2
Overweight (≥25.00)	17	27.9
Obese (≥30.00)	3	4.9
Education attainment		
Year 10 or equivalent	8	13.1
Year 12/ trade certificate/diploma	25	40.9
Bachelor degree/Graduate diploma/Postgraduate	28	46.0
Annual Income (AUD)		
< 40,000 per annum	18	30.5
40,001 - $80,000 per annum	26	44.1
>80,001 per annum	15	25.4
Country of origin		
Australia	46	75.4
Others	15	24.6
Self-rated health		
Fair/Good	36	57.1
Very good/Excellent	37	42.9
Smoking Status		
Smoker	6	8.1
Non-smoker	57	77.0
Ex-smoker	11	14.9

Epidemiology of AA

As shown in Table 2, all the participants were diagnosed with a least one form of AA, however only 56.6% (95%CI=45.3%-67.5%) of the participants reported the specific forms of AA. Alopecia Universalis was predominant among the participants with 52.8% (95%CI=38.6%-66.7%) of them reporting this, followed by Patchy Alopecia (37.7% ;95%CI=24.8%-52.1%) and Alopecia Totalis (9.4%; 95%CI=3.1%-20.6%). Mean age of AA onset was 24.5 ± 15.48 years ranging from 1 to 65 years, whereas the mean duration of living with this condition was 15.2 ± 13.36 years, ranging from 1 to 66 years. The scalp is the most common site of involvement, with or without involvement of other body sites such as the eyebrows, eyelashes, and pubic hair. Participants diagnosed with Alopecia Universalis (65.9%; 95%CI=49.4%-80.0%) had more hair loss affecting more than half the scalp

compared to participants diagnosed with Alopecia Totalis (12.2%; 95%CI=4.1%-26.2%) and

Patchy Alopecia (22.0%; 95%CI=10.6%-37.6%). A high percentage (65.9%; 95%CI=49.4%-

80.0%) of hair loss affecting more than half the scalp was significantly associated (p=0.004)

with participants with Alopecia Universalis as shown in Table 2. Hair loss affecting

eyebrows, eyelashes and pubic hair were reported to be 56.6% (95%CI=45.3%-67.5%),

44.6% (95%CI=33.7%-55.9%), and 47.0% (95%CI=35.9%-58.3%) respectively. The

treatment of choice of the participants for their hair loss were topical creams or lotions at

45.8% (95%CI=34.8%-57.1%) followed by prednisolone or cortisone tablets at 33.4% (95%

CI=23.7%-45.0%), intra dermal injections at 25.3% (95%CI=16.4%-36.0%), other

immunosuppressants at 19.3% (95%CI=11.4%-29.4%) and 12.1% (95%CI=5.9%-21.0%) did

not opt for any treatment.

Table 2. Relationship of Alopecia Areata (N= 47) age groups (N=61) and scalp involvement

Variables	N	Alopecia Areata								
		Alopecia Totalis			Alopecia Universalis			Patchy Alopecia		
Age (years)		n	%	p	n	%	p	n	%	P
18-24	7	0	0		1	14.3		2	28.6	
25-44	29	4	13.7		8	27.6		10	34.5	
45-64	22	0	0	0.174	15	68.2	0.036*	5	22.7	0.236
>64	3	0	0		2	66.7		0	0	
Affected scalp surface										
<10%	6	0	0		0	0		6	100	
10% to 25 %	3	0	0	0.656	0	0	0.004*	3	100	0.000*
>25% but <50%	3	0	0		1	33.3		2	66.7	
50% and above	41	5	12.2		27	65.9		9	22.0	

* $p < 0.05$, significant correlation

Depression, Anxiety and Stress Scale (DASS21)

The severity for each subset of mental health was categorized to normal, mild, moderate, severe and extremely severe, as shown in Table 3. Participants with normal severity for all scales were considered asymptomatic while mild, moderate, severe and extremely severe were considered as symptomatic. [15] All the participants were considered symptomatic for anxiety and depression, however 8.4% (95%CI=3.4%-16.6%) of participants had normal levels of stress and were considered as asymptomatic. More than half of participants at 66.3% (95%CI=55.1%-76.3%) reported extremely severe for anxiety and a slightly lower percentage reported being extremely depression (47.0%; 95%CI=36.0%-58.3%) and stress (37.3%; 95%CI=27.0%-48.6%).

Table 3. Severity Ratings Index of Depression, Anxiety and Stress (DASS21) N=83

Severity	Depression		Anxiety		Stress	
	n	%	n	%	n	%
Normal/Mild	0	0	0	0	12	14.4
Moderate/Severe	44	53.0	28	33.7	40	48.3
Extremely Severe	39	47.0	55	66.3	31	37.3
Total	83	100	83	100	83	100

Physical Activity (PA) participation

The majority of the participants did not meet PA guidelines (81.9%; 95%CI=72.0%-89.5%). As shown in Table 4, only one-fifth of participants reported meeting PA guidelines (18.1%; 95%CI=10.5%-28.1%). An age dependency relationship was observed with PA participation. Among participants meeting PA guidelines, results indicated that middle-aged adults (45-64 years) were significantly (*p*=0.021) more likely to meet PA guidelines (33.3%; 95%CI=11.8%-61.6%) than all other age groups, as shown in Table 4. Among participants who do not meet PA guidelines, adults aged 25 to 44 years old (39.7%; 95%CI=28.0%-52.3%) were significantly less likely (*p*=0.021) to participate in PA than other age groups.

Body mass index (BMI) and forms of alopecia did not show any significant association with PA. Respondents were symptomatic (mild, moderate, severe and extremely severe) with anxiety, depression regardless of meeting or not meeting physical activity.

Table 4. Characteristics of AA participants meeting and not meeting PA guidelines

Variables	Physical Activity						p value
	Meeting Guidelines (N=15)			Not Meeting Guidelines (N=68)			
	n	%	95% CI	n	%	95% CI	
Age in years							
18-24 yrs	4	26.7	7.8-55.1	3	4.4	0.0-12.4	
25-44 yrs	2	13.3	1.7-40.5	27	39.7	28.0-52.3	0.021*
45-64 yrs	5	33.3	11.8-61.6	17	25.0	15.3-34.0	
>64 yrs	1	6.7	0.1-32.0	2	2.9	0.0-10.2	
Body Mass Index (BMI)							
Underweight (<18.50)	1	6.7	0.1-32.0	2	2.9	0.0-10.2	
Normal (18.50 - 24.99)	4	26.7	7.8-55.1	13	19.1	10.6-30.5	0.873
Overweight (≥25.00)	5	33.3	11.8-61.6	25	36.8	25.4-49.4	
Obese (≥30.00)	2	13.3	1.7-40.5	9	13.2	6.2-23.6	
Forms of Alopecia Areata							
Alopecia Universalis	3	20.0	4.3-48.9	25	36.8	25.4-49.4	
Alopecia Totalis	2	13.3	1.7-40.5	3	4.4	0.0-12.4	0.242
Patchy Alopecia	3	20.0	4.3-48.9	17	25.0	15.3-34.0	
DASS 21- Depression							
Normal	0	0.0	0.0-21.80	0	0.0	0.0-5.3	
Mild	0	0.0	0.0-21.80	0	0.0	0.0-5.3	0.134
Moderate	7	46.7	21.2-73.4	25	36.8	25.4-49.4	
Severe	0	0.0	0.0-21.80	12	17.7	9.5-28.8	
Extremely Severe	7	46.7	21.2-73.4	18	26.5	16.5-38.6	
DASS 21- Anxiety							
Normal	0	0.0	0.0-21.80	0	0.0	0.0-5.3	
Mild	0	0.0	0.0-21.80	0	0.0	0.0-5.3	0.585
Moderate	1	6.7	0.1-32.0	7	10.3	4.2-20.1	
Severe	3	20.0	4.3-48.9	17	25.0	15.3-34.0	
Extremely Severe	10	66.7	38.4-88.2	31	45.6	33.5-58.1	
DASS 21- Stress							
Normal	1	6.7	0.1-32.0	6	8.8	3.3-18.2	
Mild	0	0.0	0.0-21.80	5	7.35	2.4-16.3	
Moderate	4	26.7	7.8-55.1	10	14.7	7.3-25.4	0.708
Severe	5	33.3	11.8-61.6	21	30.9	20.2-43.2	
Extremely Severe	4	26.7	7.8-55.1	13	19.1	10.6-30.5	

* $p < 0.05$, significant correlation

Association of physical activity, quality of life and mental health

Physical activity did not show any association with QoL and mental health. This is due to the relatively small number of participants reporting meeting PA guidelines 18.1% (95%CI=10.5%-28.1%) compared to not meeting PA guidelines 81.9% (95%CI=72.0%-89.5%). The mean QoL score observed was 47.36±12.63 ranging from 26 to 75. QoL has

significant association with stress (B=0.094, SE=0.044, p=0.031) (not shown in table). Participants who have low QoL are significantly more likely to experience stress.

Table 5. Odds ratio and 95%CI for participants meeting PA guidelines

Variables	Physical Activity							
	B	SE	Wald	df	p	95% CI		
						OR	LB	UB
Age (y)	0.010	0.027	0.149	1	0.700	1.010	0.959	1.064
Body mass index (kg/m2)	-0.049	0.080	0.383	1	0.536	0.952	0.814	1.113
DASS depression	0.073	0.048	2.304	1	0.129	1.075	0.979	1.181
DASS anxiety	0.035	0.066	0.287	1	0.592	1.036	0.911	1.178
DASS stress	-0.053	0.065	0.651	1	0.420	0.949	0.835	1.078
QoL score	0.018	0.038	0.235	1	0.628	1.019	0.946	1.097
Hair loss: scalp involvement of 50% and above *	1.088	0.770	1.994	1	0.158	2.968	0.656	13.437
Constant	-2.933	2.891	1.029	1	0.310	0.053		

*Data were expressed as categorical variable
** $p < 0.05$, significant correlation
SE = standard error, CI = confidence interval, LB = lower bound, UB = upper bound

DISCUSSION

This study examines the association between PA, QoL and mental health among the AA participants. Alopecia universalis was the most common condition, followed by patchy alopecia and alopecia totalis. In contrast, a recent review indicated that patchy alopecia is the most common pattern of alopecia.[4] The onset of AA might be at any age, however most patients develop the condition before 40 years of age, with a mean age of onset between 25 to 36 years.[4] Our findings reported similar observations, as the mean age of AA onset was around 25 years old.

The DASS- 21 questionnaire was used to evaluate mental health status. All the respondents were symptomatic with anxiety and depression. The results are in agreement with an earlier study conducted in 1991 where high rates of anxiety (39%) and depression (39%) were reported in a cohort of 31 AA participants in United States.[16] Similar results were also

observed in a study conducted in Iran, with a high proportion of participants suffering from anxiety (47%) and depression (56%) respectively.[17] Gulec et al. (2004) suggest that stressful life events may act as a trigger in the onset and/or exacerbation of these symptoms.[5]

This study fndings indicated that PA did not have any associations with QoL and mental health. In contrary, PA participation has shown to improve QoL outcomes among general population in Australia. Perales et al. (2014) concluded that a change in PA participation from undertaking no MVPA at all to undertaking some activity once a week was remarkably associated with higher QoL.[18] Results from our study remain inconclusive due the small number of participants who meet the PA guidelines. Based on self-report data from 2011 to 2012 in the Australian Health Survey (AHS), over 1 in 2 adults (56%) do not meet PA guidelines.[12] Therefore, the proportion of participants who did not meet PA guidelines (81.9%) in the current study was much higher than that in the general Australian population. This indicates that there is a need to engage AA participants to participate in PA and enjoy health benefits.

Psychological intervention such as counselling and support groups is the most common intervention for AA.[19] Interventions in the form of PA among AA participants have not been reported before. Several studies have shown that PA participation have positive impact on QoL and mental health among Australian population. [18,20] Therefore, PA interventions need to be developed to improve QoL and mental health outcomes in AA populations as well.

STRENGTHS

To the best of our knowledge, this was first study to investigate the relationship between PA, QoL and mental health among AA participants. We also attempted to use an AA specific questionnaire to elicit responses about participants' QoL.

LIMITATIONS

As this was a pilot study, we did not consider gender effects nor was the gender of the participant was recorded. Therefore, this study was not able to interpret any findings in relation to gender. The participants did not answer all the stated questions hence leading to missing data in the statistical analyses. Apart from that, missing data lead to inconsistency in reporting descriptive statistics.

Finally, the AA-QLI instrument used (as part of the PALM study) has its shortcomings. Although Fabbrocini and colleagues (2013) validated their instument using structural equation modelling (SEM) with DLQI, it must be noted that the relatively low number of participants (50 participants) in their study created reliability issues in the modeling. To yield reliable outcomes, a sample size of at least 200 participants are recommended for accurate estimates in SEM modeling.[21]

RECOMMENDATIONS

This study only involved adult participants. It is important to consider children and adolescents for future studies. Growing children undergoing hair loss may experience bullying at school leading to lower QoL, coupled with depression, anxiety and stress.[22] Therefore, it is important to include children and adolescents to assess their mental health, QoL status and the impact of PA. Further research is required to investigate the sustainability

of the positive effects of PA over time, and to determine essential attributes of exercise (mode, intensity, frequency, duration, timing). Considerations of objectively measured PA through accelerometry or pedometers for optimal effects on QoL and mental health could be utilized for future studies. Expanding this study to bigger pools of participants which data on gender would give a greater insights and associations between PA, QoL and mental health on a population-based study.

CONCLUSION

Our study findings indicate that there is an urgent need for increased PA levels among AA participants. As PA participation is known to bring about a wide range of health benefits,[23] it is possible that it may also help to improve QoL and mental health in AA patients.

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The **P**hysical **A**ctivity, quality of **L**ife and **M**ental health (**PALM**) study

Questionnaire

Participant ID: _____

Your answers are strictly **PRIVATE and CONFIDENTIAL**

Section 1: Physical activities you might do

The following questions will ask about the time you spent being physically active in the **last 7 days.** Please answer each question even if you do not consider yourself to be an active person.

These questions need an estimate of the time (hours, minutes) or number of times you engaged in certain activities. **For example**:

Days per week
3

AND

Total time	
Hours	Minutes
3	30

If none, just write zero:

Days per week
0

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aero-bics, of fast bicycling?

    If zero →→ skip to question 3.

Days per week	

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

    ☐ Don't know/Not sure

Total time	
Hours	Minutes

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

Days per week	

If no moderate physical activities →→ skip to question 5.

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

Total time	
Hours	Minutes

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**.
This includes at work and at home, walking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

Days per week	

If no walking →→ skip to question 7.

6. How much time did you usually spend doing **walking** on one of those days?

Total time	
Hours	Minutes

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

Total time	
Hours	Minutes

☐ Don't know/Not sure

Section 2: Quality of Life

The aim of this questionnaire is to measure how much alopecia areata has affected your life. Please read each statement and cross the description that indicates how much the statement applied to you **over the past week**. There are no right or wrong answers.

Have you been diagnosed with alopecia areata by a clinical professional?

If Yes→→ proceed with Section 2

If No →→ skip to Section 3

1. I feel uncomfortable using a wig

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

2. I tend to hide my scalp with hats or bandanas

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

3. I am sad about the appearance of my hair/eyebrows/eyelashes

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

4. I worry about this hair problem for the rest of my life

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

5. I cannot forget that I have this hair problem

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

6. I worry that it might spread

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

7. I do not take my wig/hat/bandana off in front of my partner/relatives/friends

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

8. It cost me a lot of money to look after my hair

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

9.   I am afraid my children may have alopecia areata

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

10.   I feel that people find it unpleasant to look at me

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

11.   I think other people notice my hair/eyebrows/eyelashes problem

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

12.   I am afraid that other people think my hair looks badly cared for

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

13.   I am embarrassed when going out to a party

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

14.   I have to explain to others what is wrong with my hair/eyebrows/eyelashes

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

15.   I feel that others are afraid of catching diseases from me

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

16.   I feel I have sexual difficulties because of alopecia areata

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

17.   I feel I have difficulties in establishing relationships with friend and/or relatives

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

18.   My work/studying has deteriorated because of alopecia areata

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

19.   My scalp is visible

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

20.   I lose tufts of hair when I comb or shampoo

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

21.   I feel itchy on my scalp

Not affected	A little	A lot	Highly affected
☐☐	☐☐	☐☐	☐☐

22.   How old were you when you first experienced alopecia areata?

_____ years old

23.   When was the last relapse?

Time of last relapse	
Months	Days

24.   What was the percentage of the affected skin?

_____ %

Section 3: Mental Health

The following questions will ask about your state of mind.

Please read each statement and cross the description that indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The *rating scale* is as follows:

Never- Did not apply to me at all

Sometimes- Applied to me to some degree, or some of the time

Often- Applied to me to a considerable degree, or a good part of the time

Almost Always- Applied to me very much, or most of the time

1. I found it hard to wind down

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

2. I was aware of dryness of my mouth

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

3. I couldn't seem to experience any positive feeling at all

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

5. I found it difficult to work up the initiative to do things

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

6. I tended to over-react to situations

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

7. I experienced trembling (eg, in the hands)

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

8. I felt that I was using a lot of nervous energy

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

9. I was worried about situations in which I might make a fool of myself

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

10. I felt that I had nothing to look forward to

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

11. I found myself getting agitated

Never	Sometimes	Often	Almost Always

	Never	Sometimes	Often	Almost Always
	☐☐	☐☐	☐☐	☐☐

12.   I found it difficult to relax

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

13.   I felt down-hearted and blue

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

14.   I was intolerant of anything that kept me from getting on with what I was doing

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

15.   I felt I was close to panic

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

16.   I was unable to become enthusiastic about anything

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

17.   I felt I wasn't worth much as a person

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

18.   I felt that I was rather touchy

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

19.   I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

20.   I felt scared without any good reason

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

21.   I felt that life was meaningless

Never	Sometimes	Often	Almost Always
☐☐	☐☐	☐☐	☐☐

Section 4: Lifestyle behaviours

The following questions will ask about your diet, smoking and alcohol consumption and general health.

1.   How many serves of vegetables (including fresh, dried, frozen and tinned vegetables) do you usually eat each day?

One serve of vegetables is a cup of salad, half a cup of cooked vegetables or a medium-sized potato (excluding chips).

☐☐	None
☐☐	Less than 1 serve
☐☐	1 serve
☐☐	2 serves
☐☐	3 serves
☐☐	4 serves
☐☐	5 serves
☐☐	6 + serves

2.   How many serves of fruit (including fresh, dried, frozen and tinned fruit) do you usually eat each day?

1   serve of fruit is 1 medium-sized piece (or 2 smaller-sized pieces) of fresh fruit, 1 cup of canned or chopped fruit, half a cup of fruit juice, or 1½ table-spoons of dried fruit.

☐☐	None
☐☐	Less than 1 serve
☐☐	1 serve
☐☐	2 serves
☐☐	3 serves
☐☐	4 serves
☐☐	5 serves
☐☐	6 + serves

3. **Have you had an alcoholic drink of any kind in the last twelve months?**

☐☐**Yes**

☐☐**No**

4. **Please record how often in the last 12 months you have had each of the following number of standard drinks in a day?**

100ml small glass of wine, 12% alc./vol
or
285ml full strength beer, 4.9% alc./vol
or
30ml spirit nip, 40% alc./vol
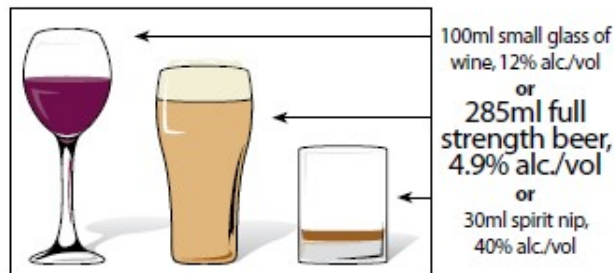
Examples of one standard drink

Drinks/day	Every day	5-6 days/ wk	3-4 days/ wk	1-2 days/ wk	2-3 days/ mth	About 1day/ mth	Less often	never
20+	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
11-19	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
7-10	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
5-6	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
3-4	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
1-2	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
<1	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
0	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐

5. **Do you currently smoke cigarettes, cigars, pipes or other tobacco products?**

☐☐Yes

☐☐No

6. **If you smoke, but not daily, on average, how many cigarettes do you smoke per week?**

Cigarettes Per week		

7. **Have you smoked at least 100 cigarettes in your entire life?**

☐☐Yes

☐☐No

8. **In the last 12 months, have you successfully given up smoking for more than a month?**

☐☐Yes

☐☐No

9. **In the last 12 months, have you tried to give up smoking but been unsuccessful?**

☐☐Yes

☐☐No

10   In general, would you say your health is...

Please choose **only one** of the following:

Poor	Fair	Good	Very good	Excellent
☐☐	☐☐	☐☐	☐☐	☐☐

Section 5: About you

The following questions will ask some general questions about you.

1.   What is your current age?

Years	

2.   What is your weight?

Kilograms		

3.   What is your height?

Centimetres		

4.   Which country were you born?

Please choose **only one** of the following:

☐☐	Australia
☐☐	Other English-speaking country (e.g. UK, New Zealand, USA, Canada, South Africa)
☐☐	Non-English speaking country in Europe (e.g. Italy, Greece)
☐☐	Non-English speaking country in the Middle East or Asia (e.g. Iran, Thailand, Japan)
☐☐	Non-English speaking country in the South America or Africa (e.g. Brazil, Somalia)
☐☐	Other _____(please write)

5. **Which language do you mainly speak at home?**

☐☐ **English**

☐☐ **Other**

6. **Are you of Aboriginal or Torres Strait Islander origin?**

No	Aboriginal	Torres Straits Islander	Both
☐☐	☐☐	☐☐	☐☐

7. **What is the postcode where you live?**

8. **Which of the following best describes your household type?**

Please choose **only one** of the following:

☐☐ Person living alone

☐☐ Married or defacto couple only

☐☐ Married or defector couple living with children

☐☐ One person living with children

☐☐ Shared household

☐☐ All other households

9. **What is the highest qualification you have ever COMPLETED?**

Please choose **only one** of the following:

☐☐ No formal qualifications after school

☐☐ Primary school only

☐☐ Year 10 or equivalent

☐☐ Year 12 or equivalent

☐☐ Technical or trade certificate

☐☐ Diploma or advanced diploma

☐☐ Bachelor degree

☐☐	Graduate diploma or graduate certificate
☐☐	Postgraduate degree

10.   How do you manage on the income you have available?

Please choose **only one** of the following:

☐☐	It is impossible
☐☐	It is difficult all of the time
☐☐	It is difficult some of the time
☐☐	It is not too bad
☐☐	It is easy

11.   Do you work…

Full time	Part time	Casual
☐☐	☐☐	☐☐

12.   In a usual week, how much time in total do you spend at work in paid employment?

Total time	
Hours	Minutes

13.   How would you describe your work?

☐☐	Manager (e.g., chief executive, general manager, legislator, farm manager, sales manager, service manager)
☐☐	Professional (e.g., journalist, accountant, engineer, scientist, teacher, nurse or allied health professional, IT worker, solicitor, social worker)
☐☐	Technician or trades worker (e.g., electrician, mechanic, carpenter, butcher, chef, horticulturalist, hairdresser)
☐☐	Community or personal service worker (e.g., health support worker, childcare worker, teacher aide, waiter, security officer, personal trainer)
☐☐	Clerical or administrative worker (e.g., secretary, receptionist, book keeper)
☐☐	Sales worker (e.g., real estate agent, retail sales assistant, checkout operator)
☐☐	Machinery operator or driver (e.g., plant operator, delivery driver, bus driver, store person)

14. **How much do you earn in a typical year? Please discount any bonuses from this figure.**

Please choose **only one** of the following:

☐☐	Under $20,000 per annum
☐☐	$20,000 - $40,000 per annum
☐☐	$40,000 - $60,000 per annum
☐☐	$60,000 - $80,000 per annum
☐☐	$80,000 - $100,000 per annum
☐☐	$100,000 - $120,000 per annum
☐☐	More than $120,000 per annum
☐☐	Other

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

PARTICIPANT INFORMATION

Project Title: Associations between physical activity, quality of life (QoL) and mental health in patients with Alopecia Areata: *The **P**hysical **A**ctivity, quality of **L**ife and **M**ental health (**PALM**) study.*

Investigators:
Dr Isaac Selva Raj, PhD
Discipline of Exercise Sciences
RMIT University
Ph: 9925 7037
Fax: 9467 8181
Email: isaacselva.raj@rmit.edu.au

Dr Jason Wong, PhD
Discipline of Exercise Sciences
RMIT University
Ph: 9925 7454
Fax: 9467 8181
Email: jason.wong@rmit.edu.au

Professor David Castle
University of Melbourne and St. Vincent's Hospital

Dr Alvin Chong
St. Vincent's Hospital

Dr Jack Green
St. Vincent's Hospital

Dear Participant,

You are invited to participate in a research project being conducted by RMIT University. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?

This project, which has been approved by the RMIT Human Research Ethics Committee, is being conducted by Dr Isaac Selva Raj and Dr Jason Wong from RMIT University with expert advice from Dr Jack Green, Dr Alvin Chong and Professor David Castle from St. Vincent's Hospital. This research project will investigate the relationships between physical activity, quality of life and mental health in patients diagnosed with Alopecia Areata (AA).

Why have you been approached?

Participation in physical activity is related to better scores in quality of life and mental health domains. However, this relationship is not well understood in AA patients. We would like to understand how physical activity impacts on your quality of life and mental health.

What is the project about? What are the questions being addressed?

The aims of this study are to examine the associations between physical activity, quality of life and mental health among Australian AA patients.

If I agree to participate, what will I be required to do?

You will be required to complete an anonymous survey either online or in hardcopy. It should take you about 15 minutes to complete the survey. The survey will ask you questions about the time you spent being physically active, your state of mind, your lifestyle, general health and about how much alopecia areata has affected your life.

What are the possible risks or disadvantages?

There may be a small risk of psychological issues being brought up as a result of completing the survey. A counselling service provided by a trained clinical psychiatrist will be made available in these cases. If you are unduly concerned about your responses to any of the questionnaire items or if you find participation in the project distressing, you should contact Professor David Castle as soon as convenient. He will discuss your concerns confidentially and suggest appropriate follow-up, if necessary.

Contact details are as listed below.

Professor David Castle
Professor of Psychiatry
Tel: (03) 9288 4751
Email: djcastle@unimelb.edu.au

What are the benefits associated with participation?

This study may benefit the wider community by adding new scientific knowledge regarding the effects of physical activity on quality of life and mental health in Alopecia Areata (AA) patients. The results of this study may contribute to recommendations and promotion of physical activity for AA patients to improve quality of life and mental health.

What will happen to the information I provide?

Your survey responses are completely anonymous. We expect to publish a scientific paper in an appropriate peer-reviewed journal and present the results at a scientific conference. We will report only aggregated data. The scientific manuscript will also be published in the RMIT Repository, which is a publicly accessible online library of research papers. You are invited to contact the researchers to obtain information regarding the findings of the project.

The research data (i.e. the raw information) will be kept securely at RMIT University for 5 years, before being destroyed, whereas the final research paper will remain online. We assume that you have given your written informed consent to this study when you complete and return the anonymous survey.

Security of the website

Users should be aware that the World Wide Web is an insecure public network that gives rise to the potential risk that a user's transactions are being viewed, intercepted or modified by third parties or that data which the user downloads may contain computer viruses or other defects.

Security of the data

This project will use an external site to create, collect and analyse data collected in a survey format. The site we are using is Qualtrics. If you agree to participate in this survey, the responses you provide to the survey will be stored on a host server that is used by Qualtrics. No personal information will be collected in the survey so none will be stored as data. Once we have completed our data collection and analysis, we will import the data we collect to the RMIT server where it will be stored securely for five (5) years. The data on the Qualtrics host server will then be deleted and expunged.

What are my rights as a participant?

You have the right:

- To withdraw from participation at any time without the need to provide any reason. Choosing not to participate or withdrawing from this project will not affect your relationship with the researchers, research assistants or RMIT University.
- To request that any recording cease.
- To have any unprocessed data withdrawn and destroyed, provided it can be reliably identified, and provided that so doing does not increase the risk for you.
- To be de-identified in any photographs intended for public publication, before the point of publication.
- To have any questions answered at any time.

Whom should I contact if I have any questions?

Please contact either Dr Isaac Selva Raj or Dr Jason Wong if you have any questions. Contact details for Dr Selva Raj and Dr Wong are provided at the start of this letter.

What other issues should I be aware of before deciding whether to participate?

This project does not have any funding sources.

Yours sincerely

Dr Isaac Selva Raj
PhD, AEP

Dr Jason Wong
PhD

Professor David Castle
FRANZCP, FRCPsych

Dr Alvin Chong
MBBS, M.Med (Melb), FACD

Dr Jack Green
MBBS(Hons), FRACGP, FACD

If you have any concerns about your participation in this project, which you do not wish to discuss with the researchers, then you can contact the Ethics Officer, Research Integrity, Governance and Systems, RMIT University, GPO Box 2476V VIC 3001. Tel: (03) 9925 2251 or email *human.ethics@rmit.edu.au*