

Involving patients in research – experiences from the eczema priority setting partnership

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- What is a Priority Setting Partnership (PSP)?
- Why are PSPs important?
- Experience from our eczema PSPs



What is a Priority Setting Partnership?

- **A collaborative project to:**
 - identify unanswered questions about eczema treatments
 - prioritise these in order of importance
 - inform the future research agenda / funders.
- **Partnership between patients, carers, health professionals and researchers.**

Three reasons to conduct a PSP

- Research funding is finite – need to ensure value for money by investigating the most important questions
- More likely to change practice and have an impact – if research addresses topics of importance to patients and healthcare professionals
- Makes it easier to get funding – particularly for traditionally neglected areas

Steering Group & funding

- Sally Crowe (Independent Chair -James Lind Alliance)
- Kim Thomas (researcher)
- Tessa Clarke (researcher)
- Margaret McPhee (administrator)
- Amanda Roberts (patient)
- Amina Ahmed (patient)
- Anjna Rani (patient)
- Marjorie Howard (patient)
- Margaret Cox (representing National Eczema Society)
- Jonathan Batchelor (dermatologist)
- Jane Ravenscroft (dermatologist)
- Matthew Ridd (GP)
- Sandra Lawton (dermatology nurse)



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- What is an uncertainty?





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Should I bathe once a week or
more often?



Is it better for my eczema if I bathe once a week or daily?

Mmm, good question – I'm not sure



The Process



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Survey 1

- **CONSULTATION**
- Survey - Advertised to all appropriate stakeholders e.g. patient support groups, Dermatological Nursing, Primary Care Dermatology Society, British Association of Dermatologist

Interim

- **COLLATION**

Survey 2

- **RANKING / PRIORITISATION**

Workshop

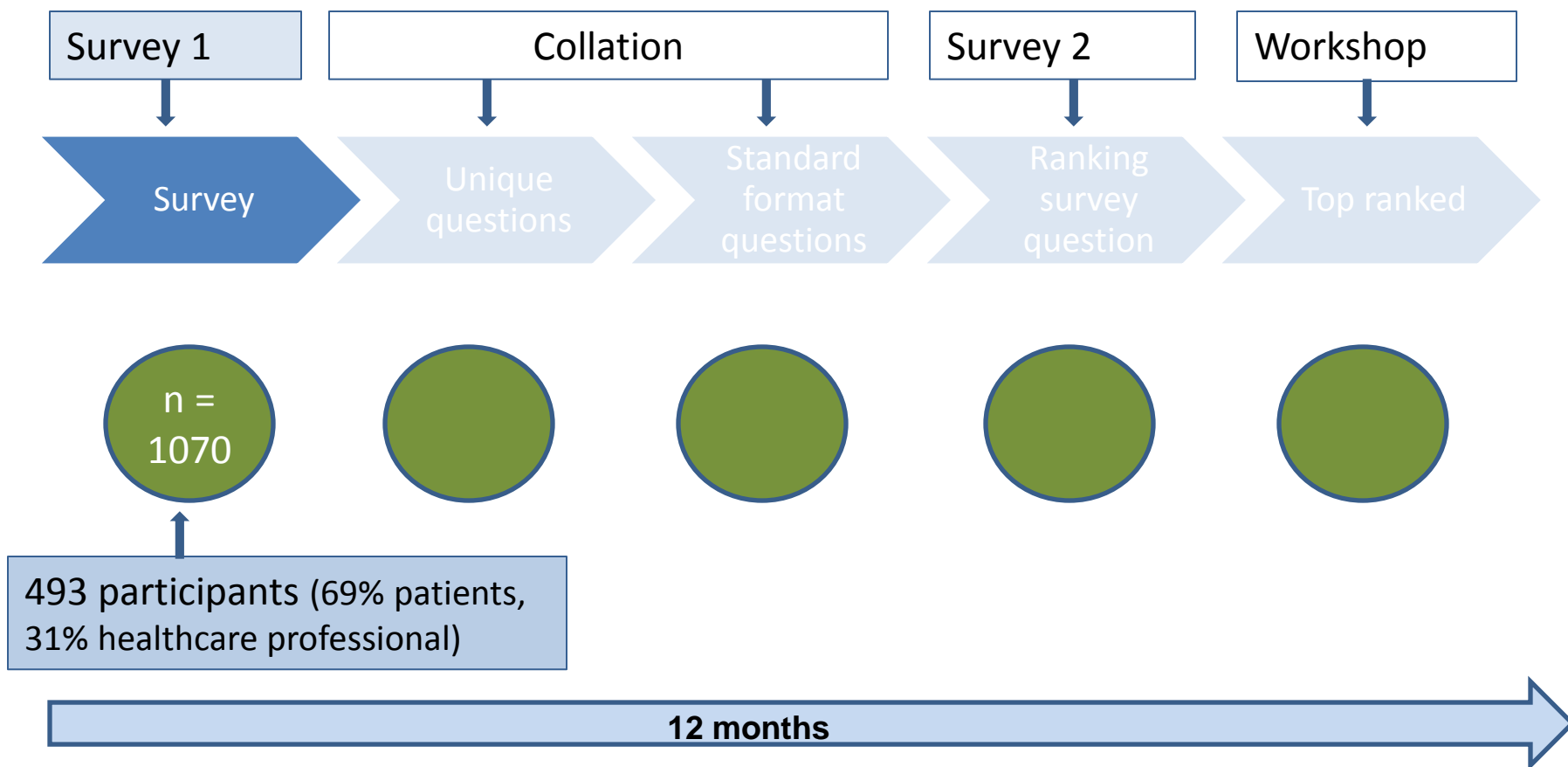
- **FACE-TO-FACE WORKSHOP**

Flow of data



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The Process



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Survey 1

- **CONSULTATION**

Interim

- **COLLATION**
- Duplicates removed / reworded to create “indicative uncertainty”.
- Indicative uncertainties entered into the DUETs (Database of Uncertainties about the Effects of Treatments).

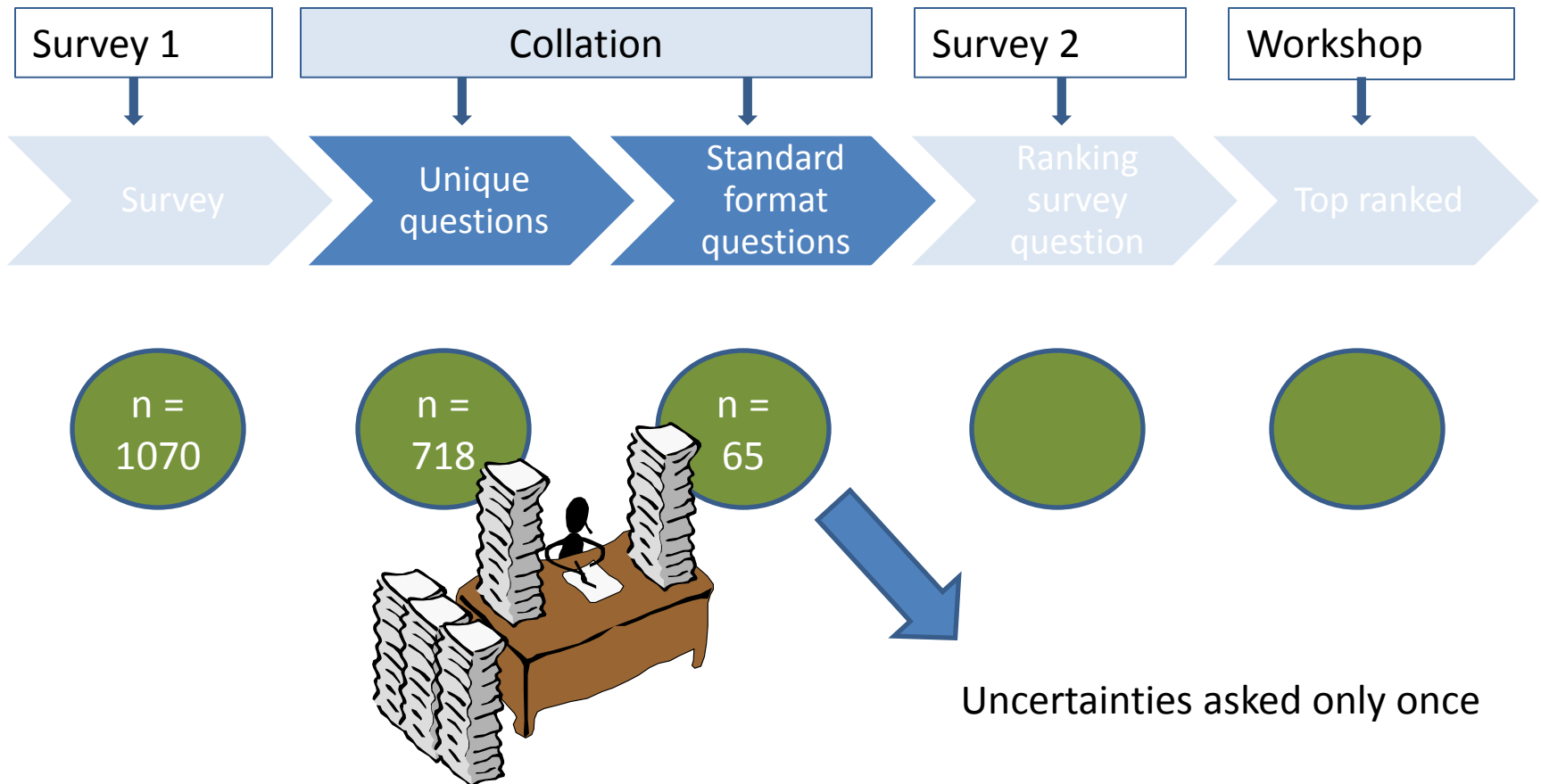
Survey 2

- **RANKING / PRIORITISATION**

Workshop

- **FACE-TO-FACE WORKSHOP**

Flow of data



Example of standard question

Standard question

- What is the long term safety of topical steroid use?
- *51 questions in this category.*

Actual questions

- What are the long term health effects of using steroid creams compared with the long term effects of leaving the skin untreated?
- Aren't I causing long term damage to my skin by constantly using steroid creams
- how long is too long when using hydrocortisone?
- I am worried about the long term use of steroids on the skin. Should I be worried?
- How appropriate is prolonged steroid use?

The Process



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Survey 1

- **CONSULTATION**

Interim

- **COLLATION**

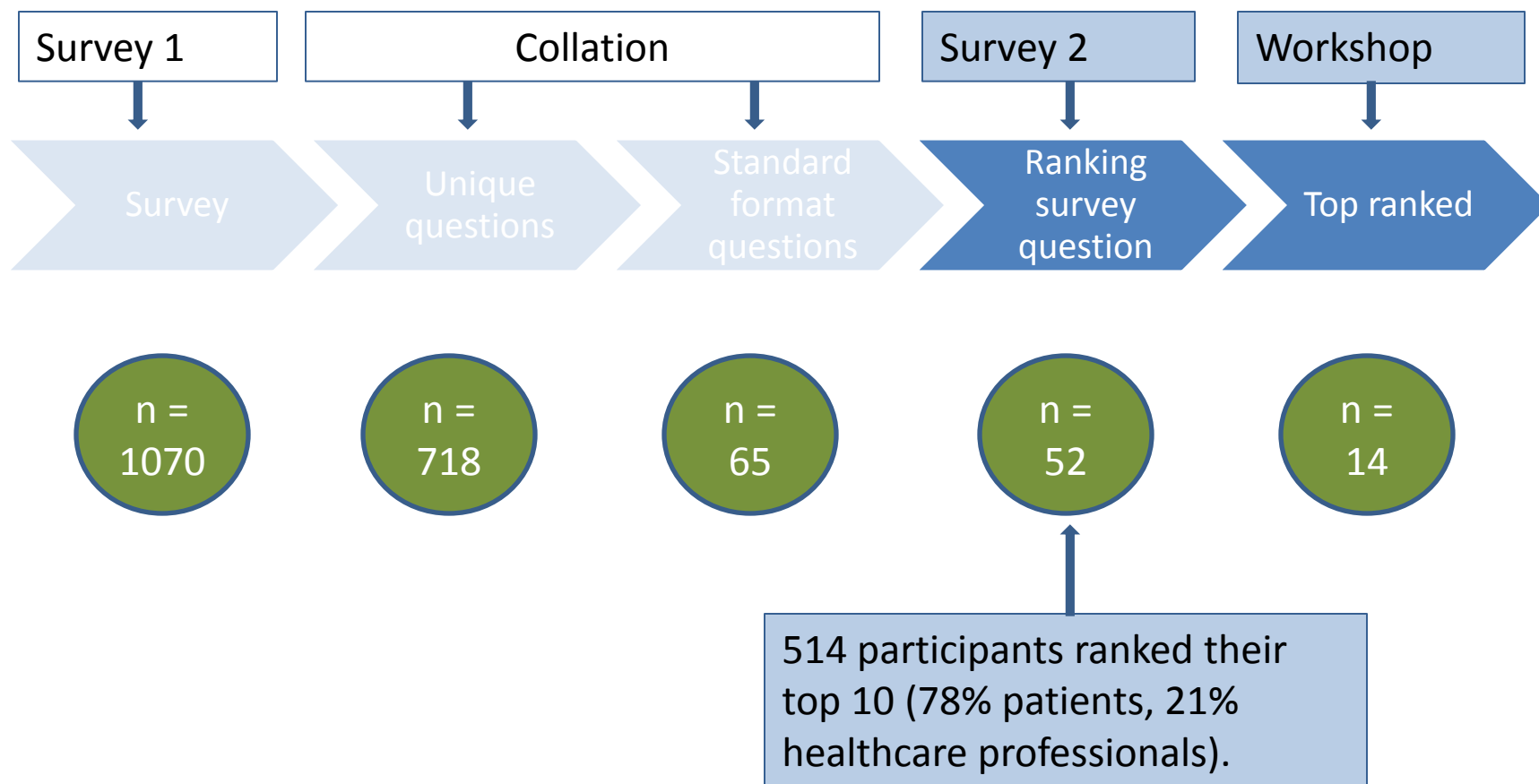
Survey 2

- **RANKING / PRIORITISATION**
- Top 50 uncertainties (based on frequency) from **Survey 1** sent out to participants.
- Participants choose a list of 10 uncertainties which are most important to them

Workshop

- **FACE-TO-FACE WORKSHOP**

Flow of data



What we did



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Survey 1

- **CONSULTATION**

Interim

- **COLLATION**

Survey 2

- **RANKING / PRIORITISATION**

Workshop

- **FACE-TO-FACE WORKSHOP**
- Group of researcher, patients, carers and health professionals.
- Develop top ranked uncertainties into research questions.



Eczema Top 14 Uncertainties

Shared priorities

- Best way of using topical steroids
- Long term safety of topical steroids
- Role of food allergy tests
- Best emollients

Patient and carer priorities

- Psychological interventions for itching/scratching
- Best way to wash
- Best natural products
- Role of allergen avoidance
- Role of diet and nutritional supplements

Health professional priorities

- Best way of providing eczema care: education programmes, GP, nurses, dermatologists or multi disciplinary teams
- Effectiveness of topical steroids compared to calcineurin inhibitors
- Effectiveness of interventions to reduce skin infections
- Order of application of emollients and topical steroids
- Best systemic therapies

Other skin-related priority setting partnerships

- **Vitiligo (2010)** – led to funding for national trial of UVB light and topical steroids (HI-LIGHT trial)
- **Epidermolysis Bullosa (2013)** - Spain
- **Acne (2014)**
- **Hidradenitis suppurativa (2014)**
- **Hair and nails (in development)**
- **Psoriasis (in development)**

Want to find out more?

- JLA Guidebook
www.jlaguidebook.org
- Centre of Evidence Based Dermatology
www.nottingham.ac.uk/dermatology



Publications:

- Eczema PSP: Batchelor JM *et al* (2013) *Br J Dermatol* 168: 577–582
- Vitiligo PSP: Eleftheriadou VE *et al* (2011) *Br J Dermatol* 164: 530-536.

Summary

- What is a Priority Setting Partnership (PSP)?
- Experience from our eczema PSP
- What was it really like for patients?





Patient partners - Anjna, Amina and Amanda

Example standard questions

Question submitted

1. Effectiveness of a single treatment

2. One treatment compared with another

3. Avoidance

Standard question

1. How effective is [treatment x] in treating eczema?

2. Which is more effective in treating eczema [treatment x or treatment y]?

3. How much does avoiding help patients with eczema?

Top tips

- Understand the difference between “uncertainties” and “research questions”

Uncertainty	Research question
What is the best and safest way of using topical corticosteroids for the treatment of eczema?	<ul style="list-style-type: none">• Does weekend therapy with a moderate potency topical corticosteroid prevent eczema flares compared to normal care in children with eczema ?• Does early treatment with a more potent topical corticosteroid lead to better disease control than standard practice in patients with eczema?

Patients' role in the workshop

Priority Setting Partnerships are a fabulous idea. And so flavour of the day- dermatology alone has done four of these : vitiligo, eczema, hidradentis and acne. Hurrah for the James Lind Alliance for providing the impetus and the structure for all these PSPs to tap into. And in our case – hurrah for the Centre of Evidenced Based Dermatology, without whom I would not be here, giving you this race through a patient's experience of the Eczema PSP.

Patient Plea

The role of patient in research, when not actually the subject, is quite alien to most of us. The uniqueness of PSPs is that they try to give equal weight to patient contribution. But it is a big ask for patients to be involved.

PSPs are trying to identify uncertainty in treatment. Uncertainty – a difficult concept. The wording our PSP used to introduce the first survey “questions you feel are important about the treatment of eczema that may not have been answered by research” is still not easy to address.

What has been researched?

- Most patients have absolutely no idea about what has been researched, let alone whether that research was of good quality and meaningful.
- There are licensing organisations for medicines and interventions. Surely they would be looking after patients' interests?
- What is the difference between what your doctor prescribes, what you can get over the internet and what a friend swears blind is the wonder cure for all eczema ills.

Tendency not to question medical treatment

- Health Care Professionals have authority – you could be excommunicated from your doctor, you could look silly or you might make it obvious you had not understood what you had been told by the doctor. A recent poll ⁱ52% of dermatologists would discharge rude patients earlier than expected.
- NHS surely would not cause harm. The NHS is still thought of as paternalistic and authoritative by much of the population.
- Treatments are scientific and doctors have studied for a long time – so how could we possibly be able to contribute to that?
- GPs have such little time to educate patients and gone are the days when it was expected that patient would see the same GP all the time, so that a relationship could build up.

We do not know what we do not know

- Own prejudices and experiences – every person is different and one patient is not necessarily representative of any other patient with the same condition. “we do not see things as they are, we see as we are”ⁱⁱ
- Easy to take personal testimony as universal truth
- Under represented patients still have important experiences with different concerns. In the case of eczema, things matter like skin colour, chaotic households lacking routine, cultural practices .

Patients are conditioned to live with a certain amount of uncertainty

- Eczema is multifactorial and episodic, with a time lag between trigger and effect

- Treatments often evolve – a mixture of history and mystery

Manage expectations

- Responding to the PSP may generate a patient outpouring of their own problems with eczema
- Just because a patient makes a suggestion, it does not mean that it will be short listed, let alone researched
- Time scales are mind blowingly long in research. And that does not even touch on the vagaries of translating research into practice.

Personal Plea

Participating in the whole process was enjoyable – but to my mind the research questions workshop where we decided research questions had to be the zenith.

- It was the culmination of the exercise – so by then those on the steering committee felt more comfortable with the process
- Positive atmosphere
- Knowledgeable professionals – brilliant to see their interactions together
- Patient input really valued
- Lots of exciting potential

It would be great to do it again – how about if JLA contact the steering group to review the PSP periodically (like NICE does with guidelines).

ⁱ The dermatology outpatient discharge decision: understanding a critical but neglected process
N.A. Harun, S. Salek, V. Piguat and A.Y. Finlay This summary relates to DOI: 10.1111/bjd.12826
British Journal of Dermatology, 170, 1029–1038, May 2014

ⁱⁱ GeorgeJulian @GeorgeJulian 21/5/14