Hidradenitis Suppurativa Section
Introductory Meeting
March, 2016
Washington, DC

Goals for Today
• Introduce ourselves to each other.
• Learn more about our collective work in HS.
• Begin our research planning for a comprehensive effort to define a core set of domains and measurements to assess relevant disease aspects in HS.
• Introductions to Acne Outcomes initiative.

In your opinion, have HS domains been comprehensively defined by physician experts and researchers?
• A. Yes
• B. No
• C. I’m not sure

In your opinion, have HS domains been comprehensively defined by patients?
• A. Yes
• B. No
• C. I’m not sure

In your opinion, is it important to involve stakeholders in the development of outcome measurement instruments?
• A. Yes
• B. No
• C. I’m not sure

From your perspective, does any of the following measurement instruments accurately assess most of the critically important (ie, core) disease aspects?
• A. Hurley staging
• B. Modified Sartorius score
• C. HS Physician’s Global Assessment (HS-PGA)
• D. Hidradenitis Suppurativa Severity Index (HSSI)
• E. Hidradenitis Suppurativa Clinical Response (HiSCR)
• F. None of the above
In your opinion, does a sufficiently validated (ie, construct validity, reliability, sensitive to change) outcome measurement instrument for HS exist?

- A. Yes
- B. No
- C. I’m not sure

In your opinion, are any of the existing outcome measurement instruments for HS feasible for the clinical setting?

- A. Yes
- B. No
- C. I’m not sure

**Disease Assessment in HS**

- Some commonly utilized measurement instruments
  - Hurley staging
  - Modified Sartorius score
  - HS Physician’s Global Assessment (HS-PGA)
  - Hidradenitis Suppurativa Severity Index (HSSI)
  - Hidradenitis Suppurativa Clinical Response (HiSCR)

**Domain Assessment in HS**

- Lesion count
- Physician’s global assessment
- Recurrence rate
- Duration of recovery from surgical treatment
- Cosmesis
- Pain
- Patient lesion count
- Patient global assessment
- Quality of life
- Impairment of function
- Patient overall satisfaction with treatment

**Existing Instruments**

- Domains and outcomes not comprehensively defined.
- Most instruments not developed with the collaboration of stakeholders.
- Most instruments not sufficiently validated for construct, reliability, sensitivity to change, or feasibility.
- Heterogeneity in use of measurement instruments (30+) in observational studies and trials.
- Instruments developed for the research setting may not be applicable to or feasible in the clinical care setting.

**Our Task Ahead**

- **Phase I: Development of Core Domain Sets**
  - Literature review of existing outcome measures.
  - Develop a core outcome set of domains for clinical trials.
  - Develop a core outcome set of domains for clinical care.
  - Assess ability of existing measurement instruments to capture consensus domains.

- **Phase II: Development of Core Measurement Sets**
  - Develop and validate any new measurement instruments needed to capture domains.
  - Disseminate and implement work products.
Development of core outcome sets in hidradenitis suppurativa: a systematic review of outcome measure instruments to inform the process
John Ingram
S. Hadjavand
V. Figuer
Br J Dermatol Feb 2016 [Epub ahead of print]

Measurement Properties of Outcome Measures for Hidradenitis Suppurativa: Protocol for a systematic review
Limena Thorlacius, MD, PhD student
Peter Thaut Ris, MD, PhD student
Amit Garg
Loise Stolker
Dima Marie Sarte
Alice Gottlieb,
Elke Marie Bartels
Caroline Terwee
Robin Christensen
Gregor Buzet Ernst Jemec

HiSCR Overview
Alexa Kimball
Distinguishing Outcomes for Activity and Scarring
Joslyn Kirby

Patient Reported Outcome Measures in Hidradenitis
Gregor Jemec

Systematic Review of Outcome Measure Instruments in Hidradenitis: the IDEOM-CSG-COUSIN collaboration
John Ingram

ACORN (Acne Core Outcomes Research Network)
Jerry Tan

Discussion and Strategic Planning
Amit Garg

HS Section
Discussion & Planning
Protocols

- Establish protocols for consensus studies
  - Core set of measurement domains in trials
  - Core set of measurement domains for medical treatment
  - Core set of measurement domains for surgical treatment
  - Protocols for patient participation

- Delphi workgroup

Recruitment of Participation

- Physician experts (also surgeons?)
- Patient partners
- Payers
- Regulatory representation
- Scientific Liaisons from Industry
- Methodologists
- Others?

- Recruitment workgroup

Timeline

- Date and location for first standalone consensus meeting
  - October 15
  - Toronto or NYC

Funding

- Grant for proposed work has been funded by Abbvie

- Considering additional sources of support

HS Advocacy Initiative

- North American based advocacy initiative
  - Disease Awareness and Education
  - Patient Support / Networks
  - Advocacy and Legislative support
  - Research
  - Fund raising

- Advocacy workgroup

Thank you for your collaboration. There is a lot of work to be done.

Please gather for our inaugural group photograph.