SPRUSD
Setting Priorities & Reducing Uncertainties for people with Skin Disease

The University of Nottingham

VITILIGO SOCIETY

SETTING PRIORITIES FOR VITILIGO RESEARCH – WORKSHOP REPORT

Report of a workshop held on the 25th March 2010

at the

British Association of Dermatologists, Fitzroy Square, London

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1 About the Vitiligo Priority Setting Partnership

The James Lind Alliance (JLA) Vitiligo Priority Setting Partnership (PSP) was established in 2009 as part of a project commissioned by the National Institute for Health Research (Research for Patient Benefit) under the Programme Grants for Applied Research. The project, called Setting Priorities and Uncertainties for People with Skin Disease (SPRUSD), is being co-ordinated by the Centre for Evidence Based Dermatology in Nottingham, which incorporates the National Library for Health Skin Disorders Specialist Library, the Cochrane Skin Group and the UK Dermatology Clinical Trials Network. For the Vitiligo PSP, it partnered with The Vitiligo Society, the leading patient organisation for the condition. The Priority Setting Partnership began its process in April 2009 and held its final priority setting workshop in March 2010, where a top 10 list of vitiligo treatment uncertainties for research were agreed by patients and clinicians.

1.1 Objectives of the Vitiligo Priority Setting Partnership

- Identify and prioritise research questions that are important to people with vitiligo (their carers/parents) and clinicians
- Develop a research trial proposal from one of the top ten priorities

1.2 Partners

The Vitiligo Society, British Association of Dermatologists, University of Nottingham (and related skin disease networks such as Cochrane Skin Group), Changing Faces, James Lind Alliance, and NHS Evidence - UK DUETs, (Database of Uncertainty about the Effects of Treatments) - A Steering Group of representatives from these organisations, met to plan the whole process, including the final priority setting workshop.

2 About the workshop

2.1 Workshop objectives:

1. *To give an overview of the priority setting process and work so far*
2. *To reflect on, and discuss participants' individual views of the short list of vitiligo treatment research questions*
3. *In small and larger groups priority order the short list, noting areas of agreement and disagreement across groups, together agree the 10 most important research questions*
4. *Consider next steps, so that the 10 are taken forward for research funding.*

2.2 Workshop participants

44 people participated in the workshop:

People with Vitiligo – 16
Clinicians – 6
Nurses – 4
Other professionals – camouflage for example – 4

Members of the vitiligo society - 4

Researchers – 4 (1 with vitiligo)

Observers – 2 (National Institute for Clinical and Health Excellence NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC),

James Lind Alliance - 4 (acting as support staff and facilitators)

2.3 Pre workshop request of participants

During the workshop most of the discussion about vitiligo research was in groups. However all participants were sent the shortlist so that they could individually reflect on the research questions prior to the workshop. They were encouraged to record their views and comments on each of the questions, and rank them in order of priority. This had a dual purpose; it enabled participants to be familiar with the research questions under discussion, and ensured that everyone had something to contribute in the first discussion session.

2.4 Workshop content

Jennifer Viles, from the Vitiligo Society welcomed everyone and acknowledged the hard work that the steering group had done to get to this, final priority setting point. Sally Crowe from the JLA outlined the workshop objectives, the role of facilitators and observers, and welcomed the views and perspectives of all workshop participants.

Dr Viktoria Eleftheriadou MD, Research Associate, from the Centre of Evidence Based Dermatology outlined the work done so far to gather and prioritise treatment uncertainties in vitiligo. By sharing the methods and results of each stage of the work, participants were able to see the journey of the data from start to this point - final priority setting. Key points included:

- Awareness raising of the partnership, and the project by partner organisations
- Completion of an update of a review of all relevant research in treating vitiligo
- Survey of uncertainties (about treatments for vitiligo) sent to people with vitiligo and clinicians (professionals who treat or care for them) whereby 461 surveys were returned (online or paper).
- Within the survey responses 1427*potential* uncertainties are identified, of these 660 were treatment related, others (e.g. natural history, causes, prevention) numbered 767. In addition, 58 treatment uncertainties from the updated Cochrane systematic review and the British Association of Dermatologists guidelines for diagnosis and management of vitiligo were added making a total of 718 treatment uncertainties for vitiligo.
- Two thirds were submitted by patients and parents, one third by clinicians.
- Agreeing categories that the treatment uncertainties belong in, and where there is duplication in submissions
- Removing uncertainties that are actually answered by current research
- This results in a ‘long list’ of 93 treatment uncertainties in vitiligo
- The voting process (online and paper) in early 2010 helps to reduce this long list to a shortlist of 23 to be considered at the final workshop.

Sally Crowe, from the James Lind Alliance, who was chairing the workshop, invited questions and points of clarification at this stage. It was interesting that even at this early stage some participants wanted to influence the discussions, and voting in small groups.

Participants were then placed into four, facilitated groups each with a balance of clinician and patient participants.

Round 1 discussions (11.00 – 11.30)

This round focussed on the similarities and differences between the individual rankings with people beginning to appreciate the different (or similar!) points of view. Many participants brought their pre workshop ranking forms and had clearly given this stage of the process due care and thought. Facilitators were briefed to ensure that everyone had an opportunity to say something about their list before the end of this session.

Round 2: (11.45 – 12.45) same three groups

This round focused on creating a group rank order of all the shortlisted treatment uncertainties Facilitators used the cards (see example below) provided to position them where there was already consensus, and/or to reflect the discussion pre coffee break. Group members were encouraged to handle the cards, read the context information on the back and move them around according to group views.

Agreed ranking of treatment uncertainties was recorded by using the ID of letter/number and handed to Mark Fenton who was in charge of collating all the ranks from the four discussion groups.

The afternoon session was opened by Hilary Fassnidge, Chair of the Vitiligo Society.

After lunch Mark Fenton from UK DUETs presented the groups scores and the aggregate score so far. Participants were encouraged to challenge other groups about their choices, and appraise the aggregate rank order together.

Round 3: (14.00 – 14.45) Different group composition

For this round groups were mixed up, keeping the balance of clinicians and patients but facilitating different combinations.

The groups were now working with an aggregate list of treatment uncertainties and discussions were steered towards focussing on a top ten. Working with an aggregate list can be challenging but participants *have to accept this it is part of consensus development.* If any participant felt very strongly about the position of a particular uncertainty they were asked to hold onto this and make a case to the whole group later on the process.

Following a well earned refreshment break a large group session was convened. The combined results of all the small groups ranking resulted in a final aggregate rank order for all of the treatment uncertainties. Participants were asked to focus on the top ten of these. This was a final opportunity for participants to make a case for any particular uncertainty and its placing. Mark kept a 'live aggregate rank order going on the projection screen so that everyone could see the changes as the discussion developed. Despite some technical hitches at this stage (we used cards blu tacked on the

wall as a back up at one stage!) and some very strong and passionate arguments for particular placing of uncertainties, the group agreed a shared ranking order for the shortlisted research questions.

Participants were reminded that **all of the uncertainties** are a resource for researchers, including the original dataset, the shortlist and the top ten.

The sort of issues that emerged in the final session were very interesting and included:

- The need for robust well conducted trials for treatments that were contentious amongst the vitiligo community
- The need to balance research that explores new territories in vitiligo and addresses current regimens of treatment
- The top priorities to reflect a balanced portfolio of current and potential treatments
- Two areas of uncertainty were designated 'ones to watch' – these were areas that should be revisited at a later stage; How effective is piperine (black pepper) cream in treating vitiligo? What role might stem cell therapy play in treating vitiligo?

3. Workshop results

3.1 Final TOP10 list of vitiligo treatment uncertainties

1	Does treatment with immunosuppressants help patients with vitiligo?
2	How much do psychological interventions (such as counselling) help people with vitiligo? *SG Recommendations: systematic review to find out available/potential interventions*
3	Which treatment is more effective for vitiligo: light therapy or calcineurin inhibitors (e.g. tacrolimus, pimecrolimus)?
4	How effective is UVB light therapy when combined with creams or ointments (e.g. steroid creams) in treating vitiligo?
5	What role might gene therapy play in the treatment of vitiligo?
6	How effective are hormones or hormone related substances that stimulate pigment cells (MSH analogues, afamelanotide) in treating vitiligo?
7	Which treatment is more effective for vitiligo: calcineurin inhibitors (e.g. tacrolimus, pimecrolimus) or steroid creams/ointments?
8	Which treatment is more effective for vitiligo: steroid creams/ointments or light therapy?
9	Does the addition of psychological interventions (e.g. counselling, support) to patients receiving cosmetic camouflage improve their quality of life?
10	Is pseudocatalase cream combined with brief exposure to UVB light as recommended, effective in treating vitiligo?

4 Workshop Evaluation

4.1 Feedback on Vitiligo Priority Setting Partnership Workshop

As part of the JLA's ongoing commitment to improving its processes all participants are asked to feedback on the workshop process immediately after the workshop using a simple questionnaire. This is designed to capture people's immediate feelings and observations about the workshop process and outcomes. 25 people submitted feedback. Some respondents didn't complete all sections of the form.

Pre-Workshop Pack

How helpful was the pre-workshop pack in preparing you for the workshop?

19 respondents found it helpful, 6 very helpful

Workshop Facilitation

How satisfied were you with the way the James Lind Alliance Team facilitated the workshop?

19 respondents were very satisfied about the facilitation, 6 were satisfied.

Workshop Content

How satisfied were you that you were able to communicate your views in the workshop?

17 respondents were very satisfied that they communicated their views, 9 were satisfied.

Priority Setting Process

How satisfied are you that your views and preferences shaped the final list of vitiligo uncertainties?

16 respondents were very satisfied that their preferences were taken into account, 6 were satisfied.

Workshop outcome

How satisfied are you that we achieved the objective of establishing a top ten vitiligo treatment uncertainties for research?

8 respondents were very satisfied that the objective had been met, the rest (14) were satisfied.

Venue

How satisfied were you with the venue for the workshop?

19 respondents were satisfied or very satisfied, 1 expressed no preference.

Other free text comments about the workshop - i*n short form*

What worked well?

- Enjoyable, well organised, excellent exchange of views

- Format allowed for varied expertise and sharing of views and opinions, people were listened to
- Pleased to be involved, such an interesting and successful day
- Very interesting experience and process
- Good clean fun!
- A difficult day (but well managed and successful)

What could have been improved?

- Would have liked more on basic research, too much focus on clinical research
- Didn't like the cards, they were awkward
- Presentation materials could have been better

4.2 Longer term evaluation of Vitiligo Priority Setting Workshop

On completion of the JLA process, each PSP member was asked to feed back their views on how the process itself worked for them, via an anonymous online survey. This was an opportunity to identify strengths and weaknesses in the process, following a period of reflection from partners. Data captured by the survey will be used by the JLA to inform, develop and improve future PSPs.

This report summarises the responses from members of the Vitiligo PSP in relation to the final priority setting workshop. For the evaluation of the full priority setting process please visit http://www.lindalliance.org/Vitiligo_Priority_Setting_Partnership.asp

Thirty responses were received, so the report focuses on actual numbers, rather than percentages. Where totals do not add up to 30, it should be assumed that some respondents skipped the question. While the survey was anonymous, care has been taken to ensure the analysis does not reveal any individual identities.

The respondents

Of the 30 respondents, 17 were patients, six were clinicians and four were researchers. Three respondents indicated 'other'.

Final priority setting meeting

Twenty four of the respondents attended the final priority setting meeting. Of the 24, 11 were satisfied and 11 were very satisfied with the process. The group discussions were rated highly and the mix of participants was noted as an interesting opportunity to hear different views, and even to revise one's own view as a result. The complexity and intensity of the day, and the skill of the facilitators in managing that, were acknowledged. The information on the back of each uncertainty card was seen as particularly helpful.

> *I was satisfied with the process on the whole as uncertainties were explained to the groups and we were all asked for our opinions.*
>
> *We were able to both express our uncertainties and be heard and hear other's views. This enabled me to change my view in some cases and I think it enabled the honing down process.*

I liked the brain storming process they employed. It is difficult for me to see how it could be done better any other way.

It was an open, cooperative and enlightening process where everyone participated positively and aired their views without friction.

Although there was a tight schedule it appeared to me that many valid points were raised and decisions made. We could, I'm sure have spent many more hours debating the same thing and coming to the same conclusions, but those running the workshop kept us all on track!

It was well managed and harder as we had a bigger group and still had to work through issues where people felt strongly about items that they felt should or should not be in. It was well managed throughout.

A suggestion was added for how it might be improved:

It was more difficult as we were working with the ideas of those who felt very strongly that some should be included or not be there, but the process was well managed throughout and enabled a final result

A couple of reservations were also expressed:

The only thing I felt was that there were some there with very strong opinions, which is fair enough but those people probably influenced the way each group voted at the end.

One person was neither satisfied nor dissatisfied, while one person was dissatisfied.

I had some concerns that some of the participants' points of view were disregarded during the sorting process.

Overview of the JLA process

Twenty three respondents said they thought the priority setting process was fair and in line with the JLA's objectives of independence and freedom from bias. One did not agree and two were not sure. Some people expressed that they had been concerned that those who were more vocal or articulate may dominate and influence the final outcome, but generally felt that this had not been allowed to happen. That the JLA clearly had no vested interest, or intention to steer the outcome towards a particular type of treatment was seen as very positive. While most people felt that the discussion had been balanced and fair, there were a small number of comments about participants who had been perceived to be trying to dominate the discussion – this was levied at both clinician and patient representatives.

Twenty respondents felt that working with the JLA to prioritise treatment uncertainties for research will make a positive difference to patients, clinicians and researchers in the field of vitiligo. The mixed-stakeholder approach was seen as particularly credible and valuable. Several people expressed their sincere hope that researchers would now listen and take the outcome of the exercise seriously. It was also felt that particularly from a patient point of view, simply getting involved in this way had been personally beneficial.

Any findings from these (whether research suggestions, treatment suggestions, non-treatment psychological support, etc) will go a long way in improving the life quality with people with vitiligo and make for better satisfaction amongst the various workers concerned.

Great idea in that it puts Vitiligo on the map with other skin ailments.

I think that good management of the prioritisation process and the perception of independence is important. It felt fair. It was good to be involved. Being someone with Vitiligo, I felt that I had done something useful to help others like me, and that in itself made me feel better!

Three people said they were not sure about the impact of the JLA process, while one person did not agree – they said they felt sceptical about the prioritisation process as it was run.

Twenty three respondents said they would recommend the JLA process to their colleagues or peers. Reasons included the fact that it involves a wide variety of patients and professionals, the fact that it increases understanding of a condition among those different stakeholders and because it was professionally run.

It was most interesting to listen to everyone's viewpoint. The process was educational and enlightening to all involved.

I was extremely impressed with the way they managed the different working groups and guided them towards forming a consensus for the most satisfactory order for the top ten priorities.

Two people were not sure if they would recommend the process, because they were uncertain how applicable it would be to other conditions in their field. One person said they would not recommend it due to it being a "long-winded" process. They were unsure that the process was truly bias-free.

Aspects of the JLA process which respondents felt worked particularly well were:

- the democratic process
- the equal value of patient and clinician input
- the small mixed-group discussions
- the level of organisation and clarity of purpose
- the breadth of the initial consultation to collect uncertainties

This was the first time I was in a room with clinicians and we were all on the same level. It allowed us to voice our concerns in an informal environment.

Aspects which participants would like to have changed were:

- perceived attempts by some parties to dominate the final workshop
- a briefing session at the beginning of the day to update people on the current situation for vitiligo research and create a level playing field
- a plenary half way through the final workshop to ensure significant issues are captured before the end, may ease the pressure at the end of the workshop and ensure that there is ample opportunity for all views to be aired to all participants

Overall, it was suggested that the JLA Vitiligo priority setting process had been a "good" and "worthwhile" exercise, with the final workshop described by several respondents as "a very enjoyable day". Several respondents asked to be kept informed of the next steps and stated that they looked forward to seeing what would happen with the top 10.

Thanks to all of the Steering Group members of the Priority Setting Partnership for helping to plan and organise the event, thanks to the Nottingham team for preparing the data and presentations, to UK DUETs for keeping tabs on the ranking results and mostly to the participants who gave a whole day to the effort of reviewing research priorities in vitiligo, their energy, humour, and breadth of experience and insight proved invaluable on the day.

5 What next for priorities?

- All of the uncertainties will be added to DUETs, and are freely available at www.duets.nhs.uk. There is ongoing work to direct research groups and research funders to this source of important research questions in vitiligo.

The SPRUSD team will conduct a feasibility study on one of the top ten uncertainties, and then a funding application for a clinical trial. They will work closely with the UK Dermatology Clinical Trials Network (www.ukdctn.org)

Appendix 1

GLOSSARY of research terms (workshop pack resource)

Types of studies

Case Series: A study reporting on a consecutive collection of patients, treated in a similar manner, without a **control group** (comparison group).

Case control studies: studies used to investigate causes of diseases, or to identify adverse or side-effects of treatments. They include people with an outcome of interest and a suitable control group of people unaffected by the outcome. The occurrence of the possible cause is compared between **cases** (people with the disease/condition) and **controls** (people not know to have the disease/condition).

Cohort Studies (or follow-up studies): Studies which begin with a group of people (the cohort) free from disease but who have been exposed to a potential cause of disease or outcome. The cohort is followed up to see the subsequent development of new cases of the outcome of interest. Cohort studies provide the best information about the causation of disease and the most direct measurement of the risk of developing disease. They can also be used to measure the outcome of treatments or exposure when, for ethical reasons, it is not possible to perform an **RCT** or to investigate the effects of a rare exposure.

Controls/control group: is the comparison group, in a **Random Controlled Trial**. They receive the usual treatment (or a **placebo**) while the experimental group receives the treatment being tested.

Multi-centre trial: Refers to a study that is being done at several hospitals at once. If you see a study listed as *multicenter* you may want to choose a centre based on how close to you it is, how experienced they are with this type of treatment, or financial aid they offer.

Observational study: A type of study in which individuals are observed or certain outcomes are measured. No attempt is made to affect the outcome (for example, no treatment is given).

Parallel study: is a type of clinical study where two groups of treatments, A and B, are given so that one group receives only A while another group receives only B.

Pilot study: A pilot study is a small-scale methodological test intended to ensure that proposed methods and procedures will work in practice before being applied in a large, expensive investigation. Pilot studies provide an opportunity to make adjustments and revisions before investing in, and incurring, the heavy costs associated with a large study.

Randomised Controlled Trial (RCT): a research trial in which participants are randomly assigned to two groups: one (the experimental group) receiving the intervention that is being tested, and the other (the comparison group or controls) receiving no treatment or a conventional treatment. The two groups are then followed up to see if any differences between them result. This helps people assess the effectiveness of the intervention.

Survey: Observational or descriptive non-experimental study in which individuals are systematically examined for the absence or presence (or degree of presence) of characteristics of interest.

Within - participant study: This is most often used in dermatology trials where a particular disease is apparent in a symmetrical distribution as in common vitiligo. Instead of comparing the effect of treatment or placebo in groups of individual participants (parallel study), one side of the body is compared with the opposite side I n the same individual.

Trial Design Terminology

Adverse effects: an adverse effect is a harmful and undesired effect resulting from a medication or other intervention such as surgery. An adverse effect may be termed a "side effect", when judged to be secondary to a main or therapeutic effect, and may result from an unsuitable or incorrect dosage or procedure, which could be due to medical error.

Arms: Any of the treatment groups in a randomized trial. Most **Randomised Controlled Trials** have two *arms*, but some have three *arms* or even more.

Bias: A systematic tendency to produce an outcome that differs from the underlying truth

There are many different types of bias.

Blinding: Blinding means that whoever is assessing the effects of treatment will not know which treatment the person has received. This helps to prevent bias. Randomised trial is *Double Blind* if neither the patient nor his doctor are told which arm of the trial he is on. This information is kept at

a central office, and is typically revealed only at the end of the trial. The purpose is to prevent any bias in treatment or reporting of results from creeping in.

Conventional Therapy: a currently accepted and widely used treatment for a certain type of disease, based on the results of past research. Also called conventional treatment.

Focus Groups: Investigators use focus groups, typically gatherings of 4 to 8 people with similar background or experience, to understand their attitudes or their response to a particular situation or experience.

Incidence: Number of new cases of disease occurring during a specified period of time; expressed as a percentage of the number of people at risk.

Outcome: This is what a clinical trial is trying to measure or find out. In essence, the goal of the trial. It is scientifically very important that the goals for clinical trials be selected and clearly defined in advance. For example an outcome might be that your blood pressure is reduced as a result of taking tablets prescribed by the doctor. Outcome measures are measurements of the effects of a treatment. They might include physical measurements - for example measuring blood pressure, or psychological measurements - for example measuring people's sense of well-being. So if someone takes part in research, they may be asked questions, or may be asked to have extra tests to assess how well the treatment or service has worked.

Placebo therapy: is an inactive treatment often given to controls in trials. The **placebo** is delivered in a form, which is apparently identical to the active treatment being tested in the trial, so that the research participant is unaware of which they are taking, this helps to eliminate psychological effects on the outcome.

Prevalence: Proportion of persons affected with a particular disease at a specified time.

Randomisation or Random Allocation: Allocation of individuals to groups by chance, usually done with the aid of table of random numbers. Not to be confused with systematic allocation (e.g. on even and odd days of the month) or allocation at the convenience or discretion of the investigator

Risk: Measure of the association between exposure and outcome (including incidence, side effects, toxicity).

Other useful research terms

Evidence-Based Medicine (EBM): Using current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine requires integration of individual clinical expertise and patient preferences, with the best available evidence from good quality research.

Meta-analysis: a statistical technique, which summarises the results of several studies into a single estimate. More importance is given to studies, which have been done with larger groups of people.

Quality of life: As well as measuring the physical effects of a treatment (for example changes to your blood pressure), many trials now try to assess the impact of treatments on people's quality of life. For example, a 'quality of life' study might ask you about:

- Your mood and general sense of well-being
- Whether you feel more tired than usual
- Whether you are managing to do more things than before
- Whether your sleep patterns have changed

Systematic review is a ***review*** in which evidence on a topic has been systematically identified, appraised and summarised according to predetermined criteria.

Toxicity: An adverse effect produced by a drug that is detrimental to the participant's health. The level of toxicity associated with a drug will vary depending on the condition which the drug is used to treat.

Uncertainty: Uncertainties about treatment or the effects of treatments, that cannot currently be answered reliably by referring to up-to-date systematic reviews of existing research evidence.

Vitiligo-specific terms

Afamelanotide: This drug is being developed in Australia as a skin implant and as an injection. Afamelanotide is a man made (synthetic) form of a naturally occurring hormone called *alpha melanocyte stimulating hormone (a-MSH).* Although it can produce a tan in anyone white skinned, the aim of the development of afamelanotide is to produce a drug that can help to protect people particularly prone to skin damage and burning from exposure to the sun. The drug is not licensed yet in the UK or USA.

Autoimmune disease: An autoimmune disorder is one in which a person's immune system which normally protects the body from harmful foreign organisms, mistakenly reacts against the body's own organs or tissues, thus destroying them.

Autologous melanocyte transplantation: In this procedure, the doctor takes a sample of the patient's normally pigmented skin and places it in a laboratory dish containing a special cell culture solution to grow melanocytes. When the melanocytes in the culture solution have multiplied, the doctor transplants them to the patient's depigmented skin patches. A fairly new technology, this procedure is still in the experimental stages.

Calcineurin inhibitors: tacrolimus (Protopic ointment) or **pimecrolimus** (Elidel cream) have a moderating effect on the immume system

Corticosteroids: creams; usually potent or very potent types are prescribed for vitiligo (e.g. Betnovate, Dermovate, Cutivate, Synalar)

Depigmentation: involves gradually fading the normal skin on the body to match the already white areas. For people with more than 50 percent vitiligo, depigmentation may be the best treatment option. Patients apply the drug monobenzylether of hydroquinone (monobenzone or Benoquin) twice a day to pigmented areas. This process destroys the pigment cells, leaves the skin unprotected from sunlight and is considered irreversible.

Gene therapy: is the insertion of genes into an individual's cells and tissues to treat a disease, such as a hereditary disease. If one can isolate a gene for the non-diseased state, multiply it up, one can try introducing it into the patient. It is often very difficult to get the healthy gene into the affected tissue and to get it expressed there. It would be very difficult to treat a melanocyte disorder in this way. The genetics of vitiligo are very complicated and do not fit that pattern.

Genetic engineering: This is manipulation of genetic DNA after its isolation from a living organism. It may involve removing or adding sequences to improve gene expression. For gene therapy, the DNA is usually inserted into a virus which can invade the patient's tissues and get the therapeutic DNA into cells where it can be expressed. Genetic engineering is now very advanced but using it for gene therapy has usually had disappointing results even for theoretically suitable diseases.

Immunotherapy: a variety of strategies of treatment based upon the concept of modulating the immune system to achieve a desired outcome in therapy or preventative therapy.

Intralesional – injections into the affected areas (e.g. intralesional steroids)

Khellin: A drug which was originally developed to treat angina, asthma and bronchial conditions. When used topically it has a similar effect to psoralen and can be used with UVA to treat vitiligo.

Laser therapy: usually excimer laser, a form of light therapy which directs a beam of light from the same part of the spectrum as Narrow band UVB (308-311 nm). This targets small areas of vitiligo thus avoiding damage to normal skin.

Lesion: can be any abnormality involving any tissue or organ due to any disease or any injury – specifically an area of skin affected by vitiligo

Light therapy: The use of any source of light including sunlight to treat vitiligo, often in combination with drugs taken orally or applied to the skin. This includes for example, UVA, broad and narrow band UVB, excimer laser and monochromatic excimer light.

MSH analogues: is a man made (synthetic) form of the *melanocyte-stimulating hormones.* They stimulate the production and release of melanin (melanogenesis) by melanocytes in skin and hair.

NB-UVB: Narrow Band Ultra Violet B Light is a relatively new treatment for vitiligo. It uses a narrow spectrum of light (308-311nm) without psoralen, which allows exposure to light with less risk of severe burning or other harmful effects.

Piperine – extract of black pepper, a recent discovery, still being tested and not yet available for use in humans. Can be used topically or orally (by mouth)

Pseudocatalase: also called Pcat for short, is a cream, which is applied twice a day, and purported to reduce epidermal hydrogen peroxide in vitiliginous skin, found to be in higher levels in those with vitiligo. Pseudocatalase is normally used in combination with brief exposure to narrow band UVB light and unlike psoralen does not make the skin more sun sensitive.

PUVA: For *oral PUVA* therapy, the patient takes a prescribed dose of psoralen, drug which makes the skin sensitive to light, by mouth about 2 hours before exposure to artificial UVA light or sunlight.

For *topical PUVA*, the doctor or nurse applies a thin coat of psoralen to the patient's depigmented patches about 30 minutes before UVA light exposure.

Vitamin D analogues: Topical vitamin D analogues are man made copies of vitamin D, such as calcipotriol and tacalcitol, commonly used to treat skin diseases such as psoriasis. They are reported to be beneficial in combination with light for the treatment of vitiligo.

Stem cell therapy: Stem cells are mainly found in umbilical cord blood, embryos and in bone marrow at all ages. Stem cells have the ability to develop into other types of cells if given suitable treatment, e.g. white blood cells. Those developed cells, from a healthy cell line, could be used to replace diseased cells in a patient, but it is difficult. Often one has to destroy the sufferer's own bone marrow by radiation or chemical means, before introducing the therapeutic stem cells. This can be very dangerous.

Systemic treatment : tablets, pills or liquid taken by mouth.

Topical Treatments: treatments applied to the skin such as creams and ointments.

Types of Vitiligo

Acrofacial vitiligo: loss of pigment in areas such as face, head, hands and feet

Focal vitiligo: one or more white patch confined to a particular area of the body.

Segmental vitiligo: vitiligo affecting only one side of the body. This form of vitiligo occurs most commonly in children and usually has a limited progression, which may be rapid and is generally less responsive to conventional treatment though small areas respond well to surgical interventions such as grafting.

Vitiligo vulgaris/common vitiligo: scattered areas of pigment loss all over the body. This form is usually in a symmetrical pattern although corresponding sites may appear at different stages of the condition

Vitiligo totalis or vitiligo universalis: complete or almost complete loss of normal pigment in the skin

Vitix: plant extract from cucumis melo (melon) said to have antioxidant properties. Supplied as gel, cream or oral (by mouth) preparations and available on the internet

Adapted from materials developed by CASP (Critical Appraisal Skills Programme) 2000; Institute of Health Sciences (Oxford) and other sources; Vitiligo terminology provided by Vitiligo Priority Setting Partnership. March, 2010