

# Eczema and Psoriasis Service Patient and Public Involvement Group

PPI Meeting

Tuesday 31<sup>st</sup> October 2017

Atrium 1, Southwark Wing

Guy's Hospital

# Meeting theme: Psoriasis

Time	Agenda
3pm – 3.05pm	Welcome and Introduction - Prof Catherine Smith
3.05pm – 3.20pm	Genetics of psoriasis - Dr Satveer Mahil
3.20pm – 3.35pm	Psoriasis Priority Setting Partnership - Lucy Moorhead
3.35pm – 4pm	Q&A

# Welcome

Catherine Smith

Consultant Dermatologist &  
Professor of Dermatology & Therapeutics

# Psoriasis: a common, chronic, inflammatory skin disease



# A serious non-communicable disease with major societal burden



## Important comorbidities

- Psoriatic arthritis
- Cardiovascular disease
- Obesity and related problems
- Metabolic syndrome
- Alcohol-related disease
- Depression

125 000 000

Affected world wide

1 800 000

In the UK

Global report on Psoriasis 2016

# World Psoriasis Day and Psoriasis Awareness Week

29<sup>th</sup> Oct – 5<sup>th</sup> November 2017

- Focussing on “Small Steps” – a practical guide to living well with psoriasis

<http://www.seepsoriasislookdeeper.co.uk/home/smallsteps>



# Genetics of psoriasis

Dr Satveer Mahil

Dermatology Specialist Registrar

# Plan

- Overview of psoriasis
- Genetics of
  - plaque psoriasis
  - pustular psoriasis



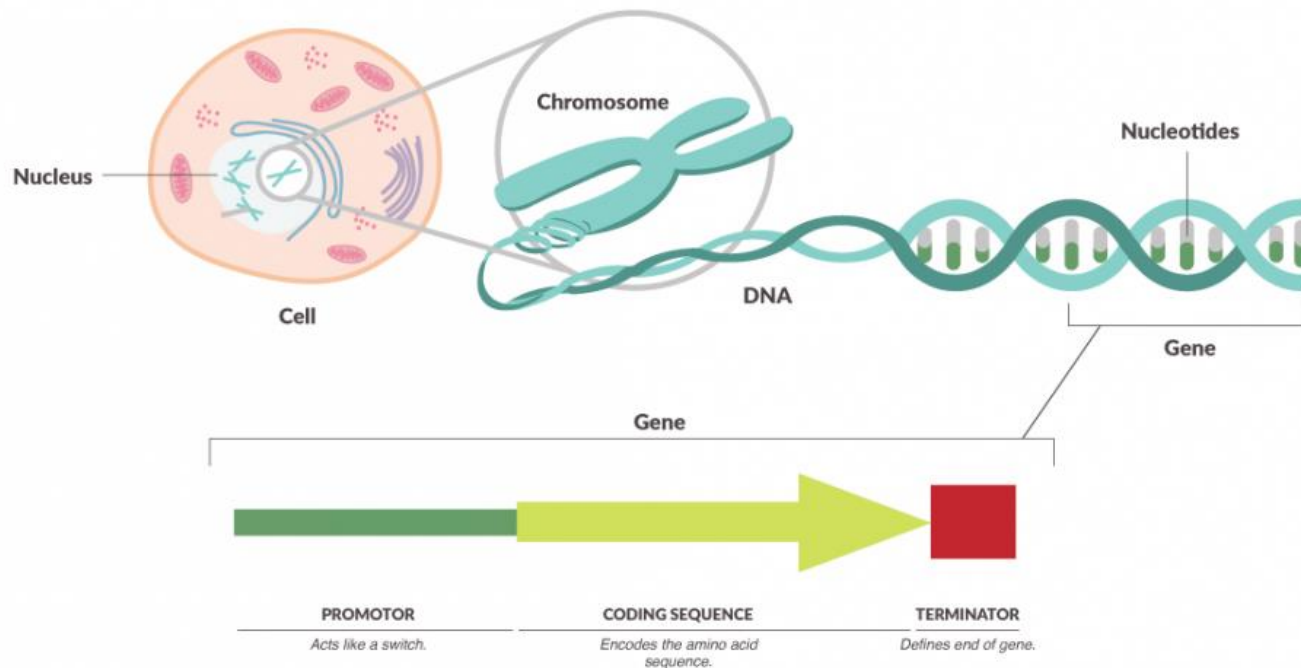
# Psoriasis

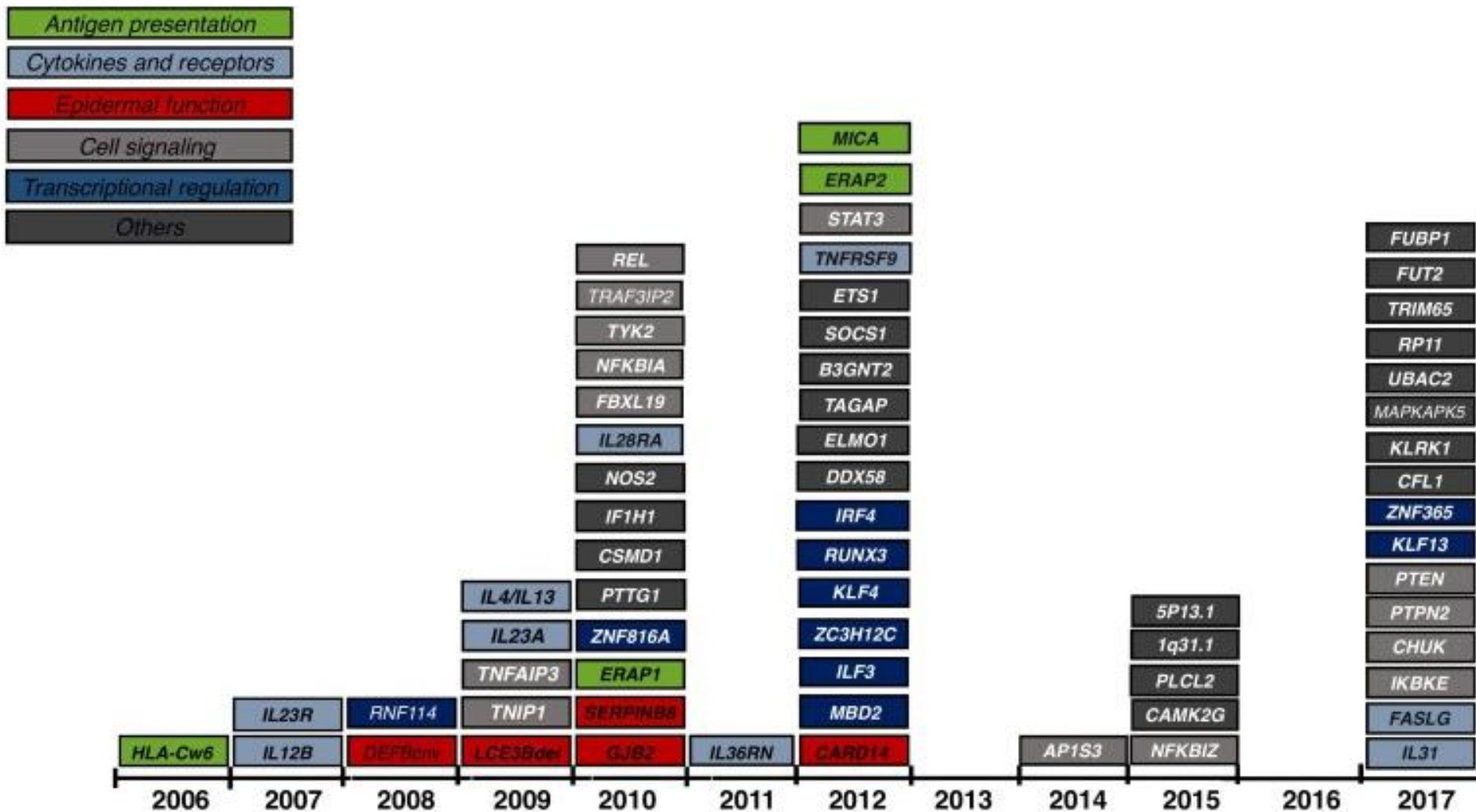
- Immune-mediated skin disease
- Common: 2% of population
- Males and females equally affected
- Associated diseases beyond skin:
  - Arthritis
  - Heart disease
  - Psychosocial impact
- Variable presentations



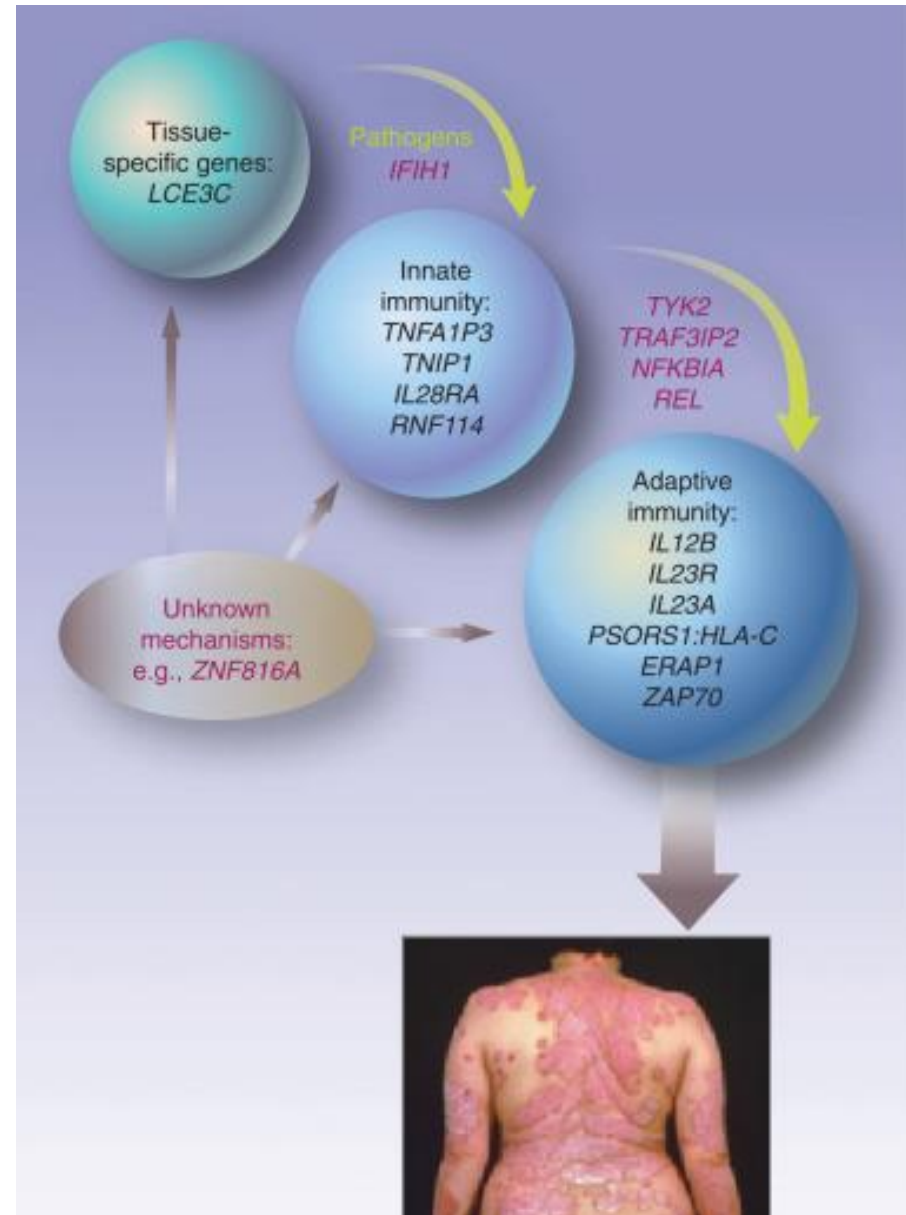
# Plaque psoriasis

- Common, complex disease
- >60 regions of our DNA are associated with plaque psoriasis





- Genetic studies have provided insights into how plaque psoriasis develops
  - Disruption of skin barrier function
  - Dysregulation of the immune system

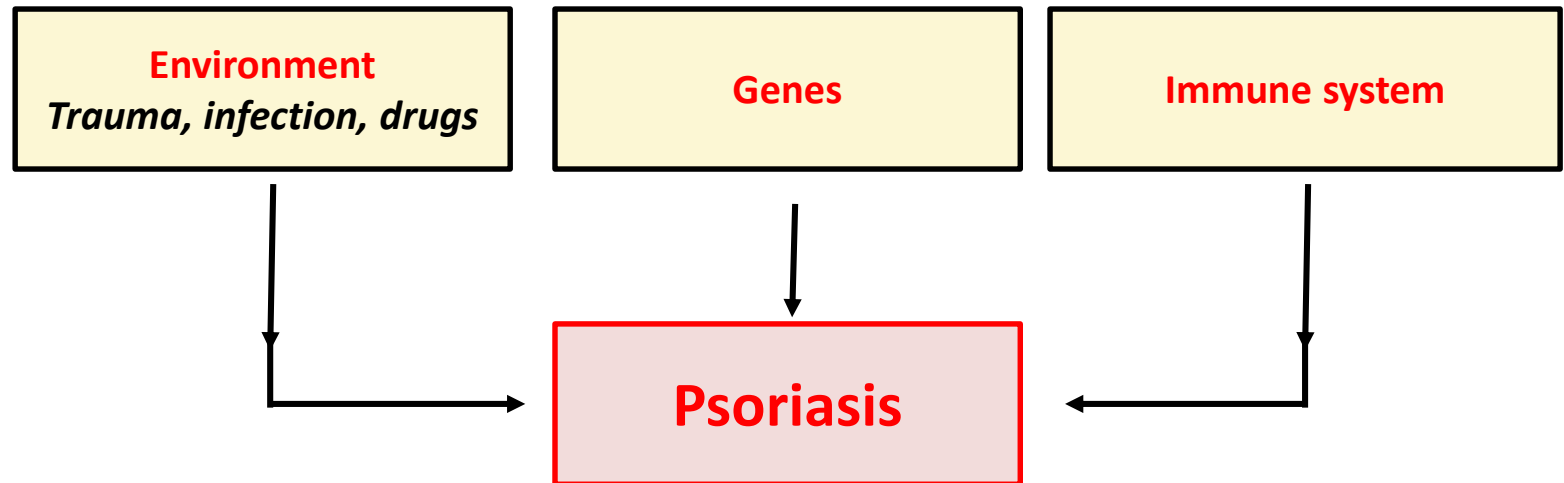


- Genetic studies have informed the development of new treatments



- Next challenges

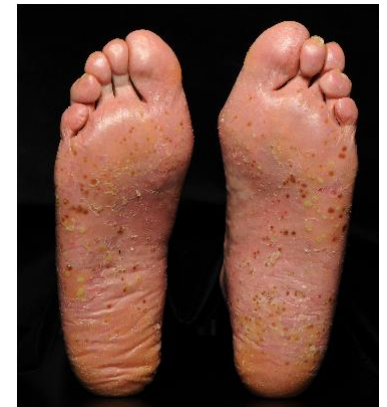
- Find other genes that contribute to psoriasis
- How does the environment impact on genes and the immune system?



- Quest for new treatments

# Pustular psoriasis

- Sterile pustules on red skin
  - Generalised pustular psoriasis
  - Acrodermatitis continua of Hallopeau
  - Palmoplantar pustulosis
- Improved understanding of the causes of disease may help to design new treatments



# Pustular psoriasis

- Rare, severe
- Single genes more influential
- 3 genes found to date:
  - *IL36RN*
  - *AP1S3*
  - *CARD14*
    - May converge on increased IL-36 signalling



- Next challenges
  - Find other genes that cause pustular psoriasis
  - Better understand mechanisms of diseases

[Home](#) [Register Interest](#) [About](#) [Healthcare Professionals](#) [Our Research](#) [Contact](#) [PLUM](#)

## PLUM – pustular psoriasis, elucidating underlying mechanisms

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PLUM is a study for patients with **all types** of pustular psoriasis. This study aims to identify genetic causes of the disease and to increase our understanding of why pustular psoriasis seems to be distinct from other more common forms of psoriasis.

### What does PLUM involve?

Participants in PLUM will be asked to provide blood samples and clinical data at one study visit. Participants may then be invited to return (up to 4 times) to provide additional samples (including optional skin samples), depending on early results.

Every effort will be made to co-ordinate the study visit with scheduled clinic appointments. If participants have

- Next challenges
  - Test new treatments



The screenshot shows the homepage of the APRICOT clinical trial website. At the top, the logo features an orange apricot icon next to the word "APRICOT" in orange capital letters. Below the logo, the text "Anakinra for Pustular psoriasis: Response In A Controlled Trial" is displayed in green. A navigation bar contains links: "Home" (underlined), "Register Interest", "About", "Healthcare Professionals", "Our Research", "Contact", and "PLUM". The main heading reads "Anakinra for Pustular psoriasis: Response in a Controlled Trial" in large orange font. Below this, a welcome message states: "Welcome to our trial website! We are looking for participants to take part in our clinical trial for patients with palmo-plantar pustulosis (PPP)." At the bottom, an orange text block reads: "\*\*Oct 2017 news: We have successfully recruited our first batch of 24 participants. We are now looking for 40 new participants to start in January 2018\*\*".

**APRICOT**  
Anakinra for Pustular psoriasis:  
Response In A Controlled Trial

[Home](#) [Register Interest](#) [About](#) [Healthcare Professionals](#) [Our Research](#) [Contact](#) [PLUM](#)

## Anakinra for Pustular psoriasis: Response in a Controlled Trial

Welcome to our trial website!

We are looking for participants to take part in our **clinical trial** for patients with palmo-plantar pustulosis (PPP).

**\*\*Oct 2017 news:** We have successfully recruited our first batch of 24 participants. We are now looking for 40 new participants to start in January 2018\*\*



# Thank you

# Psoriasis Priority Setting Partnership

Lucy Moorhead

Advanced Nurse Practitioner

# Contents

- What is a PSP?
- Who is involved?
- Who facilitates a PSP?
- Who is James Lind?
- How does it work?
- What can you do?

# What is a PSP?

- A PSP aims to determine the issues that matter most about a particular condition
- Aims to involve all not just clinicians and patients
- The aim is to publish top 10 uncertainties in an area of healthcare
- Well established methodology
- Completed PSPs in dermatology include HS, cellulitis and alopecia

# Who is involved?



- We want responses from all involved with psoriasis!
- Led by Dr Helen Young, Senior Lecturer and Consultant Dermatologist, Manchester
- Steering committee comprises of;
  - 7 healthcare professionals
  - 7 x psoriasis patients
  - Representatives from stakeholders such as Psoriasis Association and Centre for Evidence Based Medicine, Nottingham
  - PsPSP management team from Manchester

# Who is James Lind?

- James Lind Alliance are key facilitators of PSP
- Non profit - making initiative established by Sir Ian Chalmers, Dr John Scadding and Sir Nick Partridge
- Named after James Lind, 18<sup>th</sup> century surgeon who pioneered RCTs' testing vitamin C in sailor as a cure for scurvy

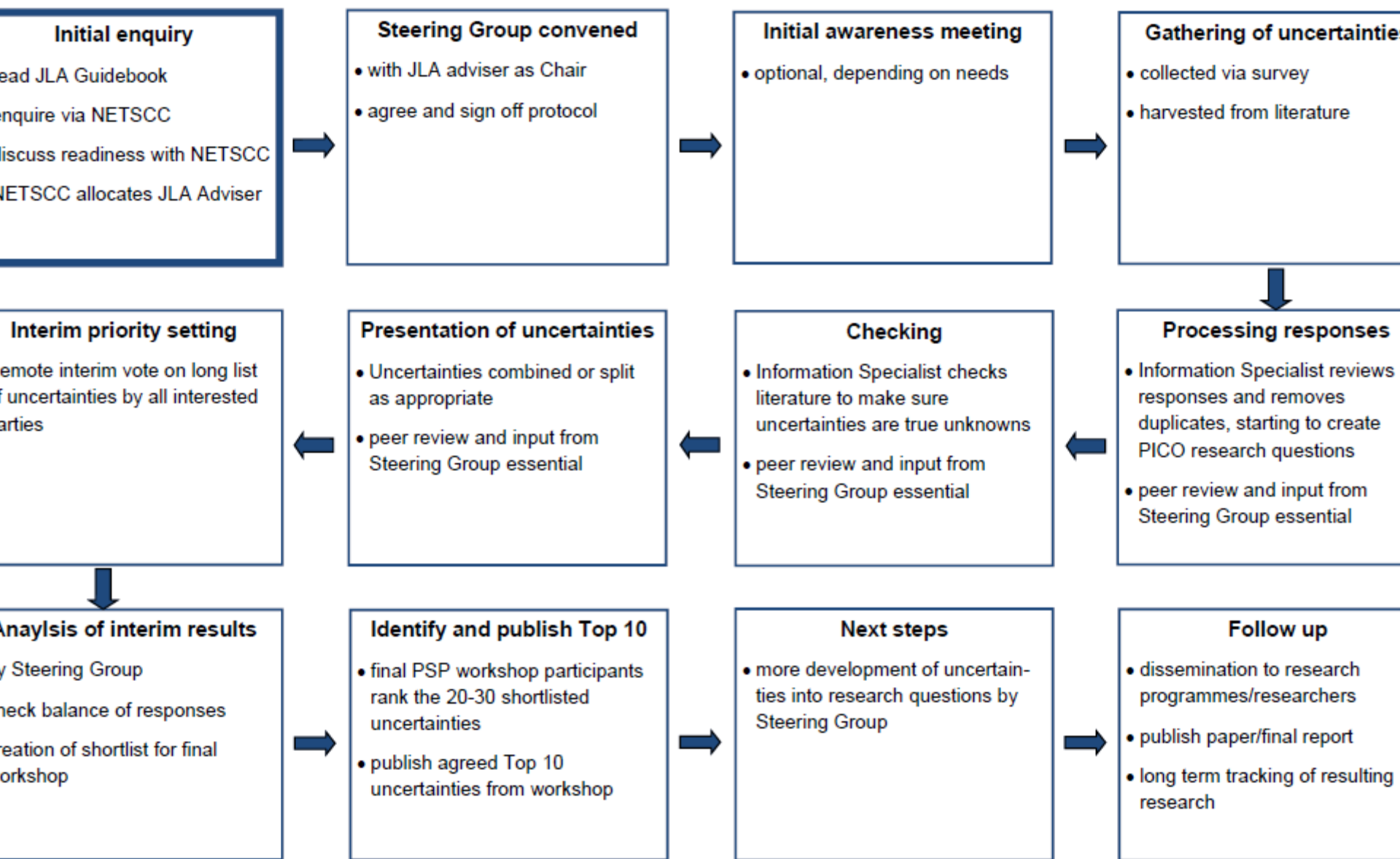


*"The consequence was, that the most sudden and visible good effects were perceived from the use of oranges and lemons; one of those who had taken them, being at the end of 6 days fit for duty."*

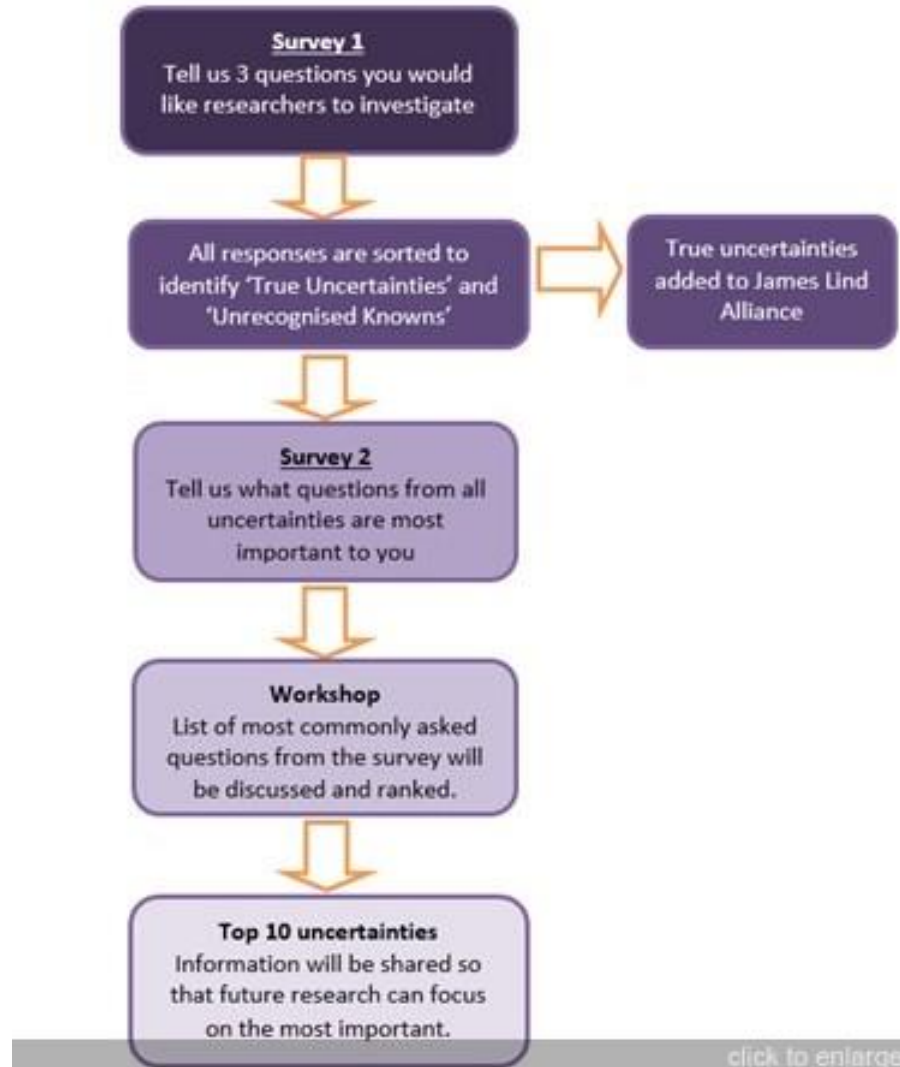




## Outline of JLA PSP Process



# Or more simply put.....



# What can you do?

Participate!

Encourage participation!

<https://www.psoriasis-association.org.uk/research/psp/process>

And don't forget.....



# Psoriasis inside out

[www.ifpa-pso.com](http://www.ifpa-pso.com)

World Psoriasis Day is presented by  and supported by      



29 OCTOBER 2017

We are celebrating on the 31<sup>st</sup> October with a stall and patient and public involvement meeting so please come and say hello!

# Any questions?

## Reference:

Moorhead, L et al (2017) Psoriasis Priority Setting Partnership: A vision for future psoriasis research, Dermatological Nursing, Vol 16, No 3

# Q&A

## The panel:

Mark Turner, Clinical Psychologist

Lucy Moorhead, Advanced Nurse Practitioner

Louise Griffiths, Research Nurse

Satveer Mahill, Dermatology Registrar

Francesca Capon, Senior Lecturer

Catherine Smith, Consultant Dermatologist

# Questions to the group

- Where do you find out about research and trials?
- How acceptable are skin samples?
- How much is a reasonable sum for reimbursement of inconvenience? Should we separate out travel expenses?
- What are your thoughts on whole body imaging (eg airport scanners) for skin assessments?

# THANK YOU!

[dermatologytrials@gstt.nhs.uk](mailto:dermatologytrials@gstt.nhs.uk)