

## Psoriasis Priority Setting Partnership

PROTOCOL [14/07/17]

### 1. Purpose of the PSP and background

This protocol sets out the aims, objectives and commitments of the Psoriasis Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is agreed that the Protocol is reviewed by the Steering Group and updated on a regular basis.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The National Institute for Health Research (NIHR – [www.nihr.ac.uk](http://www.nihr.ac.uk)) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

The Psoriasis PSP was made possible following investment and funding of the partnership by the Psoriasis Association and will be led by Dr Helen Young (Clinical Senior Lecturer in Dermatology and Consultant Dermatologist) who is based at The Centre for Dermatology Research at The University of Manchester.

### 2. Aims and objectives of the Psoriasis PSP

The aim of the Psoriasis PSP is to identify the unanswered questions about psoriasis treatment from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important.

The objectives of the Psoriasis PSP are to:

- work with patients and clinicians to identify uncertainties about psoriasis – including childhood and adult psoriasis; all severities of psoriasis; all areas of the body (scalp/nails/flexures); psoriatic arthritis; comorbidities; pathways / access to care; treatments; lifelong management strategies.

#### **Excluded from the scope of the psoriasis PSP – palmoplantar pustular psoriasis**

- to agree by consensus a prioritised list of those uncertainties, for research
- to publicise the results of the PSP and process
- to take the results to research commissioning bodies to be considered for funding.

### 3. The Steering Group

The Partnership and the priority setting process will be supported and guided by The James Lind Alliance (JLA). The Steering Group includes representation of patient/carer groups and clinicians. The Steering Group will agree at the initial steering group meeting, the resources, including time and expertise that they will contribute to each stage of the process.

The Psoriasis PSP Steering Group will be led and managed as follows:

#### Chair

- Maryrose Tarpey - JLA Advisor

#### Funding body

- Helen McAteer - Psoriasis Association
- Carla Renton - Psoriasis Association

#### Patient representatives

- Paul Fitzpatrick
- Carolyn Hughes
- Vanessa Lawrence-French
- Alison Austin - patient and parent representative
- Damini Mistry
- Brian Rochford

#### Clinician representatives

- Helen Young – Psoriasis PSP Lead, Consultant Dermatologist (The University of Manchester)
- Christopher Griffiths - Consultant Dermatologist (The University of Manchester)
- Joyce Leman - Consultant Dermatologist (Scotland)
- Christine Bundy – Psychologist (Cardiff)
- Julie Van Onselen – Dermatology Nursing (Oxfordshire)
- Lucy Moorhead - Advanced Nurse Practitioner in Dermatology (St John's, London)
- Emma Le Roux - Primary Care – (Bristol)

#### PSP

- Rabiya Majeed-Ariss – Psoriasis PSP Investigator, The University of Manchester
- Naomi Wells – Psoriasis PSP co-ordinator, The University of Manchester
- Maggie McPhee - UK DCTN (University of Nottingham)

- Douglas Grindlay UK DCTN (University of Nottingham)

The Psoriasis PSP will involve close collaboration with colleagues from the UKDCTN based at the University of Nottingham's Centre for Evidence Based Dermatology. This group have significant experience in conducting other dermatology focused PSPs including those on hidradenitis suppurativa and eczema. The UKDCTN team will support the psoriasis PSP through sharing of their previous experience, Identification and invitation of potential PSP partners and Steering Group members, supporting the dissemination of the initial survey and providing access to expertise for the assembly and categorisation of "collated indicative questions", uncertainty checking and priority setting stages of the process.

A schedule of the SG meetings is included in Appendix A.

## 4. The wider Partners

Organisations and individuals will be invited to be involved with the PSP as partners. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical clinical importance relating to the treatment and management of Psoriasis. Partners will represent the following groups:

- people who have had Psoriasis
- carers of people who have had Psoriasis
- medical doctors, nurses and professionals allied to medicine with clinical experience of Psoriasis

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA Adviser will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

### Exclusion criteria

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

The following groups have already committed to partnership with the Psoriasis PSP:

- The British Association of Dermatologists
- The British Dermatological Nursing Group
- The Primary Care Dermatology Society
- The International Psoriasis Council

## 5. The methods the PSP will use

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods

adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details can be found in the Guidebook section of the JLA website at [www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk) where examples of the work of other JLA PSPs can also be seen.

### **Step 1: Identification and invitation of potential partners**

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Psoriasis PSP and may be invited to participate.

### **Step 2: Initial stakeholder meeting**

The initial stakeholder meeting will have several key objectives:

- to welcome and introduce potential members of the Psoriasis PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP.

### **Step 3: Identifying treatment uncertainties**

The PSP will identify questions and uncertainties of practical clinical importance relating to the treatment and management of Psoriasis. A period of up to 4 months will be given to complete this exercise. Decisions on closing the survey ahead of this time point will be taken by the SG. A postal and web-based survey will be used.

Existing sources of information about treatment uncertainties for patients and clinicians will be searched in this initial survey. These can include question-answering services for patients and carers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: [www.evidence.nhs.uk](http://www.evidence.nhs.uk).

### **Step 4: Refining questions and uncertainties**

The consultation process through the initial survey will produce "raw" unanswered questions about diagnosis and the effects of treatments. These raw questions will be assembled and categorised and refined by Rabiya Majeed-Ariss (Psoriasis PSP Investigator, The University of Manchester) into "collated indicative questions" which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews and guidelines will be identified and checked by Rabiya Majeed-Ariss and the steering group to see to what extent these refined questions have, or have not, been answered by previous research. The recency of existing evidence will be an important consideration. Evidence published in the last 5 years will be considered sufficiently recent. Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – i.e. they are "unrecognised knowns" and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests

that information is not being communicated effectively to those who need it. Accordingly, the JLA recommends strongly that PSPs keep a record of these 'answerable questions' and deal with them separately from the 'true uncertainties' considered during the research priority setting process.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a template (supplied by the JLA) by Rabiya Majeed-Ariss. This will demonstrate the checking undertaken to make sure that the uncertainties have not already been answered. Further uncertainties identified when checking existing systematic review evidence will be added to this list. The data will be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

### **Step 5: Prioritisation – interim and final stages**

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties relating to the treatment or management of Psoriasis. This will be carried out by members of the Steering Group and the wider partnership that represents patients and clinicians.

- The interim stage, to proceed from a long list of uncertainties (e.g. up to 80 questions) to a shorter list (e.g. up to 20 questions) to be discussed at the final priority setting workshop, will be carried out in a second survey by post or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. There are examples of how other PSPs have achieved this at [www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk). Individuals who have completed the initial survey and agreed to be re-contacted will be informed of the second survey and invited to participate.
- The final stage, to reach, for example, 10 prioritised uncertainties, will be conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA Adviser.

The JLA will facilitate this process and ensure transparency, accountability and fairness. Participants will be expected to declare their interests in advance of this meeting.

A timeline is included as Appendix B.

## **6. Dissemination of findings and research**

### **Findings and research**

It is anticipated that the findings of the Psoriasis PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities. Steering Group members and partners are expected to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.<sup>1</sup>

### **Publicity**

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Psoriasis PSP using both internal and external communication mechanisms. The Steering Group may capture and publicise the results through descriptive reports of the process itself in Plain English. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

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<sup>1</sup> Add further detail here about how and where the priorities will be developed and researched.

## 7. Agreement of the Steering Group

### Signed by the Steering Group

The undersigned agree to follow the [health problem] Priority Setting Protocol.

[Insert name and organisation]

.....

Date: .....

[Insert name and organisation]

.....

Date: .....

[Insert name], The James Lind Alliance

.....

Date: .....

## Appendix A: Schedule of Steering Group Meetings

### Face to face meeting

### Teleconference meeting

\* Monday, 19<sup>th</sup> June 2017

\* Friday, 14<sup>th</sup> July 2017

\* Friday, 25<sup>th</sup> August 2017

\* Tuesday, 12<sup>th</sup> September 2017

\* Tuesday, 7<sup>th</sup> November 2017

\* Tuesday, 12<sup>th</sup> December 2017

\* Tuesday, 23<sup>rd</sup> January 2018

\* Tuesday, 6<sup>th</sup> March 2018

\* Tuesday, 17<sup>th</sup> April 2018

\* Tuesday, 5<sup>th</sup> June 2018 ok

\* Tuesday, 3<sup>rd</sup> July 2018

\* Tuesday, 4<sup>th</sup> September 2018

\* Tuesday, 23<sup>rd</sup> October 2018

Appendix B: Timeline

TASK	Apr 17	May17 START	Jun 17	Jul 17	Aug 17	Sep 17	Oct 17	Nov 17	Dec 17	Jan 18	Feb 18	Mar 18	Apr 18	May 18	Jun 18	Jul 18	Aug 18	Sep 18	Oct18 FINISH
Invite people to SG	█																		
Invite partners	█																		
Draft survey		█																	
Draft protocol		█	█																
Draft SG Terms of Ref.		█																	
Face to face/Teleconf. SG Meetings***			1 9			1 2		7	1 2	2 3		6	1 7		5	3		4	2 3
Finalise protocol and survey, SG sign off			█																
Prepare PSP website, promotion and publicity strategy			█																
Pilot Survey 1 to collect uncertainties*				█															
Agree Survey 1			█																
Activate publicity mechanisms				█															
Survey 1 open nationally				█	█	█	█												
Analyse Survey 1: Refine uncertainties and generate long list. SG sign off							█	█	█	█	█	█							
Interim priority setting exercise: Open Survey2													█						
Analyse Survey 2: SG agree and sign off short list of q's for w/shop														█	█	█	█		
Priority setting workshop																		█	
Publication and results dissemination																			█
Conference presentation							P.A. 1/52		Gene to Cl**			BSID				BAD		P.A. wk.	

\*To coincide with 4-6 July Liverpool Annual Meeting of the British Assn of Dermatologists (Psoriasis Association will house PSP survey at their conference stand.

\*\*For Psoriasis from Gene to Clinic Meeting 30 Nov-2 Dec 2017 <http://psoriasisg2c.com/programme/>

\*\*\*Schedule for Steering Group meetings in Appendix A