

## Hair Loss Research Priority Setting Partnership

### Form A: Long list of research questions

#### Alopecia Areata, Totalis, Universalis & Barbae

The uncertainties listed on this form have been gathered from a survey, last September, in consultation with people with hair loss, their parents/carers and healthcare professionals.

You are being asked to choose and rank 10 of these uncertainties.

The questions have been grouped into categories to make the document easier to follow. This grouping is for presentation only and will not influence which questions get prioritised.

**Please read through the list of questions to identify your priorities, then link to Form B (see SurveyMonkey web link found below) to rank the top 10 that you would like to see prioritised for research.**

*(A glossary of medical terminology is at the end of this document)*

	Biopathology, causes
1	What are the causes of alopecia areata? For example- medications, medical problems, lifestyle, vaccinations.
2	Does stress cause alopecia areata?
3	How can alopecia areata be prevented?
4	Are there any factors that predict who will develop alopecia areata?
5	What is the likelihood of children of affected individuals developing alopecia areata?
6	In alopecia areata, why does hair loss occur in certain localised areas and patterns?
7	Why does hair re-grow white in alopecia areata?
8	In alopecia areata, does less frequent washing/shampooing improve hair growth/ prevent loss?
9	In whom does alopecia areata hair loss progress and why?
10	In alopecia areata, what are the chances that hair will fall out again after re-growth?
11	Is alopecia areata associated with other illnesses? For example arthritis, acne.
12	Does numbness/ tingling of the skin precede hair loss in alopecia areata?
13	What can be learnt about alopecia areata from other autoimmune conditions?
14	Is alopecia areata associated with night sweats and what causes them?
15	Is Alopecia areata an 'evolutionary' condition, as hair is not needed for survival?
16	In alopecia areata, do ingredients in shampoos, conditioners, styling products and hair dyes contribute to hair loss?

Nutritional/alternative therapies	
17	Do certain foods, vitamins or nutritional supplements improve hair re-growth in alopecia areata?
18	Does iron supplementation or an iron rich diet help in the treatment of alopecia areata?
19	In alopecia areata, do vitamin D supplements improve hair growth or halt hair loss?
20	What is the role of nutrition/diet in the prevention of alopecia areata?
21	How effective are alternative therapies in alopecia areata?

Psychological aspects	
22	Are psychological interventions helpful in alopecia areata?
23	What are the psychological effects of alopecia areata on the affected individual?
24	In alopecia areata, how aware are GPs regarding the psychological impact of hair loss?
25	Do wigs improve psychological measures for people with alopecia areata?
26	Does cosmetic enhancement (e.g. tattooed eyebrows) make a significant difference to mental health in alopecia areata?

Treatment	
27	Can progression of alopecia areata be prevented by early diagnosis and treatment?
28	In alopecia areata, are biological therapies (including JAK inhibitors and anti-cytokine therapies) more effective than placebo in causing hair re-growth?
29	What is the best treatment for alopecia areata of the eyebrows and eyelashes?
30	In alopecia areata, do steroid tablets improve re-growth compared to placebo?
31	In alopecia areata, do intralesional steroid injections improve re-growth compared to placebo?
32	In alopecia areata, does PUVA phototherapy improve re-growth compared to placebo?
33	Is gene therapy effective in the treatment of alopecia areata?
34	Are intralesional steroid injections better than steroid lotions or creams in inducing hair re-growth in alopecia areata?
35	Is hair transplantation effective in alopecia areata?
36	What is the most effective treatment for childhood/adolescent alopecia areata?
37	Do any treatments have a long-term effect in alopecia areata?
38	Does wearing a wig or scarf affect hair re-growth in alopecia areata?
39	Is hormone therapy helpful in the treatment of alopecia areata?
40	Is stem cell therapy an effective treatment in alopecia areata?
41	In alopecia areata, how long should topical steroids be used for?
42	How often should intralesional steroids be given in alopecia areata?
43	Are immunosuppressant therapies (for example- methotrexate, mycophenolate mofetil) better than placebo in the treatment of alopecia areata?
44	In alopecia areata, what is the most effective treatment for turning thin re-growth into thicker hairs (terminal hairs)?
45	In alopecia areata, what factors predict whether treatment will be successful?

Miscellaneous	
46	In general practice, what is the best method of assessment of alopecia areata (for example- are blood tests helpful)?
47	In alopecia areata, what outcome measures should be used to assess severity of hair loss and impact?
48	How can wigs for alopecia areata be made more comfortable?
49	Is wig provision on the nhs for alopecia areata equitable across the UK?
50	Are support groups effective in the management of alopecia areata?
51	Is alopecia areata associated with difficulty in conceiving naturally or maintaining a pregnancy to full term?

Please use the web link below for Form B where you can rank your top ten:

<https://www.surveymonkey.com/r/areatahairlosspsp2015>

#### Glossary:

**Alopecia areata (AA)** – Alopecia areata patchy areas of hair loss. Within the context of this survey AA also includes Alopecia Totalis (AT) total loss of hair from head and Alopecia Universalis (AU) total loss of body hair.

**Biological therapies** - treatment designed to stimulate or restore the ability of the body's immune (natural internal defence) system to fight infection and disease.

**Cytokines** - are cell signalling molecules that aid cell to cell communication in immune responses and stimulate the movement of cells towards sites of inflammation, infection and trauma.

**Equitable** – fair and reasonable for all.

**Gene therapy** - a type of biological therapy. It is an experimental technique that uses genes to treat or prevent disease.

**Immunosuppressant** - a class of drugs that suppress or reduce the strength of the body's immune system.

**Intralesional steroids** – injection of a steroid solution into abnormal skin.

**JAK inhibitors** - are a type of medication that functions by inhibiting the activity of one or more of the Janus kinase family of enzymes. These inhibitors have therapeutic application in the treatment of cancer and inflammatory diseases.

**Patient outcomes** – assessing the quality of care delivered to NHS patients from the patient perspective.

**Placebo** – dummy treatment or treatment without specific activity for the condition being treated.

**Psychological intervention** - activities used to modify behaviour, emotional state, or feelings, for example cognitive behavioural therapy, hypnotherapy, mindfulness.

**Psychological measurement** - is the assignment of scores to individuals so that the scores represent some characteristic of the individuals. Psychological measurement is often referred to as psychometrics.

**PUVA phototherapy** - a combined treatment using the drug Psoralens (P) taken by mouth and then exposing the skin to UVA (long wave ultraviolet radiation) to induce UV immunosuppression.

**Stem cell therapy** - introduces new cells (stem cells) into damaged tissue in order to treat disease or injury.

**Terminal hairs** - are pigmented hairs found on the scalp, beard, armpits, and pubic area.

**Topical steroids** – creams, gels, lotions or ointments applied to the skin, containing corticosteroids.