GENERATING RESEARCH QUESTIONS FROM TREATMENT RESEARCH PRIORITIES IN ECZEMA

Report of a workshop held on the 9th January 2012

at the British Association of Dermatologists, London

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James Lind Alliance (JLA)

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Report overview

This report comprises three sections; the first describes, the Eczema Priority Setting Partnership, and process for developing the priorities and results, which was presented in the first part of the workshop; the second section describes the small and larger group discussions that developed these priorities into research questions, this was the main part of the workshop; the final section reflects on the process and the feedback from participants.

Workshop overview

Workshop objectives:

- To describe the eczema research priorities, in context with the Priority Setting Partnership (PSP)
- To formulate research questions from some of the priorities

Workshop participants

There were 40 participants in the workshop (1 person sent apologies on the day), split roughly into a third patients and carers, a third health professionals, and a third researchers. These were drawn from partner organisations, and individuals that had contributed to the prioritisation process. All participants received information about the workshop beforehand, including some background information and general notes about clinical research methods, and a research glossary.

A full programme is available in Appendix 1.

1. The Eczema Priority Setting Partnership

The James Lind Alliance (JLA) Eczema Priority Setting Partnership (PSP) was established in 2010, as part of NIHR Programme Grant, 'Setting Priorities and Reducing Uncertainties for the Prevention and Treatment of Skin Disease 2008 – 2013'. The objectives of the Eczema PSP were:

- To work with patients and health professionals to identify the unanswered questions about eczema treatment from patients and clinical perspectives.
- To agree a prioritised list of those uncertainties, for research purposes.
- To publicise the process and results of the PSP.
- To take the results to research commissioning bodies to be considered for funding.

1.1 Partners and participants

Partners include the National Eczema Society, Nottingham University Hospitals NHS Trust, and the University of Nottingham, as well as patient support groups such as Nottingham Support Group for Carers of Children with Eczema, clinical and professional groups, such as the Society for Academic Primary Care Skin Research Group, the James Lind Alliance and UK DUETs. These organisations were all represented on the Steering Group.

1.2 Setting the scene – developing the priorities

During 2011 a process of gathering and prioritising treatment uncertainties in eczema was undertaken, under the supervision of a Steering Group. The following were key steps in this process as described in the first part of the workshop:

- Initial survey undertaken – 1071 'uncertainties' of which 353 were not related to treating eczema or unusable.
- 718 unique questions (i.e single questions), and 65 indicative questions (developed from multiple similar submissions) identified. Where possible these were standardised into a format of; Population, Intervention, Comparison and Outcomes (PICO) format.
- Of the 65 standard format questions, 52 had been asked by more than one person and were included in Survey 2.
- Survey 2 was sent to those who participated in Survey 1
- Participants were asked to select a maximum of 10 of the standard format questions that they considered to be the most important

The Steering Group reviewed the results of the voting, and the top 14 priority topics were agreed based on frequency rankings. Four of the uncertainties were shared between patients, carers and health professionals; these were viewed as being top priority areas for further research. Of the remaining uncertainties, the priority topics for patient and carers were very different to the priority topics for health professionals. As a result the rank orders for these groups were examined separately, and the top 5 for each group were confirmed as priority topics (resulting in a total list of 14 priority areas for further research). The top 14 research priorities were:

Shared priorities (important to patients and health professionals)

- What is the best and safest way of using topical steroids for eczema: frequency of application, potency, length of time, alternating with other topical treatments, and age limits for treatment?
- What is the long term safety of applying steroids to the skin for eczema?
- What role might food allergy tests play in treating eczema?
- Which emollient is the most effective and safe in treating eczema?

Patient and carer priorities

- What is the best psychological treatment for itching/scratching in eczema?

- Which is the best way or people with eczema to wash: frequency of washing, water temperature, bath versus shower?
- What are the best and safest natural products to apply to the skin for eczema?
- How much does avoidance of irritants and allergens help people with eczema?
- What is the role of diet in treating eczema: exclusion diets and nutritional supplements?

Health Professional Priorities

- Which is more effective in the management of eczema: education programmes, GP care, nurse-led care, dermatologist-led care or multi disciplinary care?
- Which is safer and more effective for treating eczema; steroids or calcineurin inhibitors?
- How effective are interventions to reduce skin infections in the management of eczema?
- Which should be applied first when treating eczema, emollients or topical steroids?
- What is the best and safest way of using drugs that suppress the immune system when treating eczema?

Following the morning's presentations there was time for reflection and discussion. There was a request for clarification between treatment and prevention uncertainties, this PSP only dealt with treatment but some prevention uncertainties were submitted and these are available on request. Another participant was interested in the differences and similarities between the priorities for people with eczema and their carers, and health professionals. It was noted that whilst patients and carers bring their own experience and that of others, health professionals will have a different perspective perhaps because of the many hundreds of different patients that they will have worked with. This probably explains some of the differences. One participant was surprised that there weren't more psychological questions in the top 14, it was noted that there was an uncertainty relating to itch and psychological treatments for this. There are other uncertainties relating to psychological treatments that didn't make the top 14, however they will be published in UK DUETs http://www.library.nhs.uk/duets/ over time, for researchers and research funders to see and use.

On the whole participants were impressed by the level of work to achieve progress so far and that the process had resulted in a list that everyone felt comfortable with.

2 Turning priorities into research questions

Following presentations that set the context for the discussions, there were four discussion groups, with a balance of participants; people with eczema; carers; health professionals; and researchers in each group. Participants chose their discussion group according to first or second preference. This ensured that groups had people with relevant interests and experiences. Each group had a neutral facilitator. The four groups addressed priorities in the following areas:

- Topical Steroids
- Allergy and Diet
- Emollients and Bathing
- Education and long term management

All four groups were asked to focus on their shared priorities to start with, as these were considered most important by the Steering Group. Each small discussion group had priority cards to work with that contained important contextual information about the priority under discussion, such as examples of original survey submissions relating to the priority, and patterns of voting that the priority had attracted.

The priority was introduced by the facilitator, and some time was spent sharing related experience and expertise from either a patient/carer or health professional/research perspective. Different groups then took different approaches to generating and developing the priority. Some groups 'scoped' the priority taking into account all the issues that any good research question would need to address, and then finessed a research question (s) out of this. Others brainstormed all of their research ideas relating to the priority and chose to develop the ones that seemed to show the most promise. A proforma was provided to try and ensure structure and consistency in output from each group. Some groups used this well, others felt that it constrained their thinking and made less use of it, but still delivered structured research questions.

All group facilitators reported high patient input in the early stages of the discussion, as well as clinical and research input. As groups moved on to actually formatting the research questions from the priorities there seemed to be much more input from the clinicians and researchers, but the facilitators thought this was appropriate. Areas that patients and carers could participate in included risks/concerns/recruitment to studies, and they were encouraged to share their views in these areas.

Not all groups were able to move beyond their first shared priority – however this wasn't seen as a negative outcome as the quality of decisions and research questions was high. The development of well formed research questions is often an iterative process that can take many months to achieve.

2.1 Research questions from the discussion groups

The table below shows the outcomes of discussion on the 14 research priority topics. These research questions are intended to be a broad reflection on how the priority topics might be usefully interpreted and addressed, as viewed by the workshop participants on the day. They are not intended to be exhaustive in their scope, or to be fully developed in terms of detail and breadth.

Original priority	Research question(s)
What is the best and safest way of using topical steroids for eczema: frequency of application, potency, length of time, alternating with other topical treatments, and age limits for treatment?	• In patients with eczema seen in primary care does a regular 'weekend' therapy of topical steroids lead to better management than a reactive approach? • Does an early aggressive treatment policy lead to better outcomes than standard practice? • Does inducing remission with a stronger/longer duration of topical steroids have a long term impact on disease exacerbations?
What is the long term safety of applying steroids to the skin for eczema?	• What are the specific long term side effects of applying steroids to the skin, as opposed to non treatment or under treatment?
What role might food allergy tests play in treating eczema?	• What is known already about the accuracy of food allergy tests and about which foods should be tested in eczema patients? This should include background to the prevalence of food allergies in eczema patients.

	• What is the predictive value of different food allergy tests? • What role might food allergy tests play in the treatment of eczema in the 0-5 age range?
Which emollient is the most effective and safe in treating eczema?	• What determines patient choice and use of emollients and does choice affect outcome? • What is the optimal amount of emollient to use? • What are the most harmful and beneficial ingredients of an emollient?
What is the best psychological treatment for itching/scratching in eczema?	*As this is already the subject of a funding proposal currently being considered by the NIHR HTA, this was not discussed in detail but some members of the group were very interested in the topic.*
Which is the best way for people with eczema to wash: frequency of washing, water temperature, bath versus shower?	*Not discussed at the workshop*
What are the best and safest natural products to apply to the skin for eczema?	*Not discussed at the workshop*
How much does avoidance of irritants and allergens help people with eczema	*Not discussed at the workshop*
What is the role of diet in treating eczema: exclusion diets and nutritional supplements?	*Not discussed at the workshop*
Which is more effective in the management of eczema: education programmes, GP care, nurse-led care, dermatologist-led care or multi disciplinary care?	• What is the clinical and cost effectiveness of educational interventions for the administration of long term treatment for eczema? • (This could include patient education or education of health professionals.)
Which is safer and more effective for treating eczema; steroids or calcineurin inhibitors?	*No change*
How effective are interventions to reduce skin	*Not discussed in detail as an NIHR HTA-funded trial*

infections in the management of eczema?	*addressing this topic is currently underway.*
Which should be applied first when treating eczema, emollients or topical steroids?	*Not discussed at the workshop*
What is the best and safest way of using drugs that suppress the immune system when treating eczema?	• What is the best and safest way of using Azathioprine (versus non-systemic treatment / normal care) in children (over 3 years) and adults?

Some of these research questions have some considerable context that has been captured from the discussion, for example relating to populations within studies. This information will help to further develop and finesse the research questions as they are used for proposals.

2.2 Final thoughts on the process from Hywel Williams (UK DTCN) and Margaret Cox (National Eczema Society)

Margaret expressed her thanks for all of the hard work of the partnership. She had welcomed this process as a means of representing patient and clinical interests in eczema research. Having reached the end of the process she was pleased that her initial enthusiasm had been well founded, and and was looking forward to seeing the priorities turned into clinical research studies.

Hywel thanked everyone for their efforts during the workshop and commented on the pioneering nature of the task. He quoted Alessandro Liberati's recent Lancet article [1] about the need to realign patient orientated, commercial and academic research. Alessandro spoke from a position of professional knowledge as a researcher and as a someone with a long-term life-limiting condition, he sadly died on New Years' day 2012. Hywel challenged the assembled participants to champion the ideas developed during the day, to utilise the existing and new partnerships that had developed during the process, to develop new research proposals and to target research funders.

3. Workshop evaluation and reflection

28 participants completed an evaluation form directly or very soon after the workshop. Respondents were equally split between patients and carers and health professionals. The ratings of the elements of the workshop were high, with people either satisfied or very satisfied with administrative aspects of the workshop, facilitation and workshop content. In the workshop outcomes 2 people expressed a more measured view about whether it had achieved its stated outcomes, this may be to do with some groups not addressing all of the priorities in the allocated time.

Since the workshop the facilitators have discussed whether it was realistic to expect groups to work on more than one priority area. However, it was thought that there were advantages in sharing all the priorities within each group: it gave the groups context about the priorities in the category and allowed them to see the bigger picture of the prioritisation exercise as a whole; enabling participants to see where there might be overlap between the priorities and adjust subsequent research questions developed accordingly. The process of discussion was not to finalise everything about the questions (this can take research teams anything up to 12 months of really hard discussion and counter-argument) but to make sure that outputs of the workshop were heading in broadly the right direction, and could be endorsed by both patients, carers and clinicians.

There was a section of the evaluation form for people to express their own views about the day and the following were noted:

Generally positive:

- Very useful day
- Mix of people – and the interaction between them
- Ensuring that patients were able to contribute fully in the process
- Highly productive
- Liked the fact that research questions were generated from groups with good ideas
- Excellent facilitation
- Very equitable in terms of how it was run

More negative:

- More time for discussion, too much to work with, fewer priorities to work on
- Room too stuffy
- Declarations of interest would have been helpful
- More time in small groups less time in feedback
- A ‘getting to know you’ exercise in all small groups would have helped
- Culture and ethnicity play an important part in developing questions, please consider these

3.1 Longer term evaluation of Priority Setting Partnership

On completion of the JLA process, each PSP member, and participants in any aspect of the process will be asked to feed back their views on how the process itself worked for them, via an anonymous online survey. This gives the JLA and the Eczema PSP team 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, and when compiled will be available on the JLA website.

4 What next for the eczema priorities?

Over the coming months the Eczema PSP Steering Group will be concentrating on completing the following tasks:

- Publishing all of the uncertainties on UK DUETs.
- Targeting research funders, with details of the prioritised uncertainties.
- Checking for levels of interest in the partnership to further develop ideas and champion particular priority areas for development into potential funding applications.
- Publishing a summary paper outlining the priority topics in a peer-reviewed medical journal.
- Publishing a paper describing the process in a peer reviewed journal, especially the final workshop which was a new approach in the JLA process.
- The JLA to produce a factual report of the workshop that can sent to participants and used as source text for subsequent articles and publications.
- Sending a summary of the results to all who participated in the surveys.
- Producing lay summaries of the process for use on patient support group websites.
- Attending academic conferences to present the results of the prioritisation exercise.

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[1] The Lancet, Volume 378, Issue 9805, Pages 1777 - 1778, 19 November 2011

Appendix 1

WORKSHOP PROGRAMME

Monday 9th January 2012

British Association of Dermatologists, Willan House, 4 Fitzroy Square, London, W1T 5HQ

*"Developing a good research question is the most important part of the research process"**

Workshop objectives:

- To describe the eczema research priorities, in context with the Priority Setting Partnership (PSP)
- To formulate research questions from some of the priorities

Participants: an equal mix of people with eczema, and carers/parents, health professionals that treat and care for them, and researchers

09.30 Registration and refreshments

10.00 Welcome and overview of workshop – Sally Crowe, James Lind Alliance

10.20 Background to the Eczema Priority Setting Partnership, and SPRUSD - Kim Thomas

10.30 Process and results of the Priority Setting Partnership – Tessa Clarke

10.45 Discussion

11.15 **Refreshments**

11.30 Faciliated Discussion Groups

12.45 **Lunch Break**

13.30 Discussion groups re convene to finalise their research questions

14.15 Group presentations x 2

- Each group share their research questions, for feedback

15.00 **Refreshments**

15.20 Group presentations x 2

- Each group share their research questions for feedback

16.10 Reflections on the day and next steps– Hywel Williams and Margaret Cox

16.30 Workshop ends

* What to Study: Generating and Developing Research Questions J P Campbell, R L Daft, C L Hulin, (1982)

Publisher: Sage Publications, Pages: 168, ISBN: 0803918712

Appendix 2

ECZEMA WORKHOP PARTICIPANTS LIST

Name	**Category**	**Org Info**
Sam Ankrah	Person with eczema Massage Therapist	Massage Therapy
Patricia Atkinson	JLA - Administration	JLA
Nicola Ball	Nurse	Social Enterprise
Alison Barrow	Person with eczema Community Health Trainer	Public Health and Wellbeing Social Enterprise
Jonathan Batchelor	Consultant Dermatologist	Centre for Evidence Based Dermatology NHS
Pam Carter	Research Fellow (User Involvement)	Arthritis Research UK National Primary Care Centre / West Midlands Research Design Service
Tessa Clarke	Senior Clinical Trials Development Manager	Centre of Evidence Based Dermatology
Prof Mike Cork	Person with eczema, Carer, Clinician and Clinical Researcher	Academic Unit of Dermatology Research, University of Sheffield
Katherine Cowan	Facilitator	JLA
Fiona Cowdell	Clinical Researcher	Skin Health & Skin Integrity Research Development Group, University of Hull
Sally Crowe	Facilitator	JLA
Adrian Day	CEBD Patient Panel Member	Higher Education Policy
Helen Dennis	Carer and Nurse	NHS
Lester Firkins	Facilitator	JLA
Nick Francis	Academic GP & Clinical Researcher	SAPC Skin Research Group Cardiff University
John Fuller	Person with eczema	Past National Eczema Society employee
Natalie Gibbons	Person with eczema	Recruitment
Mary Glover	Consultant Dermatologist	NHS
Karina Jackson	Nurse	NHS, Eczema education service for parents of children with eczema, South London
Sandra Lawton	Nurse	Eczema Research Group, NHS

Abby Macbeth	Observer – Clinician, Clinical Researcher	Norfolk and Norwich University Hospital, Dermatology Dept
Margaret Mcphee	Network Administrator	Centre of evidence Based Dermatology
Michael Mosley	Person with eczema	
Helen Nankervis	Research Associate	Centre of Evidence Based Dermatology
Andrew Nunn	Academic Researcher	MRC Clinical Trials Unit
Amanda Perry	Person with eczema	
Andrew Phillips	Person with eczema and carer	Member NES
Colin Powell	Consultant Paediatrician Clinical Researcher	NHS Cardiff University
Anjna Rani	Person with eczema	CEBD Panel Member
Jane Ravenscroft	Dermatologist	Consultant at Sherwood Forest Hospitals NHS Trust
Matthew Ridd	Academic GP Clinical Researcher	Society for Academic Primary Care Skin Research University of Bristol
Amanda Roberts	Person with eczema and carer	Nottingham Support Group for carers of children with eczema
Jean Robinson	Paediatric Nurse	NHS
Miriam Santer	Academic GP and Clinical Researcher Carer	Society for Academic Primary Care Skin Research Group
Heather Sharp	Paediatric Nurse	NHS
Lindsay Shaw	Consultant Dermatologist	NHS
Trevor Smith	Person with eczema	
Nick Sommer	Person with eczema & carer	Long term member of National Eczema Society
Kim Thomas	Deputy Director Person with eczema	Centre for Evidence Based Dermatology
Hywel Williams	Director Consultant Dermatologist	Centre for Evidence Based Dermatology NHS
Margaret Cox	Chief Executive	National Eczema Society