

The Hidradenitis Suppurativa Priority Setting Partnership (HS PSP) has now achieved its aim and identified the questions about Hidradenitis Suppurativa (HS) that matter most to patients, carers and clinicians. The HS PSP Steering Group are delighted to announce the top 10 research uncertainties:

TOP 10

- 1 What is the most effective and safe group of oral treatments in treating HS? (e.g. antibiotics, hormonal treatments, retinoids, immunosuppressants, metformin, steroids)**
- 2 What is the best management of an acute flare?**
- 3 What is the impact of HS and the treatments on people with HS (physical, psychological, financial, social, quality of life)?**
- 4 How effective are biologics (etanercept, adalimumab, infliximab, ustekinumab) in treating HS?**
- 5 Does early diagnosis and aggressive treatment influence the course of HS?**
- 6 What is the best surgical procedure to perform in treating HS e.g. incision & drainage, local excision, wide excision?**
- 7 Which factors are useful in determining the prognosis (disease progression) of HS?**
- 8 What is the best method of wound care after surgery or for active disease?(e.g. Skin grafts, secondary intention, dressings)**
- 9 To what extent is HS caused by genetic factors?**
- 10 What is the best management of pain associated with HS?**

HS is a chronic inflammatory skin disease, characterised by recurrent painful boils and scarring in skin creases such as the armpit and groin, which is often overlooked by clinicians and society in general. It is estimated that 1% of the population have HS, however the figure could be higher due to lack of recognition. Current treatments for HS are often unsatisfactory and so more research is needed regarding this distressing condition.

The UK Dermatology Clinical Trials Network set up a Priority Setting Partnership, using the James Lind Alliance model, to tackle this issue. The partnership included patients (including The Hidradenitis Suppurativa Trust www.hstrust.org), carers, dermatologists, dermatology nurses, GPs, surgeons, and psychologists.

The central task was to identify uncertainties about HS and its management and to prioritise the top 10 selected issues for future research. Many thanks to everyone who took part in this process; in survey one, over 1000 HS research uncertainties were submitted by patients and clinicians.

The uncertainties were collated into 55 potential priorities and released as a second survey to the public for ranking.

The final step was to discuss and finalise the top 10 research questions at a workshop of healthcare professionals and patient representatives on December 6th 2013 facilitated by the [James Lind Alliance](#). This was a fantastically successful event, having a formal debate and gaining consensus regarding the top 10 priorities.



It is essential that future research into the management of HS should focus on questions that are important to people with HS, the people who care for them and the health professionals who treat them.

We can now disseminate these results to raise awareness of HS in the wider community and to help potential funders and researchers prioritise HS research.

To all of you who contributed to the surveys a huge thank you!