



## Evaluation of the Vitiligo Priority Setting Partnership July 2010

### Introduction

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 NLH 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.

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, from a stakeholder perspective. 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. 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'.

## Information provision

Twenty six out of 31 respondents were satisfied with the level and detail of the information provided to them throughout the JLA process – half of these said they were very satisfied. Four people were neither satisfied nor dissatisfied. On the whole, people were positive about the way in which the process was explained and run. Comments included:

*The workshop was very clearly explained and very well organised, both before and during the day.*

*The initial information gave us a good start before the day. The process was well explained and managed as we went along.*

Where people had issues with the provision of information, it was suggested that this was because the process appeared to be long and bureaucratic.

Suggestions for improvements included:

- Distribution of references to relevant scientific publications.
- Distribution of a glossary at interim priority setting stage – it was suggested this would help in the understanding of the long list of uncertainties.

## Meetings and communications

Six respondents said they had attended either the introductory and/or the interim meeting. Those who had not attended explained that this was mainly due to time constraints, work commitments, not knowing about the meetings or simply not having been invited.

Twenty people were satisfied with the way the JLA communicated with them between meetings, of which eleven said they were very satisfied. Seven were neither satisfied nor dissatisfied – many said the question was not relevant to them as they had not communicated directly with the JLA.

*I received prompt helpful friendly feedback in all my communications with them.*

## Submitting uncertainties

Sixteen respondents said they had submitted uncertainties, while 11 said they had not, including researchers and those who said they were not involved at that stage of the project.

Of the respondents who did submit uncertainties, 12 were satisfied and three very satisfied. One was neither satisfied nor dissatisfied. The range of groups involved was noted, and the helpfulness of the explanations and reminders.

## Interim priority setting

Twenty two respondents said they participated in the interim priority setting exercise, ranking their top ten treatment uncertainties from the long list. Five people said they had not taken part at this stage, their reasons including lack of time and website difficulties.

Of those 22, six were very satisfied with the process and 11 were satisfied.

*I thought it was a clear and seemingly innovative process.*

Three people were neither satisfied nor dissatisfied, while two people were dissatisfied.

*It was quite difficult to do, as I felt at times I did not have enough knowledge about what previous research had been done in some areas. These were mostly clarified though later in the group sessions ...so may have answered differently if I had known a bit more.*

*Some of the listed questions were ambiguous, so I gave them low priority because as phrased they would not have made a good research question. Yet (on finding out later that it was the topic that was of interest to be ranked rather than the precise question as listed), the topic in some cases would have got higher priority. Maybe researchers could have been consulted for the process of writing down the exact questions to be listed.*

## Final priority setting meeting

Twenty four of the respondents attended the final priority setting meeting. Three people said they did not attend, which one person attributed to availability. 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!*

*Again to 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. Most people felt that the discussion had been balanced and fair. The nature of treatment uncertainties, and the mixture of patients and clinicians, often for the first time, can mean that issues which may have been presumed to take precedent turn out to be less discussed than anticipated. The JLA acknowledges that in any open discussion forum people will want to get their view across. The role of the group facilitators is to reiterate that each point of view is valid, but that everyone has the opportunity to contribute their view equally.

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:

- the balance of the final discussion between different participants
- a briefing session at the beginning of the day to update people on the current situation for vitiligo research
- a plenary half way through the final workshop to ensure significant issues are captured before the end

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.

### The top 10 vitiligo treatment uncertainties

The following table sets out the final top 10 vitiligo treatment uncertainties agreed by patients and clinicians. The table demonstrates whether or not the final uncertainties had been identified as research recommendations and were in the top 25 at both consultation and interim prioritisation stages, for both patients and clinicians, demonstrating the collaborative journey in agreeing the final 10.

Rank	Vitiligo treatment uncertainty	Research recommendations	In the Top 25 for		
			Consultation	Interim prioritisation exercise	
				Healthcare Professionals	Patients
1	How effective are immunosuppressants in treating vitiligo?	✓	✓	x	✓
2	How much do psychological interventions help people with vitiligo?	✓	✓	✓	✓
3	Which treatment is more effective for vitiligo: light therapy or calcineurin inhibitors?	✓	x	✓	x
4	How effective is UVB light therapy when combined with creams or ointments in treating vitiligo?	✓	x	✓	x
5	What role might gene therapy play in the treatment of vitiligo?	x	x	✓	✓
6	How effective are hormones or hormone related substances that stimulate pigment cells (MSH analogues, afamelanotide) in treating vitiligo?	x	x	✓	✓

7	Which treatment is more effective for vitiligo: calcineurin inhibitors or steroid creams/ointments?	✓	✓	✓	✗
8	Which treatment is more effective for vitiligo: steroid creams/ointments or light therapy?	✓	✗	✓	✓
9	How effective is the addition of psychological interventions to patients using cosmetic camouflage for improving their quality of life?	✗	✗	✓	✓
10	How effective is pseudocatalase cream (combined with brief exposure to UVB light) in treating vitiligo?	✓	✓	✗	✗

### Recommendations for the JLA

- Use the Guidebook to simplify the concept of the priority setting process, so partners can see and understand how the process has worked in practice for others.
- Ensure people feel adequately prepared to shortlist the uncertainties at the interim stage, for example by distributing a glossary and sharing information about relevant publications (the additional information on each uncertainty at the final workshop was greatly valued).
- Consider how the ground rules for the final workshop can be firmly established before the event, to mitigate against the temptation to dominate or influence the discussion.
- Maximise the opportunity to encourage people to talk to peers and colleagues about the JLA process, including in other clinical fields. Use the Guidebook to demonstrate the flexibility of the JLA approach (ie no fixed model) and the variety of PSPs undertaken so far.