



# Guiding principles in Hidradenitis Suppurativa (HS) care

June 2016



This study was commissioned and solely funded by AbbVie

AbbVie had no role in the design and conduct of the study, collection, management, analysis and interpretation of data, or preparation, review and approval of this report.

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Details on the aims and objectives of the project



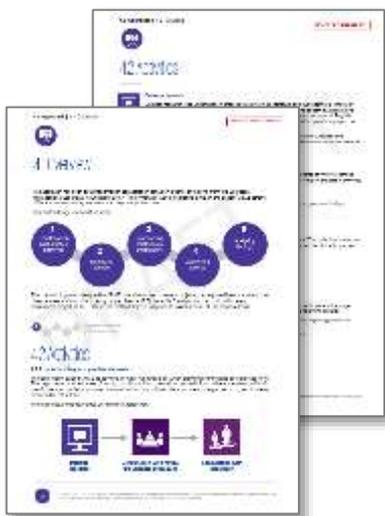
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# Foreword



## **Prof Dr Christos C. Zouboulis**

*President of the European Hidradenitis Suppurativa Foundation (EHSF)*

Hidradenitis suppurativa / acne inversa (HS) is a complex chronic disease which has a serious impact on patients.

Currently, patients and physicians face significant challenges including ill-defined and fragmented care pathways, poor use of medical treatments, late diagnosis and late referral to specialist centres. There is wide variation in the quality of care patients receive, even within the same geographical locations.

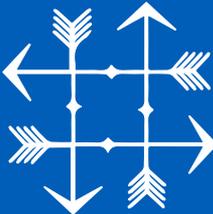
This study has been carried out to help understand how to deliver excellent HS treatment and care for patients and how to help improve care delivery across healthcare systems.

A team of clinicians and research scientists visited eight reference centres. During these visits, the team observed HS care, collected data and interviewed healthcare professionals involved in the management of HS patients.

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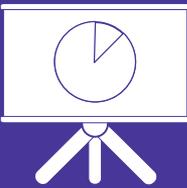
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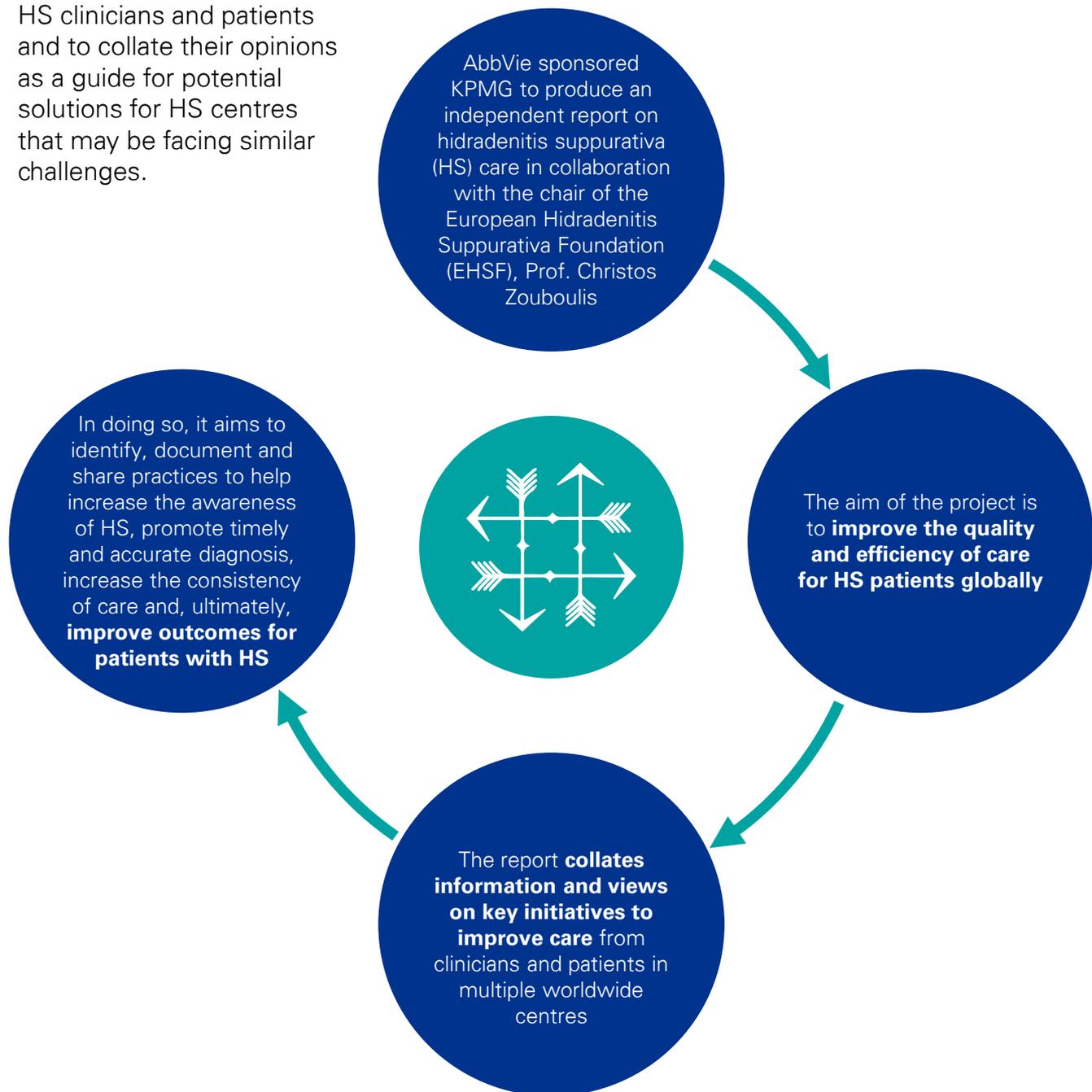
# 1.0 Executive summary



## 1.1 Goals

**This report aims to improve the quality of care for HS patients by identifying possible challenges and interventions in delivering care, raised by HS clinicians and patients.**

KPMG's role in this report is to collect the views of HS clinicians and patients and to collate their opinions as a guide for potential solutions for HS centres that may be facing similar challenges.





## 1.2 Context



Notes:

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015



## 1.3 Approach

**KPMG interviewed a range of HS experts and clinicians across 8 centres. This report collates the information and views shared by these experts and highlights interventions to improve HS care raised during the interviews.**

*Note: the interventions identified are not considered to be exhaustive of best practice, but simply represent those identified from our data collection*

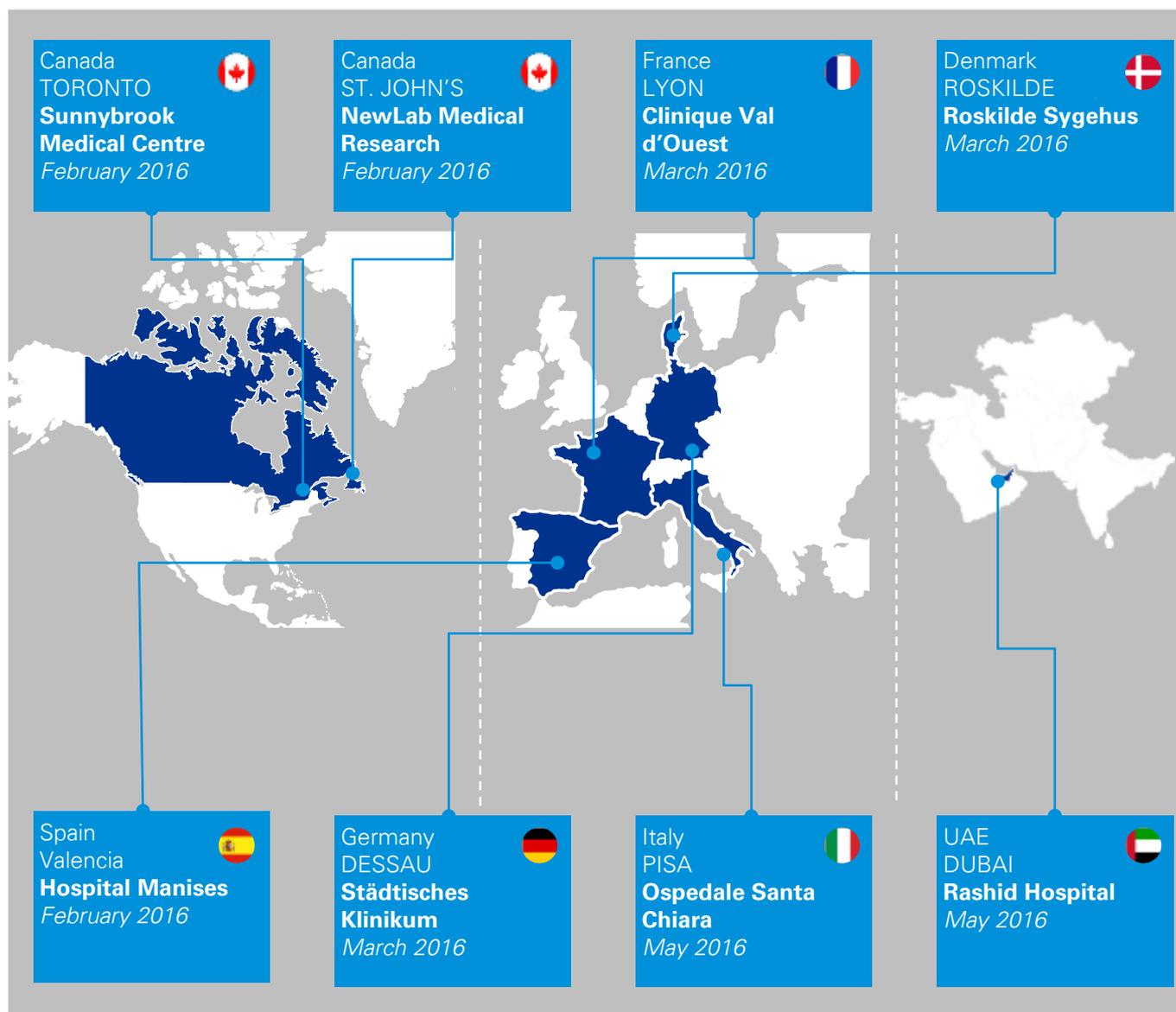
**The EHSF president and members selected centres** around the world to participate in this project

Centres were picked to represent a **variety of geographies, healthcare systems, care settings and different access to specialties**

KPMG engaged with a **range of stakeholders** including dermatologists, surgeons, specialist nurses and patient organisations

KPMG gathered **views in key areas:** challenges, interventions to address them, networks, patient-centricity and benefit creation

Findings were collated into a report which was **reviewed by the participating centres** and their lead KOL to ensure the validity





## 1.4 Findings - challenges

Through our 8 centre visits (and detailed case studies) interviewees identified a number of challenges faced in their respective centres, of which we have captured below:

### First symptoms



- Delayed presentation to clinicians.
- Patients discouraged when presenting with initial symptoms.

### Diagnosis



- Low clinician awareness causing delays in diagnosis, and mis-diagnosis.

### Referral



- Low clinician awareness causing lack of, and mis-directed referrals.
- Delayed or limited patient information transfer.
- Clinician reluctance to accept HS referrals.

### Treatment



- Difficulty in accurately identifying disease extent.
- Multiple patient needs / high comorbidity.
- Variable quality of treatment between countries.
- Variable funding for biologics, surgery and follow-up care across regions and payors.
- Low patient concurrence with treatment plans, including lifestyle change plans.
- Lack of robust, standardised outcome measures.

### Follow up and ongoing



- Heavy time burden on patient.
- Clinician capacity affected by follow-up demand.
- Undetected symptom deterioration.
- Physical, psychological and financial strain on patients.
- Limited understanding of disease mechanism.
- Professional siloes.



## 1.4 Findings - interventions

Through our 8 centre visits (and detailed case studies) interviewees identified possible solutions that they had recognised to be beneficial in tackling challenges stated, of which we captured below:

### First symptoms



- Public awareness campaigns
- HS awareness training for clinicians

### Diagnosis



- HS awareness training for clinicians and nurses

### Referral



- HS awareness training for clinicians and nurses
- Information sharing systems
- MDTs and strong networks

### Treatment



- CO<sub>2</sub> laser surgery
- Lifestyle support
- Ultrasound imaging
- Laser imaging
- Standardising staging and treatment across regions and settings
- Patient education

### Follow up and ongoing



- Follow-up care in the community
- Hyperbaric chamber therapy
- Physiotherapy
- Dermatology nurses
- Topographic records
- Patient association
- Patient care meetings
- HS registry
- Global networks



## 1.4 Findings

**Further detail regarding the challenges and interventions raised by the interviewees can be found below, with links to detailed write-ups and case-studies within the report.**

**Note the findings outlined below represent the views of the interviews and are not an exhaustive representation of best practice care in HS.**



### First symptoms

#### Challenge: Delayed presentation to clinicians

##### Intervention: Public awareness campaigns

- Overview: operation to raise awareness of HS, to improve recognition and understanding amongst undiagnosed sufferers and the general public.
- Benefits: increased presentation to clinicians; early identification of disease.
- Key replication tip: work with specialists in comorbidity and co-treatment fields to develop training materials; identify appropriate channels to present training through.

#### Challenge: Patients discouraged when presenting with initial symptoms

##### Intervention: HS awareness training

- Overview: training is provided for primary and secondary clinicians, including dermatologists unfamiliar with HS.
- Benefits: increased referrals; referrals made to correct specialist.
- Key replication tip: developing training materials; securing appropriate platforms for training.



### Diagnosis

#### Challenge: Low clinician awareness causing delays in diagnosis, and mis-diagnosis

##### Intervention: HS awareness training

- Overview: training is provided for primary and secondary clinicians, including dermatologists unfamiliar with HS.
- Benefits: increased referrals; referrals made to correct specialist.
- Key replication tip: developing training materials; securing appropriate platforms for training.

Other interventions:

- Patient associate conducting awareness activities 
- HS course to raise awareness amongst nurses 
- European guidelines 



## 1.4 Findings



### Referral

**Challenge: Low clinician awareness causing lack of, and misdirected, referrals**

**Intervention: HS awareness training**    

- Overview: training is provided for primary and secondary clinicians, including dermatologists unfamiliar with HS.
- Benefits: increased referrals; referrals made to correct specialist.
- Key replication tip: developing training materials; securing appropriate platforms for training.

**Challenge: Delayed or limited patient information transfer**

**Intervention: Information sharing system** 

- Overview: a cross-centre IT-based system is used to share clinicians' patient notes across different settings.
- Benefits: heightened patient trust.
- Key replication tip: secure management buy-in for this large intervention, which may have high funding and IT requirements.

**Challenge: Clinician reluctance to accept HS referrals**

**Intervention: Jointly agreed referral criteria** 

- Overview: clinicians collaborate to draw up referral criteria to ensure standardised referral triggers.
- Benefits: clinician clarity and agreement on baseline for making and receiving referrals.
- Key replication tip: initiate and maintain clear communication channels between the parties wishing to collaborate.



## 1.4 Findings



### Treatment

#### Challenge: Difficulty in accurately identifying disease extent

##### Intervention: CO<sub>2</sub> laser surgery

- Overview: tissue is vaporised in thin layers to minimise removal.
- Benefits: improved time to recovery; pain and mobility loss minimised.
- Key replication tip: consider how to develop a business case in the absence of comparative studies.

##### Other interventions

- Ultrasound imaging to gain dermal and sub-dermal images  
- Laser imaging to gain accurate image of wound or lesion 

#### Challenge: Multiple patient needs / high comorbidity

##### Intervention: Multi-disciplinary team (MDT)

- Overview: clinicians and support services work collaboratively to provide treatment that addresses the entirety of patients' needs.
- Benefits: improved treatment accuracy and comprehensiveness; strong understanding of patients' overall needs.
- Key replication tips: design working practices that work with involved parties' budgets and the region's reimbursement procedures; consider formalising interactions where large centres are involved.

#### Challenge: Variable quality of treatment between countries

##### Intervention: Standardising HS care

- Overview: individuals/groups work towards nation- and region-wide agreements on treatment practice.
- Benefits: improved patient access to high-quality care.
- Key replication tips: collaborate with other medical centres to jointly lobby health authorities across the regions.

##### Other interventions

- Treatment algorithm  



## 1.4 Findings



### Treatment

**Challenge: Variable funding for biologics, surgery and follow-up care across regions and payers**

**Intervention: National review** 🇩🇰

- Overview: individuals/groups work towards governmental-level understanding of HS prevalence and impact, and to ensure appropriate reimbursement for treatment.
- Benefits: improved disease profile and treatment reimbursement.
- Key replication tip: work towards developing data that supports the case for change.

**Challenge: Low patient concurrence with treatment plans, including lifestyle change plans**

**Intervention: Patient education** 🇩🇰

- Overview: structured education is provided to patients, and specific patient queries are addressed.
- Benefits: patient empowerment is increased, allowing them to proactively find ways to minimise HS impact.
- Key replication tip: develop a programme that addresses local needs, keeping in mind staffing and funding requirements.

Other interventions:

- Jointly developed treatment plans to encourage compliance 🇨🇦
- MDT offering lifestyle support. 🇫🇷 🇩🇰

**Challenge: Lack of robust, standardised outcome measures**

**Intervention: Develop outcome measures** 🇩🇰 🇮🇹

- Overview: measures are developed to gauge the impact of a given intervention or treatment in a way that is both specific and meaningful for patients.
- Benefits: ease of measurement of HS severity and patient QoL; standardisation across trials and clinics.
- Key replication tips: collaborate both internally and externally with colleagues engaged in similar or complementary work in order to develop outcomes that are robust and universally applicable.



## 1.4 Findings



### Follow up and ongoing

#### Challenge: Heavy time burden on patient

##### Intervention: Follow-up care in the community

- Overview: practitioners treat flares and manage wounds in a community setting, possibly with assistance for specialist staff at intervals.
- Benefits: clinicians freed up to address severe cases; reduced patient pain and inconvenience; generalist staff less obliged to contact a clinician for minor queries.
- Key replication tips: observe similar clinics in settings to replicate effectively; develop programme that works within the funding regimen in own region; develop and maintain communication between primary and secondary setting.

Other interventions:

- Hyperbaric chamber therapy to promote rapid wound healing 
- MDT offering physiotherapy 

#### Challenge: Clinician capacity affected by follow-up demand

##### Intervention: Nursing support

- Overview: specialist wound care nurses or general dermatology nurses support clinicians by assisting in the treatment of follow-up wound care.
- Benefits: clinician capacity reserved for severe cases; patient care enhanced.
- Key replication tip: work within local funding and employment regimens to develop a suitable offering.

Other interventions:

- Follow-up care in the community to deal with flares and wound management. 



## 1.4 Findings



### Follow up and ongoing

#### Challenge: Undetected symptom deterioration

##### Intervention: Topographic records

- Overview: 3D images of HS lesions are created and recorded in order to track the swelling of lesions over time.
- Benefits: this is a novel approach in this field and the work is currently being evaluated with an aim to publish findings of the approach.
- Key replication tip: ensure technological capability and supporting structures are in place.

#### Challenge: Physical, psychological and financial strain on patients

##### Intervention: Patient associations

- Overview: patient associations offer pastoral support and clinical legal and financial advice to members, run campaigns to raise HS awareness and lobby government.
- Benefits: patient isolation reduced; access to experience on how to navigate medical, funding and legal systems.
- Key replication tips: consider how clinicians or centre staff might support the initiative in the first instance until it gains momentum; approach industry bodies to help fund campaigns; use online platforms to draw patients together.

#### Other interventions:

- MDT offering psychological support   
- Motivational support for patients 
- Patient care meetings to incorporate patient needs into hospital operations 
- Hyperbaric chamber therapy to promote rapid wound healing 
- Patient association



## 1.4 Findings

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### Follow up and ongoing

**Challenge: Limited understanding of disease mechanism**

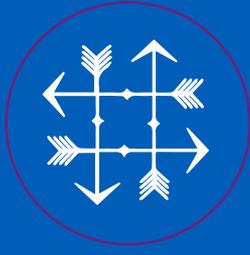
**Intervention: HS registry**   

- Overview: centres submit data to a registry in order to pool knowledge of the disease and to identify trends and patterns across a large patient cohort over time.
- Benefits: increased awareness of HS prevalence and presentation; pattern recognition across patients.
- Key replication tip: ensure resource and time is available to capture data accurately and update registry regularly.

**Challenge: Professional siloes**

**Intervention: Global network** 

- Overview: centres, clinicians and patients link to each other via virtual networks to provide global support which optimises local activity.
- Benefits: peer support for clinicians; increased research opportunities; improved patient access.
- Key replication tip: ensure teams have adequate national and local support in order to function sustainably.



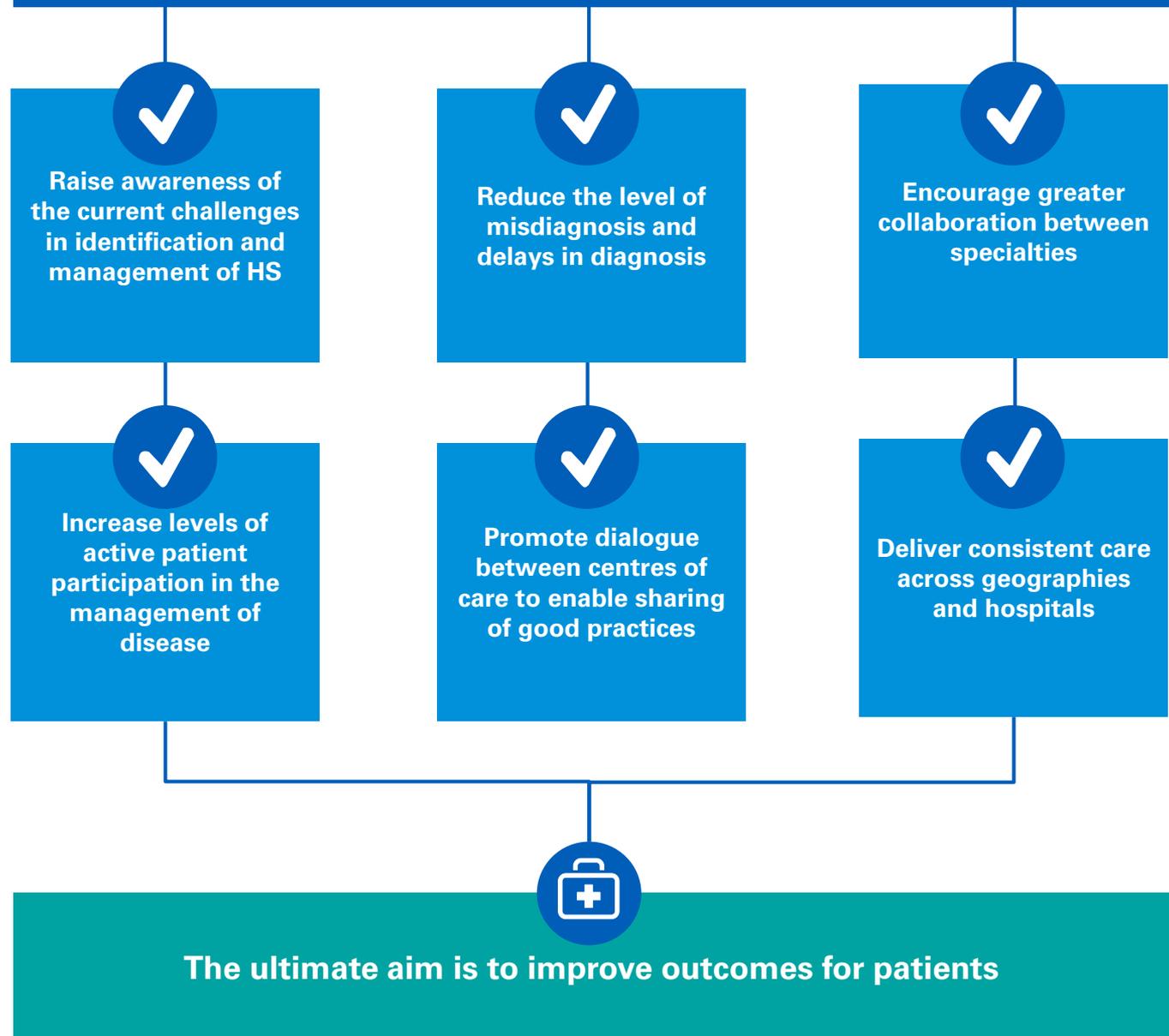
# 2.0 Goals



# 2.0 Goals

**The goal of this report is to collate information and views on key initiatives to improve care**

These views are those of clinicians and patients in multiple worldwide centres.  
In presenting these views, the report aims to:





# 3.0 Context



## 3.1 Disease overview and pathophysiology

### 3.1.1 Overview

- HS is a chronic, inflammatory, recurrent skin disease that usually presents after puberty with painful, inflamed lesions in the apocrine gland-bearing areas of the body<sup>1</sup>.
- Patients face significant delays in diagnosis – an average of seven to eight years<sup>1</sup> – which can result in significant pain and scarring.

### 3.1.2 Pathophysiology

- The initiating event in HS is thought to be due to the occlusion of the lower part of the hair follicle<sup>2</sup>.
- The cause of HS is unclear, with many believing it to have multiple associated causal factors such as genetics, environmental and endocrinology<sup>1</sup>.

## 3.2 Symptoms and diagnosis

### 3.2.1 Symptoms

- HS can affect a single area or multiple areas of the body.
- The most commonly reported symptoms include subcutaneous nodules, papules, abscesses, sinus tracts and scarring<sup>1,2</sup>.



*Mild HS: single or multiple abscesses; no tracts or scarring<sup>3</sup>*



*Moderate: recurrent abscesses with sinus tracts and scarring; single or multiple lesions<sup>3</sup>*



*Severe: diffuse/near diffuse tracts and abscesses<sup>3</sup>*

#### Notes:

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015
2. National Institute for Health and Care Excellence – Draft scope for the proposed appraisal of adalimumab for treating moderate to severe hidradenitis suppurativa.
3. Jemec GB, Hidradenitis Suppurativa, New England Journal of Medicine, 2012.



## 3.2 Symptoms and diagnosis

### 3.2.2 Diagnosis

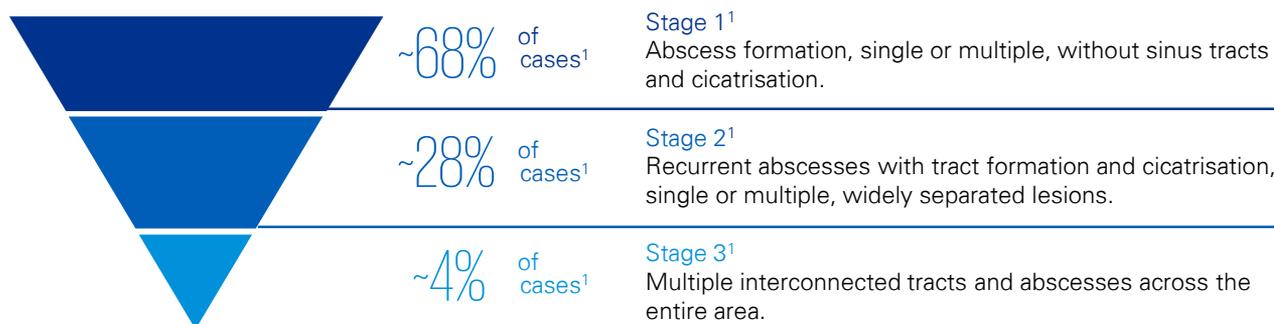
Diagnosis, including disease severity, is made using objective diagnostic criteria by a clinician.

The primary diagnostic criteria are a history of recurrent painful or suppurating lesions, occurring more than twice in six months<sup>1</sup>. Practitioners will search for:

- signs of involvement of axilla, genitofemoral area, perineum, gluteal area (and infra-mammary area of women)<sup>1</sup>
- presence of nodules, sinus tracts, abscesses, scarring<sup>1</sup>.

A family history of HS provides a secondary positive diagnostic criteria<sup>1</sup>. In addition, a negative swab or the presence of normal skin microbiota may be indicative of HS<sup>1</sup>.

To describe the severity of the disease, a staging system called Hurley's staging is often used:



## 3.3 Causes

The cause of HS is unclear, with many believing it has multiple causal factors. These can be grouped as follows:

### Genetic

Current studies show that 30 to 40% of HS patients report a family history of HS. In particular, gamma-secretase mutations seem to be responsible for approximately 5% of HS cases. Additionally, a certain haplotype of the TNF gene seems to be associated with a greater reduction of disease severity after treatment with TNF agents. Genetic factors might influence not only the appearance of HS but also the phenotype of disease<sup>1</sup>.

### Environmental

Environmental factors are unlikely to cause HS. However, there are aspects which are likely to exacerbate the condition. Smoking and obesity are both well recognised as being associated with HS. Over 75% of HS patients are obese, and the role of obesity as a severity factor is highly probable. Smoking has a similarly high correlation according to several studies, with ~89% of sufferers being active smokers according to a recent case control study<sup>1</sup>.

### Endocrine

Endocrinology has been suggested as a possible cause, since the disease onset typically occurs at the time of puberty, and additionally HS severity may be reduced after the menopause in women<sup>2,3</sup>. In one study where 93 female HS sufferers were questioned about HS flares, nearly half reported perimenstrual exacerbation<sup>3</sup>. It has also been noted that progestogens induce or worsen preexisting HS due to their androgenic properties<sup>4</sup>.

#### Notes:

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015
2. von der Werth JM, Williams HC. The natural history of hidradenitis suppurativa. Journal of the European Academy of Dermatology & Venereology 2000
3. British Association of Dermatology – Hidradenitis Suppurativa



## 3.4 Epidemiology

- There is a notable variation in the figures reported for the prevalence of HS, ranging from 0.08% to 4%<sup>1,2</sup>. Specialists have attributed this difference to varying methodologies and diagnostic criteria across different settings and geographies<sup>3</sup>. A review in 2006 put the global figure at ~1%<sup>1</sup>.
- HS affects more women than men, with a recent study estimating a prevalence of 4% in young adult women. As HS is mainly observed in young adults with a female predominance, this result is in concordance with the most accepted figure of 1% in the general population<sup>1</sup>.
- HS symptoms generally begin around puberty, and most commonly appear in the second or third decade of life<sup>1,4</sup>. For this reason, they are believed to be driven, at least in part, by endocrinal changes.
- There also appears to be a racial difference in HS prevalence, with people of African family origin having a higher incidence than people of European family origin<sup>2</sup>.

## 3.5 Treatment and prognosis

### 3.5.1 Treatment

There are a variety of treatment options for dealing with HS, with treatment based on objective severity of the disease (using Hurley's classification) and the subjective impact on the patient<sup>1</sup>. Therefore clinical judgement is required as to the optimal treatment selection of monotherapies or multiple therapies for the physician's patient.



#### Medical

Medical management can include the use of anti-inflammatories for milder disease and systemic antibiotics or biologics for moderate-severe disease stages. Analgesia has limited benefits and may be prescribed for acute exacerbations<sup>1</sup>.



#### Surgical

Surgery is often used in the treatment of moderate and severe HS, as medical therapy seldom results in cure. The type of surgery used depends on the severity and location of the disease, including excisions, reconstruction, deroofing and laser therapies<sup>1</sup>.

Given the positive correlation between HS severity and BMI and smoking, supporting patients to reduce BMI and quit smoking is regarded as important by experts<sup>1</sup>. Psychosocial support is often considered important due to HS leading to depression and social exclusion<sup>1</sup>. Many patients have also reported positive benefits from home remedies such as washing with antiseptic soaps, wearing loose-fitting clothing, reducing smoking and body weight, and managing stress levels<sup>5</sup>, although there are limited studies to support this.

#### Notes:

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015
2. Jemec GB, The prevalence of hidradenitis suppurativa and its potential precursor lesions, 1996
3. Fimmel and Zouboulis, Comorbidiites of Hidradenitis Suppurativa, 2010
4. National Institute for Health and Care Excellence – Single Technology Appraisal – Adalimumab for treating moderate to severe hidradenitis suppurativa - Final scope
5. British Association of Dermatology – Hidradenitis Suppuritiva



### 3.5.2 Prognosis

The majority of HS cases are in mild stages of the condition and can be controlled well through medical intervention<sup>3</sup>. Moderate to severe stages of the condition can require surgical intervention. Moderate to severe stages of the disease can also lead to the following complications<sup>1</sup>:



- Acute infection of sites
- Lymphatic obstruction
- Lymphodema
- Scrotal elephantiasis
- Squamous cell carcinoma
- Anaemia
- Hypoproteinemia
- Amyloidosis

## 3.6 Comorbidities

HS is associated with a variety of secondary diseases. Moderate to severe stages are most commonly associated with the following comorbidities<sup>1</sup>:



- Crohn's disease
- Spondylarthritis
- Genetic keratin defects associated with follicular occlusion

Other conditions associated with moderate to severe HS also include<sup>1</sup>:

- Obesity
- Amyloidosis
- Squamous cell carcinoma
- SAPHO syndrome
- Pyoderma gangraenosum
- Adenocarcinoma
- Arthritis
- Anaemia
- Lymphodema
- Metabolic syndrome
- Genetic keratin
- KID syndrome
- Down syndrome
- Adamantiades-Behçet's disease

#### Notes:

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015
2. British Association of Dermatology – Hidradenitis Suppurativa
3. BMJ Best Practice – Hidradenitis Suppurativa.



# 4.0 Approach



## 4.1 Overview

The approach has been designed through collaboration between a panel of experts from the European Hidradenitis Suppurativa Foundation (EHSF). The emphasis was on collating clinician and patient views across different centres and using these as a guide and example for centres who may face similar challenges.

The methodology involved five steps:



This methodology was designed by KPMG over the course of several projects that explored best practice across disease areas such as inflammatory bowel disease (IBD), hepatitis C and psoriatic arthritis. With every subsequent project, KPMG refined the methodology in response to lessons learnt at the previous stage.



## 4.2 Activities

### 4.2.1 Hypothesising good practice elements

The lead expert guided KPMG to develop an initial hypothesis on which elements constituted good practice in HS. This hypothesis provided areas for the team to focus interviews on, but did not limit potential for new additions. Where interviews with HS practitioners and patients provided information that contradicted the initial view, or expanded on it, results were amended to reflect this.

The hypothesis was developed using three approaches:





# 4.2 Activities

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### Desktop research

Desktop research was undertaken in order to review clinical literature and put together a longlist of interventions that potentially constituted best practice. This included looking at both qualitative and quantitative outcomes of interventions, as reported by practitioners. The sources were all English-based, and largely Europe-centric. The latter was driven by the geographical scope of the project, as well as the team's own language base.

The lead expert provided reading recommendations and advised familiarity with European and National Institute for Health and Care Excellence (NICE) guidelines, both of which formed the basis of our secondary research.



### Ideas workshop

The longlist of interventions generated through the literature review was shared at two internal team workshops, of whom the participants had experience of working on projects identifying best practice in other disease areas. These colleagues:

- shared their findings from other disease areas, to provide potential ideas due to disease similarity
- shared insights on challenges with other diseases areas and how they may be applicable to HS
- reviewed concepts identified in the desktop research for feasibility and applicability



### Consultation with lead expert

We also worked with the lead expert to identify critical elements of HS care. The initial hypothesis on best practice was presented to the lead expert and amendments made as per his clinical judgement. A final list was thus generated.



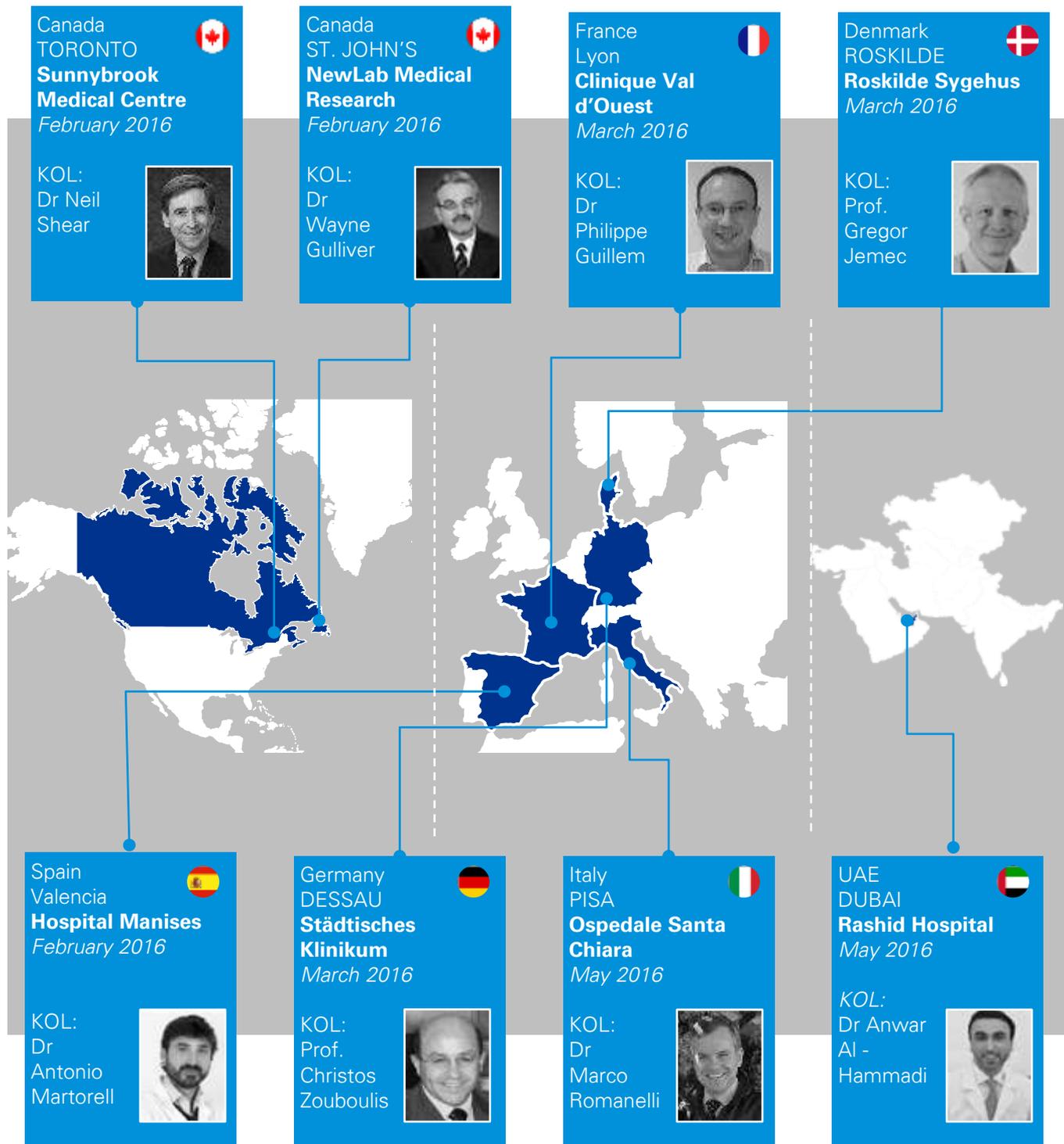
### 4.2.2 Identifying centres

Seven centres across Canada, Western Europe and the Middle East were selected to participate in the project. The lead KOL selected centres that were willing to volunteer their time, based on the following criteria:

- coverage of different healthcare systems and models of care, in order to make the report applicable to a wide audience
- the global reputation of the centres and the centre leads for quality practice in HS
- likely availability of centre leads, as these served as KOLs across the project.



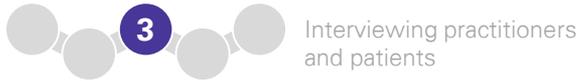
## 4.2 Activities



None of the centres taking part were paid for their involvement in the study.



## 4.2 Activities



Interviewing practitioners and patients

### 4.2.3 Interviewing practitioners and patients

- We interviewed a wide range of stakeholders including (but not limited to): clinicians from the specialist centres; community healthcare professionals; and patient association groups.
- This allowed us to develop a rounded view of the principles guiding good care across the patient pathway, across specialities, and for both the practitioners and the patients.

We conducted face-to-face interviews, lasting up to an hour, with two key objectives:

**Understand activities across the patient pathway** from different perspectives, including operational, clinical outcomes and patient experience. More specifically we explored:

- What worked well in each centre and why?
- What areas of improvement still remained and why?

**Identify practices or interventions of high impact.** This included practices which were unique to centres, research-led activities or interventions derived from day-to-day operational improvements. Where possible, we also explored data evidencing a positive outcome from these interventions.

**We asked questions across four main areas of discussion:**

1		<b>Centre background</b>	– Information about centres and patient demographic
2		<b>Best practice</b>	– Mapping challenges and activities across the patient pathway – Identifying highly valuable or unique actions the centres performed along the pathway
3		<b>Wider engagement</b>	– Considering the role of wider aspects such as patient empowerment, primary care and technology
4		<b>Benefit creation</b>	– Evidencing and data sharing for the benefits created from the best practice care



# 4.2 Activities



### 4.2.4 Quantifying benefits

In interviewing practitioners and patients, we asked them about the benefits associated with the best practice interventions. We then quantified the benefits in order to allow centres rank the interventions.

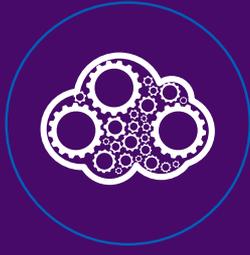
- The benefits were quantified by looking at causal data that showed direct improvements on specific KPIs as a result of implementing given interventions.
- Where data evidencing causes was not available, we looked for data to demonstrate strong correlations.
- Where neither of these approaches was possible, we listed the benefits stated by the centre, but noted that these had not been evidenced by data. In such cases, the benefits listed were generally qualitative ones, and had been corroborated by multiple interviewees.



### 4.2.5 Analysing findings

The writing up of findings was conducted alongside the interview process, in order to limit memory bias. Details included not only those interventions considered good practice, but the resources and underlying structures required to facilitate these. The totality of the findings, along with the quantified benefits were then also reviewed once all the centre visits were completed, in order to ensure a view of the larger picture and note any recurring themes. The draft was then shared with the KOLs, with a view to ensuring the maintenance of factual accuracy, as well as helping us to identify any elements of note that we had not picked up to date.

This approach has been designed to ensure that the report is representation of the opinions and views of the interviewees (and not an exhaustive list of best practice in HS care).



# 5.0 Findings



## 5.0 Findings

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### 5.1 Overview of findings

In speaking to the centres, a number of challenges were raised by the interviewees and mapped to a patient pathway. This patient pathway is outlined below.

#### First symptoms



- Patients develop initial signs of HS

#### Diagnosis



- Clinicians identify the patient as having the disease

#### Referral



- Patients transfer from primary to secondary care, or from one specialist to another

#### Treatment



- Clinicians and other practitioners undertake management of the disease

#### Follow up and ongoing



- Patients are released back to primary care, and seen for flares or wound care



The following challenges were highlighted over the course of the centre visits.

### First symptoms



- Delayed presentation to clinicians.
- Patients discouraged when presenting with initial symptoms.

### Diagnosis



- Low clinician awareness causing delays in diagnosis, and mis-diagnosis .

### Referral



- Low clinician awareness causing lack of, and misdirected referrals.
- Delayed or limited patient information transfer.
- Clinician reluctance to accept HS referrals.

### Treatment



- Difficulty in accurately identifying disease extent.
- Multiple patient needs/high comorbidity.
- Variable quality of treatment between countries.
- Variable funding for biologics, surgery and follow-up care across regions and payers.
- Low patient concurrence with treatment plans, including lifestyle change plans.
- Lack of robust, standardised outcome measures.

### Follow up and ongoing



- Heavy time burden on patient.
- Clinician capacity affected by follow-up demand.
- Undetected symptom deterioration.
- Physical, psychological and financial strain on patients.
- Limited understanding of disease mechanism.
- Professional siloes.



# 5.2 Overview of presentation

The challenges noted on the previous pages have been detailed on the following pages. We have also noted the interventions that address these challenges, as well as their benefits. Detailed case studies of the intervention and challenges have been written up and can be found via the links on the findings pages.

DRAFT FOR DISCUSSION

**5.3 Detailed findings**

**The challenge: delayed presentation to clinicians**

Patients do not always approach their primary care provider on experiencing initial symptoms, due to a number of reasons.

- A lack of awareness about HS means that patients do not always realise that their symptoms may be indicative of serious disease.
- Patients may be embarrassed speaking about symptoms, especially when the anogenital region is affected.
- Embarrassment is also a factor where patients assume that the symptoms have arisen due to a lack of hygiene.

Delayed presentation is a significant issue as the resultant disease progression may cause unnecessary pain and scarring, and end up requiring surgery.

**The intervention: Public awareness campaign**

Groups work to raise awareness of HS awareness amongst undiagnosed sufferers as well as the general public.

**Benefits**

- Sufferers develop an awareness that their symptoms are indicative of a treatable disease, and how to seek help.
- The general public are better equipped to understand the disease and to support sufferers.
- Whilst general campaigns are not targeted at practitioners, they can raise overall awareness levels, including that of nurses and clinicians.

*Evidence type: anecdotal*

**Example case studies**

**Patient association (Denmark), page 103**

The HS patient association in Roskilde run a high-profile national multi-media campaign.

*"We see women with advanced HS, where it is hard to help. They don't like to talk about [genital involvement]."*

*Dr Herman Voss, gynaecologist*

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The challenge  
Details of the challenge associated with HS care

The intervention  
Interventions that can be introduced to address the challenge, and the benefits associated with this

Case studies  
List of the case studies – presented in the next chapter – showing real-life applications of the intervention.



## 5.3 Detailed findings



### The challenge: delayed presentation to clinicians

Patients do not always approach their primary care provider on experiencing initial symptoms, due to a number of reasons.

- A lack of awareness about HS means that patients do not always realise that their symptoms may be indicative of serious disease.
- Patients may be embarrassed speaking about symptoms, especially when the anogenital region is affected.
- Embarrassment is also a factor where patients assume that the symptoms have arisen due to a lack of hygiene.

Delayed presentation is a significant issue as the resultant disease progression may cause unnecessary pain and scarring, and end up requiring surgery.

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Groups work to raise awareness of HS awareness amongst undiagnosed sufferers as well as the general public.

#### Benefits

- Sufferers develop an awareness that their symptoms are indicative of a treatable disease, and how to seek help.
- The general public are better equipped to understand the disease and to support sufferers.
- Whilst general campaigns are not targeted at practitioners, they can raise overall awareness levels, including that of nurses and clinicians.

*Evidence type: anecdotal*

### Example case studies

**Patient association (Denmark), page 110**

The HS patient association in Roskilde run a high-profile national multi-media campaign.

“We see women with advanced HS, where it is hard to help. They don’t like to talk about [genital involvement].”

Dr Herman Voss, gynaecologist



Executive summary



# 5.3.2



### The challenge: patients discouraged when presenting with initial symptoms

Of the patients who do approach a clinician on discovering symptoms, many can be told that they simply have a boil, and discharged without further investigation.

Similarly, patients can also be told that the symptoms are a result of factors such as obesity, and the burden of minimising symptoms therefore placed on them. In such cases requisite treatment is delayed, the risk of invasive future treatment heightened, and patients are often left alienated.

Clinicians note that in such cases, patients are often already suffering some degree of psycho-social difficulties. Where such patients are not supported, these difficulties may be exacerbated, resulting in an increase of poor lifestyle choices, such as increased smoking or overeating. This in turn may aggravate HS symptoms, with the vicious cycle continuing until an intervention is effected.

### The intervention: HS awareness training

Training is delivered to primary and secondary clinicians in order to improve their understanding of HS.

The breadth of course content, mode of delivery and the audience targeted varies according to local needs and the resources available.

#### Benefits

A rise in referrals has been seen by the centres that have initiated such training programmes.

*Evidence type: anecdotal*

“We are not teaching [HS] at medical school.”

Prof Denis Jullien, dermatologist

### Example case studies

 **HS awareness training (Canada), page 136**  
 A cross-specialism team in St John’s, Canada, offers training for non-dermatology physicians

 **HS awareness training (Spain), page 122**  
 Hospital Manises in Valencia offers training targeted at primary care but also available for specialists

 **GP training, page 147**  
 Ospedale Santa Chiara in Pisa, Italy, offers training targeted at GPs

 **Secondary physician training, page 149**  
 Ospedale Santa Chiara in Pisa, Italy, offers training targeted at secondary care physicians





# 5.3.3



### The challenge: delays in diagnosis and misdiagnosis

A lack of awareness amongst clinicians has been noted as the major challenge in HS. This has been raised as an issue across both primary and secondary care, and results in delayed diagnosis because clinicians:

- do not realise that the symptoms they are seeing are indicative of disease at all, or
- are reluctant to conduct examinations, especially if symptoms are in the anogenital area.

In both cases, patients are discharged with little or no treatment and obliged to seek an alternative opinion, or to return once their symptoms worsen.

Misdiagnosis occurs due to some clinicians struggling to differentiate HS from other skin conditions. This can result in patients receiving inappropriate treatments or not being referred to the correct specialist.

### The intervention: HS awareness training

Training is delivered to primary and secondary clinicians in order to improve their understanding of HS.

The breadth of course content, mode of delivery and the audience targeted is varied according to local needs and the resources available.

#### Benefits

A rise in referrals has been seen by the centres that have initiated such training programmes.

*Evidence type: anecdotal*

### Intervention 2: HS training for nurses

Training is delivered to nurses in order to equip them to recognise HS and provide appropriate care.

#### Benefits

Attendees have an improved understanding of HS, which benefits not only themselves but their colleagues as well, whom they can support in dealing with patients.

*Evidence type: anecdotal*

### Example case studies

 **HS awareness training (Canada), page 136**  
 A cross-specialism team in St John's, Canada, offers training for non-dermatology physicians



 **HS awareness training (Spain), page 122**  
 Hospital Manises in Valencia offers training focused targeted at primary care but also available for specialists



 **GP training, page 147**  
 Ospedale Santa Chiara in Pisa, Italy, offers training targeted at GPs



 **Secondary physician training, page 149**  
 Ospedale Santa Chiara in Pisa, Italy, offers training targeted at secondary care physicians






### Intervention 3: Patient association, running awareness campaigns

Patient associations run awareness campaigns that are targeted at the medical community.

#### Benefits

Improved awareness of HS, leading to quick, accurate diagnoses.

*Evidence type: anecdotal*

“There is a clear need to raise awareness of this disease”

Dr Axel Villani, dermatologist

### Example case studies



#### Nurse HS course, page 96

A centre nurse visits a local nursing college to deliver HS education



#### Patient association (France), page 81

The HS patient association in Lyon offer pastoral support, financial advice, clinician-patient meetings, awareness materials and research



#### European guidelines, page 79

The European guidelines for HS treatment outline diagnostic and staging criteria that can be used by both primary and secondary clinicians



Executive summary



# 5.3.4



## The challenge: lack of, and misdirected referrals

### Lack of referrals

Clinicians sometimes fail to realise that symptoms are indicative of disease, rather than simply being boils or the outcome of poor lifestyle choices, and therefore they are unlikely to refer patients on.

### Misdirected referrals

At other times, clinicians may recognise that investigation is required, but are unsure of the correct specialism to refer to. In such cases, patients can be referred incorrectly to specialisms such as surgery, who are unable to identify the issue. Such patients are then passed back and forth between primary and secondary care, or between various specialisms, often for years, before they are seen by a dermatologist who can recognise and diagnose their condition.

### Intervention 1: HS training for clinicians

Training is delivered to primary and secondary clinicians to improve their understanding of HS. The breadth of course content, mode of delivery and the audience targeted varies according to local needs and the resources available.

### Benefits

A rise in referrals has been seen by the centres that have initiated such training programmes

*Evidence type: anecdotal*

### Intervention 2: jointly agreed referral criteria

Clinicians collaborate to draw up referral criteria so that there is a clear and standardised agreement on what triggers referrals.

### Benefits

A sense of trust is engendered; clinicians are clear about, and agree upon the baseline for making and receiving referrals, and are therefore much more willing to accept these.

*Evidence type: anecdotal*

**"I have not yet had a patient...with a diagnosis from primary care."**

Dr Andreas Altenburg, community doctor with HS interest

## Example case studies



### HS awareness training (Spain), page 122



Hospital Manises in Valencia offers training focused on primary care but also available for specialists



### MDT (Toronto, Canada), page 118



Dermatologists and surgeons across centres jointly agree referral criteria in order to collaborate for treatment



### GP training, page 147



Ospedale Santa Chiara in Pisa, Italy, offers training targeted at GPs



### Secondary physician training, page 149



Ospedale Santa Chiara in Pisa, Italy, offers training targeted at secondary care physicians



Executive summary



5.3.5



**The challenge: delayed or limited patient information transfer**

*Delayed transfer*

There may be a notable delay in patient notes reaching the latest clinician, especially given that HS patients:

- may see several clinicians before receiving diagnosis and treatment
- may have comorbidities that require multiple specialists’ input
- require follow-up care for wounds and flares, potentially in different settings to that in which they received treatment.

In each case, the clinician has limited visibility of treatment to date and treatment recommendations, resulting in disjointed care provision. This is frustrating for both practitioner and patient.

*Limited transfer*

Interviewees also commented on occasions where undiagnosed patients present in acute care with painful boils that require lancing. In such cases, a thorough examination or lesion count is not always conducted, meaning that diagnosis, when it occurs, is difficult, as a full history is not available.

**The intervention: information sharing system**

A cross-centre IT-based system ensures that clinicians across different settings treating the same patient have ready access to each others’ notes.

*Benefits*

Patients have a strong sense of sense of trust when returning to primary care and finding that their clinician has a clear understanding of their treatment needs.

*Evidence type: anecdotal*

**Example case studies**

**Information sharing system, page 64**  
An IT system in Saxony-Anhalt, Germany, gives multiple clinicians access to hospital notes

“We can’t see the family doctors’ notes...and this makes (treatment) difficult”

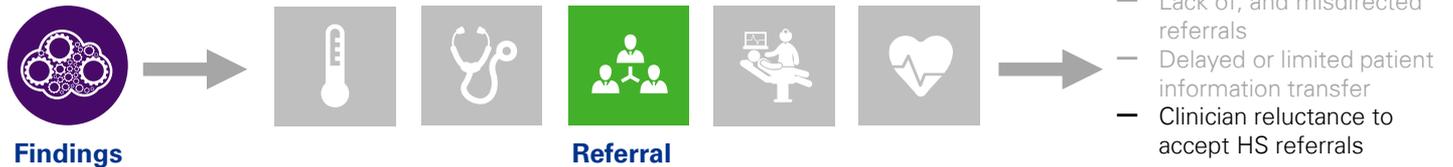
Dr Ioannis Karagiannidis, researcher



Executive summary



## 5.3.6



### The challenge: clinician reluctance to accept HS referrals

Clinicians are not always willing to accept referrals or to treat HS patients, as:

- these are high-need individuals, often requiring repeat treatment. This is especially burdensome in regions where funding is allocated on a per patient basis
- accepting a patient into surgery leads to follow-up wound care, where there is limited capacity, and thus reduces potential for surgical procedures. In addition, patients with infected wounds are seen as a potential risk to immuno-compromised in-patients
- the disease mechanism is poorly understood, and identifying the correct treatment is difficult
- the disease is unpleasant in nature and treating it is correspondingly disagreeable.

### The intervention: jointly agreed referral criteria

Clinicians collaborate to draw up referral criteria so that there is a clear and standardised agreement on what triggers referrals, and who these go to.

#### Benefits

A sense of trust is engendered; clinicians are clear about, and agree upon the baseline for making and receiving referrals, and are therefore much more willing to accept these.

*Evidence type: anecdotal*

### Example case studies

**MDT (Toronto, Canada), page 118**  
Dermatologists and surgeons across centres jointly agree referral criteria in order to collaborate for treatment

“We draw up the referral criteria jointly, so (the surgeons) know we’re referring patients correctly”

Dr Perla Lansang, dermatologist



Executive summary



# 5.3.7



Findings



Treatment



- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

### The challenge: difficulty in identifying disease extent

Identifying disease staging is difficult, especially where there is an incomplete or limited patient information transfer. Additionally, the demarcation between healthy and diseased tissue is not easily identifiable through traditional imaging techniques. This means that, where surgery is required, extensive excision can be necessary to ensure that all diseased tissue is removed.

#### Intervention 1: ultrasound imaging

Ultrasound images are used to determine disease stage accurately.

##### Benefits

In identifying the severity level, centres can more effectively manage HS patients at the minimal treatment level, thereby reducing the need for biologics or surgery.

*Evidence type: anecdotal*

#### Intervention 2: CO<sub>2</sub> laser surgery

Patients requiring surgery have diseased tissue vaporised in thin layers, so that clinicians can see where healthy tissue starts, and minimise removal.

##### Benefits

Precise, minimal removal of diseased tissue results in reduced time to healing and mobility.

*Evidence type: anecdotal*

“We have no widely accepted detection tools to exactly remove the involved right area.”

Dr Thomas Wilde, surgeon

### Example case studies



#### Ultrasound imaging (Spain), page 128

Ultrasound images are developed by trained staff at Hospital Manises in Valencia, Spain



#### CO<sub>2</sub> laser surgery, page 114

Dermatologists at Roskilde Sygehus in Denmark use the CO<sub>2</sub> laser for procedures that are not referred to plastic surgery



#### Laser imaging, page 153

Dermatologists at Ospedale Santa Chiara create a topographic record of lesion and wound evolution



#### Ultrasound imaging (Italy), page 155

Dermatologists at Ospedale Santa Chiara use ultrasound to gain dermal and sub-dermal images of lesions and wounds



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5.3.8



Findings



Treatment

- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

**The challenge: multiple patient needs/high comorbidity**

Many HS patients require input from multiple specialisms. Coordinating this care can be difficult where clinicians from various fields are not used to working together. Siloed working may arise as a result of:

- regional working ethos and preferences
- funding regimens that pay a one-off sum per patient, regardless of the extent of need. In such cases, there is a financial dis-incentive to organise extra care.

**Intervention 1: multi-disciplinary team**

Clinicians and support services work collaboratively to provide treatment that addresses the entirety of patients' needs.

The modes of operation vary depending on patient cohort size and need, the local funding regimes and the operational structures within which the centres function. However, general features are:

- meetings and cross-specialism working: at its most informal, an MDT may not have any set meetings; clinicians contact each other as required, and work together to diagnose and treat the disease. At the other end of the spectrum, there are formalised meetings, attended by many or all of those involved in the treatment of the case(s) under discussion
- A range of services: at a minimum, MDTs for HS patients consist of dermatology and surgery staff. This can be scaled up to include other medical specialties such as gynaecology and gastroenterology. Comprehensive MDTs may offer the ancillary services such as psychology, physiotherapy, addictology and dieticians.

**Example case studies**

 **MDT (France), page 87**  
An extensive MDT with established operational structures, and developing regular, formalised meetings



 **MDT (Denmark), page 105**  
An extensive MDT, with meeting regularity adapted to suit local funding regime restrictions



 **MDT (Germany), page 66**  
A close-knit MDT where clinicians informally work together to diagnose and treat HS, including providing follow-up



“The patients were talking to all these specialists, but none of the specialists were talking to each other.”

Dr Philippe Guillem, surgeon





### Benefits

The multi-disciplinary approach ensures treatment accuracy and comprehensiveness that would not be possible otherwise. Clinicians form a strong understanding of the patients' overall needs.

Patients' physical and mental wellbeing is boosted, and the improved state of being helps them feel better equipped to deal with their condition. This has an impact on treatment concurrence levels and lifestyle choices.

Clinicians are able to fine-tune their ideas by sharing them with colleagues, thereby learning from each other and delivering optimal treatment.

Where centres work together to draw up referral criteria, a sense of trust is engendered; clinicians are clear about, and agree upon the baseline for making and receiving referrals, and are therefore much more willing to accept these.

*Evidence type: anecdotal*



#### MDT (Dubai), page 159

Dermatologists at Rashid Hospital work with surgeons, dieticians and psychologists to provide holistic support



#### MDT (Toronto, Canada), page 118

Dermatologists and surgeons across centres jointly agree referral criteria in order to collaborate for treatment



#### MDT (Spain), page 126

Weekly meetings are held to discuss all HS cases, with several specialisms represented



#### MDT (Italy), page 151

Multiple specialisms' input is coordinated and offered in order to optimise medical, surgical and psychological treatment



Executive summary



5.3.9



Findings



Treatment

- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

**The challenge: variable quality of care between countries**

There is high regional variability in treatment options available, resulting in patients having to travel to other countries to find a clinician who can treat them. For those whom this is not possible, there is little alternative but to live with the disease.

**The intervention: standardising HS care**

Clinicians and support services work collaboratively to provide care across a region, and ideally globally, work towards agreeing and providing standardised treatment for HS, thereby ensuring that the same offering is available across settings.

Benefits

Patients gain access to high- quality care locally.

*Evidence type: NA. Evidence unavailable as first examples of such an intervention are currently underway.*

**Example case studies**

**Standardising HS care, page 70**  
 A potential collaboration between 18 European countries, to standardise care delivery, is being discussed




**Treatment algorithm (Canada), page 139**  
 A paper published in 2016 outlines how to treat HS medically and surgically




**Treatment algorithm (Germany), page 76**  
 A treatment algorithm based on the European guidelines for HS treatment outlines how to treat HS medically and surgically





Executive summary



## 5.3.10



- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

### The challenge: variable funding for treatment and follow-up care

The lack of knowledge about HS is reflected in relatively underdeveloped payer policies. Clinicians note that the criteria for authorising payment for biologic treatment is not always clear, and is not standardised. This is applicable to both insurance companies and governmental bodies. Similarly, the rate of acceptance for applications for funding follow-up care can vary widely from region to region.

Additionally, treatments such as laser hair removal are sometimes classed as non-essential (in this example it may be considered cosmetic), and therefore not always covered by payers, despite the important role they may play in preventing symptom recurrence and severity.

The funding difficulty is driven in part by a lack of clinician awareness. In many regions, applications for funding need to be submitted by the treating clinician. Where these clinicians are unfamiliar with HS, they are not equipped to detail treatment requirements and emphasise the need for these. As a result, applications are often declined despite a strong need.

### The intervention: national review

A country-level review is implemented to determine HS prevalence and impact, and to ensure appropriate reimbursement for treatment.

#### Benefits

The intervention can raise the profile of HS across multiple settings, and improve reimbursement.

Evidence type: anecdotal

### Example case studies

**National review, page 101**

A review of HS treatment and funding needs has been undertaken by the Danish Ministry of Health



Executive summary



## 5.3.11



- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

### The challenge: low patient concurrence with treatment plans, including lifestyle change plans

Adherence to treatment is noted as a challenge by many clinicians. This is driven by several factors:

- a mistrust of clinicians and the healthcare system, fostered by delays in diagnosis
- reliance on self-medication regimes, developed in response to pain during the period where appropriate treatment was not made available
- a lack of understanding of how the prescribed treatment will work
- unaffordability of the prescribed treatment, especially in regions where medical cover varies according to the type of insurance held by the patient
- difficulty with changing long-term habits. In some cases this affects treatment, as surgical procedures can be difficult or dangerous due to patients' obesity or high levels of tobacco use. Treatment therefore has to be delayed for as long as it takes to bring the risk factor into acceptable limits.

### Intervention 1: jointly developed treatment plans

Practitioners explain treatment decisions to patients, and address patient preferences wherever possible in making the decisions in the first place.

#### Benefits

Compliance with treatment is higher as patients are willing and/or able to follow the treatment plan.

*Evidence type: anecdotal*

### Intervention 2: patient education

Sessions are held to educate patients and to give them a platform to share experiences and concerns.

#### Benefits

The intervention can empower patients, increasing their ability to understand and accept their condition, and to manage it proactively.

*Evidence type: anecdotal*

### Example case studies



#### Multi-disciplinary wound clinic, page 144



Practitioners at the wound clinic involve patients fully in treatment decisions



#### HS awareness day, page 103



Roskilde Sygehus runs annual awareness days to provide structured education, foster relationships, and address any specific patient queries



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### Intervention 3: MDT offering lifestyle support

Patients are supported by practitioners in effecting lifestyle changes that might positively affect their symptoms, e.g. altering their diet and tobacco use.

#### Benefits

Patients are better equipped to effect lifestyle changes.

*Evidence type: anecdotal*

### Example case studies



**MDT (France), page 87**  
A very extensive MDT, offering input from addictologists, psychologists and a dietician



**MDT (Denmark), page 105**  
An extensive MDT, offering lifestyle counselling and psychiatrist input



“This condition deserves more care from all of us, from the government, from us clinicians. We [need to] look for a cure, not treatment only.”

Dr Anwar Al-Hammadi, dermatologist



Executive summary



## 5.3.12



- Difficulty in identifying disease extent
- Multiple patient needs / high comorbidity
- Variable quality of care between countries
- Variable funding for treatment and follow-up care
- Low patient concurrence with treatment plans, including lifestyle change plans
- Lack of robust, standardised outcome measures

### The challenge: lack of robust, standardised outcome measures

The clinical outcome measures currently used in HS are geared more towards use in clinical trials rather than in patient care settings. Additionally, whilst Hurley’s severity score is widely used, it is not the only measure, and the use of different measures can lead to difficulties in comparing outcomes across settings.

Quality of Life (QoL) measures such as the Dermatology Life Quality Index (DLQI) go some way towards measuring how patients’ lives are impacted. However, they are generic across dermatological conditions and so do not pick up on all aspects of patients’ lives that HS may affect.

### The intervention: developing outcome measures

Outcome measures are developed to measure the impact of a given intervention or treatment in a way that is both specific and meaningful for patients.

#### Benefits

Having robust measures can make it easier to measure HS severity and patient quality of life, so that the effect of interventions – in both clinical trials and in the hospital setting – can be accurately gauged.

Such measures can also assist in ensuring standardisation across trials and clinics.

*Evidence type: NA. Evidence unavailable as first examples of such an intervention are currently underway.*

### Example case studies



**Developing outcome measures, page 108**

Research is being conducted at Roskilde Sygehus to refine and develop clinical and quality of life (QoL) measures for HS.





**HS assessment tool, page 157**

Dermatologists at Ospedale Santa Chiara in Pisa, Italy, have proposed a new assessment tool to measure HS severity







# 5.3.13



## The challenge: heavy time burden on patients

### Post-surgical recovery

It is difficult to gauge how deep the diseased tissue runs and as a result, surgery can require deep excision to ensure that symptoms do not recur in the operable region. Wounds can therefore be severe, with a corresponding level of recovery time, pain and mobility reduction.

### Wound care

Several patients require long-term low-level medical management and/or wound care. Whilst the former can be accessed relatively easily, wound care can cause difficulty if patients are based at some distance from wound care clinics. There is an especially heavy time burden on patients who require the service for an extended period of time.

## The intervention: follow-up care in the community

Patients requiring follow-up care for flares or wound management are supported in community settings rather than returning to the hospital or medical centre.

For wound care, the bulk of the support is provided by wound care experts where possible. Where this is not feasible, generalists can be supported by specialists at suitable intervals.

### Benefits

Clinician capacity is reserved to address severe cases, as the community clinics effectively address the needs of the follow-up patients in the vast majority of cases.

Patients' pain and inconveniences is minimised.

Generalist staff feel well supported and therefore less obliged to contact a clinician for minor queries.

*Evidence type: anecdotal*

## Example case studies

**Follow-up wound care specialists, page 98**  
 Expert wound care nurses in Lyon support home care nurses in caring for patients in their homes after surgery

**Community dermatology care, page 72**  
 A dermatology clinic in the community addresses mild HS cases and ongoing wound care

**Multi-disciplinary wound clinic, page 144**  
 A surgeon from a local hospital periodically accompanies the dermatologist at this weekly wound clinic





### Intervention 2: hyperbaric chamber therapy

Patients attend a set number of sessions in a hyperbaric chamber after surgery. The number depends on wound severity and lifestyle factors, as the latter can influence the level of effect that the intervention will have.

#### Benefits

The sessions help to reduce pain and speed up tissue healing.

*Evidence type: Peer reviewed publications<sup>1</sup>*

### Intervention 3: MDT offering physiotherapy

Patients receive physiotherapy following surgery for tissue removal.

#### Benefits

Full or near-full mobility can be regained despite deep excision.

*Evidence type: anecdotal*

### Example case studies

 **Hyperbaric chamber, page 91**  
Post-surgery patients in Lyon can have hyperbaric chamber therapy to reduce pain and accelerate healing time



 **MDT (Germany), page 66**  
Post-surgery patients receive HS-gear physiotherapy in order to re-establish mobility



“I was one of the first to try [the hyperbaric chamber]. It’s difficult because you have to go every day, but it is great. I usually take two months to recover [after surgery], but with the chamber, I took one.”  
(translated)

Hélène Raynal, patient association head

#### Notes

- Recent publications
  - Eggleton P et al, Safety and efficacy of hyperbaric oxygen therapy in chronic wound management: current evidence, April 2015
  - Kranke P et al, Hyperbaric oxygen therapy for treating chronic wounds, June 2015



Executive summary



# 5.3.14



Findings



Follow-up / Ongoing

- Heavy time burden on patients
- Clinician capacity affected by follow-up demand
- Undetected symptom deterioration
- Physical, psychological and financial strain on patients
- Limited understanding of disease mechanism
- Professional siloes

### The challenge: clinician capacity affected by follow- up demand

There is a high opportunity cost to surgical departments of dealing with follow-up wound care. In the absence of wound care specialists – who can deal with the majority of cases – surgeons are obliged to juggle treatment delivery along with other surgical responsibilities.

In settings where follow-up wound care is provided by non-surgical staff, (e.g. home care nurses), practitioners may not have expert knowledge of wound care. As a result, the care provided may be sub-optimal in comparison to that provided by surgical specialists. Practitioners may also need to contact surgeons or dermatologists on a regular basis, thereby creating further demand on their services.

#### Intervention 1: nursing support

Specialist wound care nurses or general dermatology nurses support the clinicians by assisting in the treatment of follow-up wound care.

##### Benefits

Clinician capacity is reserved to address severe cases, and patient care is enhanced as clinicians are ably supported.

*Evidence type: anecdotal*

#### Intervention 2: follow-up care in the community

Patients requiring follow-up care for flares or wound management are supported in community settings rather than returning to the hospital or medical centre.

For wound care, the bulk of the support is provided by wound care experts where possible. Where this is not feasible, generalists can be supported by specialists at suitable intervals.

### Example case studies

**Tissue viability nurses, page 74**  
Staff at Städtisches Klinikum are working with a local college to deliver a course to train tissue viability nurses

**Dedicated dermatology nurses, page 120**  
A dedicated nursing team supports clinicians at Sunnybrook Health Sciences Centre

**Follow-up wound care specialists, page 98**  
Expert wound care nurses in Lyon support home care nurses in caring for patients in their homes after surgery



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### Benefits

Clinician capacity is reserved to address severe cases, as the community clinics effectively address the needs of the follow-up patients in the vast majority of cases.

Patients' pain and inconveniences is minimised.

Generalist staff feel well supported and therefore less obliged to contact a clinician for minor queries.

*Evidence type: anecdotal*



Executive summary



# 5.3.15



**The challenge: undetected symptom deterioration**

On experiencing a flare after medical discharge, some patients opt to self-medicate rather than return to a clinician. Others cease treatment once symptoms are under control, despite the likelihood that this cessation may cause a resurgence. Both of these can result in symptom deterioration which is undetected by clinicians.

**Intervention 1: topographical records**

3D images of HS lesions are created and recorded in order to track the swelling of lesions over time.

**Benefits**

Not yet measured as this is a new approach.

*Evidence type: N/A*

**Example case studies**

**Topographical records, page 132**  
 A photographic record is created at Hospital Manises in order to track lesion changes





# 5.3.16



**Findings**



**Follow-up / Ongoing**

- Heavy time burden on patients
- Clinician capacity affected by follow-up demand
- Undetected symptom deterioration
- Physical, psychological and financial strain on patients
- Limited understanding of disease mechanism
- Professional siloes

**The challenge: physical, psychological and financial strain on patients**

**Physical**

Patients can suffer significant pain during all stages of the pathway.

**Psychological**

Patients suffer social isolation, self-disgust and depression, which in some cases is severe enough to incite suicide.

**Financial**

There is an above-average representation of disadvantaged socio-economic groups amongst HS sufferers. Patients with moderate to severe HS can struggle with employment, as they can need substantial time off work. This, added to the cost of treatment, can have a significant impact on their quality of life.

**Intervention 1: patient association**

An association is formed, either independently or with the support of centre staff. Such associations have a number of benefits.

.Member level: the members can offer each other a network for pastoral peer support, and share information and advice, whether clinical, financial or legal.

- Public level: associations may also work on a larger scale to implement HS awareness campaigns. These can be aimed at undiagnosed sufferers as well as at the general public.
- Government level: well-established associations can work in conjunction with other associations, to gain scale and therefore lobby more effectively.

**Example case studies**

**Patient association (Denmark), page 110**  
 The association offers peer support and run a high-profile national multi-media campaign.



**Patient association (France), page 81**  
 The association offers support, financial advice, clinician-patient meetings, awareness materials and research



**Patient association (Germany), page 68**  
 The association collaborates with other association to put on an annual conference



“[The patients] are lost. They are just looking for someone to save them”

Ines Evain, Dermatology administrator





Benefits

- Member level: patients’ psychological wellbeing is boosted. They are also able to benefit from other members’ experience on how to navigate medical, funding and legal systems.
- Government level: patients feel highly empowered, and learn from each other’s disease areas. The joint venture also offers them scale and is therefore more effectively attracts funding.

*Evidence type: anecdotal*

**Intervention 2: MDT offering psychological support**

Patients are offered assistance to help them in dealing with the psychological effect of HS, which can be very strong. The resource capacity in different settings determine the mode and type of intervention delivered.

Benefits

Patients are equipped to deal with coming to terms with their condition, as well as with any associated issues that they may experience.

*Evidence type: anecdotal*

**Intervention 2: patient care meetings**

Regular meetings are held with staff and patient representatives in order to discuss how centre operations can be executed so as to optimise patient care.

Benefits

Patient satisfaction is high as their viewpoint and needs are incorporated into planning decisions.

*Evidence type: anecdotal*

**Intervention 2: hyperbaric chamber therapy**

Patients attend a set number of sessions in a hyperbaric chamber after surgery. The number depends on wound severity and lifestyle factors, as the latter can influence the level of effect that the intervention will have.

Benefits

The sessions help to reduce pain and speed up tissue healing.

*Evidence type: Peer reviewed publications<sup>1</sup>*

Example case studies

 **Patient association (Spain), page 130**  
The association promotes regular patient-clinician interaction



 **MDT (France), page 87**  
Patients are offered sessions with a psychologist



 **MDT (Denmark), page 105**  
Patients are offered sessions with a psychiatrist



 **Motivational support (Denmark), page 116**  
Nurses are trained to use a motivational methodology to support patients



 **Patient care meeting, page 94**  
Quarterly meetings are held at Clinique Val d’Ouest to discuss patient care



 **Hyperbaric chamber, page 91**  
Post-surgery patients in Lyon can have hyperbaric chamber therapy to reduce pain and accelerate healing time




Notes

1. Sample publication
  - Eggleton P et al, Safety and efficacy of hyperbaric oxygen therapy in chronic wound management: current evidence, April 2015



## 5.3.17



### The challenge: limited understanding of disease mechanism

It can be challenging for clinicians to diagnose and treat HS in the absence of local experts to consult, and with limited research to draw on. Relatively little investigation has been carried out on HS to date, and a comprehensive understanding of the disease mechanism is still to be developed. Similarly, there is currently limited data the effect of specific treatments and treatment mixes, at specific disease stages / on disease stage mixes.

As a result, non-dermatology specialists – and even dermatologists unfamiliar with HS – are reluctant to attempt treatment, preferring to refer patients directly on to HS specialists. This means that dermatologists with HS expertise spend an initial period administering and potentially ruling out simple first line treatment<sup>1</sup> that could have been prescribed by the referring party. Where this first line treatment is administered before referral, the observation period coincides with the waiting period so that treatment response can be gauged immediately on arrival into specialist care, and altered with minimum waiting times.

### The intervention 1: HS registry

Centres submit data to a registry in order to pool knowledge of the disease, and to identify trends and patterns across a large patient cohort over time.

#### Benefits

Evaluating the data may increase awareness of HS prevalence and presentation, and allow for pattern recognition across patients, thereby improving understanding of patient needs and of treatment impact.

*Evidence type: anecdotal*

### Example case studies

 **HS registry, page 142**  
NewLab in Canada subscribes to registry as well as submitting data to a local body that tracks patient treatment



 **Mini-registry, page 85**  
Edouard-Herriot hospital have a mini-registry in their own centre, where they record details of patient history, treatment and comorbidities





Executive summary



5.3.18



**The challenge: professional siloes**

Clinicians practising in regions where there are few HS experts are disadvantaged by the lack of an immediate network to draw upon. This is exacerbated by the fact that there is also little literature currently on the efficacy of treatment mixes and volumes that they might use instead.

Furthermore, the lack of interaction opportunities means that collaborative research opportunities are correspondingly low.

**The intervention 1: global network**

Centres, clinicians and patients link to each other via virtual networks so as to provide global support which optimises local activity.

**Benefits**

Clinicians are able to draw on colleagues’ knowledge and experience, and to provide peer support.

The stronger relationships can also lead to increased research opportunities.

Patients are able to gain informed, local access to treatment and support.

*Evidence type: anecdotal*

**Example case studies**

**HS regional network, page 62**  
 HS groups globally can link their own website to EHSF’s, thereby promoting clinician and patient knowledge sharing





# 6.0 Appendix



# Appendix

## 6.1 Case studies



## Regional HS networks



### Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

Regional networks operate locally whilst simultaneously connecting with international counterparts to establish global presence.



### 1. What was the challenge?

A lack of global networking opportunities amongst clinicians limited knowledge transfer, research prospects and patient access.

The cost and tax implications of setting up a foundation to share knowledge was an inhibiting factor for many regions.



### 2. What is the intervention?

Regional networks link up to the EHSF for support, and to raise their profile amongst HS patients.

**How long has it been running?**

The aim is to launch the intervention by the end of 2016.

**What do they do?**

Clinicians can set up a working group in their local region that functions as an arm of the EHSF, thereby avoiding extensive costs.

Whether they choose to set up a working group or their own foundation, they have the option to link their webpage to the EHSF's. This means that patients visiting the high-profile EHSF page can click through to the regional site, and see what support and services are available near them.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Regional HS networks

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### 3. What are the next steps?

The clinicians at the centres involved have already started to visit each others settings in order to learn from them and to collaborate on research. Städtisches Klinikum has already developed case studies on particularly interesting HS cases, in conjunction with centres in Spain, Portugal and Japan. They foresee such research collaboration widening in the future.



### 4. What are the benefits and how are they measured?

#### Clinicians

Clinicians are able to access global expertise whilst continuing to address local needs and considerations. As mentioned earlier, collaborative research between centres has become easier, with increased international visits to discuss special cases.

#### Patients

Patients are able to find advice and practitioners in their own region. This can positively affect their quality of life, offering them treatment options and support services without the need to travel large distances.



### 5. What are the benefits and how are they measured?

- Assemble a local team with an interest in HS. Where the working group is very large or very small, members may wish to consider which internal processes best promote smooth operations.
- Establish a working schedule that allows for visits to and from HS centres.
- Amend policies or protocols to reflect any learnings from the network.

EXECUTIVE SUMMARY  
Follow up / ongoing



# Information sharing system (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

Primary and secondary clinicians can sign up to use an I.T system that allows clinicians immediate access to hospital notes on own patient



### 1. What was the challenge?

Delays in hospital notes reaching community clinicians meant patients returning to primary care faced a suspension of treatment.

This heightened the risk of flares and caused patient frustration.



### 2. What is the intervention?

A state-wide I.T system is available for the sharing of clinician notes. All primary and secondary centres in the Saxony-Anhalt region can sign up to use the service for a fee.

**How long has it been running?**

Intervention initiation is planned, subject to clearance from multiple ethics committees.

**What do they do?**

Hospital clinicians' signatures are stored on a system where patient notes are also compiled. Once a clinician attaches their signature to any note, the note become visible to all clinicians involved in the treatment of that patient, provided that their centres also use the software.

EXECUTIVE SUMMARY  
Referral



## Information sharing system (2/2)



### 3. What are the next steps?

Information can only flow downwards in the current system; primary clinicians can view secondary clinicians' notes, but there is no facility to share notes compiled in the primary setting with hospitals. Interviewees note that two-way sharing would be a very welcome next step, although it is not known whether the service provider has plans to effect this.



### 4. What are the benefits and how are they measured?

Patients will have a strong sense of sense of trust when returning to primary care and finding that their clinician has a clear understanding of their treatment needs. Interviewees note that patients will be able to arrive at their GP appointment after being discharged from secondary care and find their new prescription prepared and ready, as the GP will have had time to familiarise themselves with the follow-up regimen.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify availability of appropriate software, and ensure own I.T. facilities are able to support the programme.
- Ensure there is adequate funding for installation costs as well as any regular licence fees. Where the cost associated with the intervention is high, consider speaking to a range of specialisms and management levels to encourage cross-specialism buy-in and cost sharing – expediting information sharing is likely to improve treatment across all disease areas.
- Communicate with key partners to encourage subscription. The system is a powerful one, but only if those that you wish to share information with are part of the network.

EXECUTIVE SUMMARY  
Referral



# Multi-disciplinary team (Germany) (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

The dermatology team work closely with other departments to provide holistic patient care



### 1. What was the challenge?

Multiple specialists' input was required in a number of common scenarios.

Patients were presenting in dermatology, gastroenterology and gynaecology comorbidities.

Non-dermatology departments could not always differentiate HS from conditions with similar symptoms, and often needed a dermatologist's input to determine a diagnosis.

Those patients undergoing surgery for HS faced a long and painful recovery time, sometimes with permanently limited mobility.



### 2. What is the intervention?

Dermatology staff liaise regularly with gynaecology, gastroenterology and physiotherapy to diagnose and treat HS.

How long has it been running?

The MDT has been running since 2006.

What do they do?

Diagnosis and treatment decisions

Dermatology, gynaecology and gastroenterology staff informally contact each other when presented with a case requiring multiple specialisms' input, or where a differential diagnosis is difficult. Once they have agreed on the diagnosis, a joint treatment decision is formulated. The collaboration is not formalised, but the size of the centre allows for it to occur with ease.

Psychological support

Patients requiring psychological support are referred to the psychology team.

EXECUTIVE SUMMARY

Treatment

Follow up / ongoing (p.14)

Follow up / ongoing (p.15)



## Multi-disciplinary team (Germany) (2/2)

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### Post-surgery care

Two therapists work regularly with HS patients, and have developed an exercise regime specific to their needs. The collaboration was set up informally; surgeons with HS expertise contacted the physiotherapy department for support and now draw regularly on this.



### 3. What are the next steps?

Continuous evaluation and improvement of the procedures in the context of evolving needs.



### 4. What are the benefits and how are they measured?

#### Joint diagnosis and treatment decisions

Each specialism notes that the multi-disciplinary approach ensures treatment accuracy and comprehensiveness that would not be possible otherwise.

#### Post-surgery care

The general surgeon notes that patients regain more mobility than they would otherwise, and in a shorter period.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify specialisms to work alongside. Where these are not present at own centre, consider working with an external institution, keeping in mind the administrative requirement associated with such an arrangement.
- The size and collaborative culture of Städtisches Klinikum allows for ad-hoc multi-disciplinary working. Larger centres may consider formalising the interaction by setting up an MDT. This has the added benefit of ensuring case expertise is not lost if a staff member leaves.
- If formalising the interaction, establish the amount of input likely to be needed in order to outline requirements accurately.

EXECUTIVE SUMMARY  
Treatment  
Follow up / ongoing



# Patient association (Germany) (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

The patient association works in conjunction with other associations to organise and present an annual conference for clinicians and other interested parties



### 1. What was the challenge?

Clinicians and patients felt frustrated at their lack of knowledge of the other's views.

There was no forum available to promote HS awareness, peer support, and clinician-patient understanding.

The KOL wanted to improve awareness of HS and other rare diseases, but arranging several small, separate events was financially and logistically challenging.

Additionally, clinicians did not have visibility of patients' opinions, and therefore found it difficult to incorporate these into treatment decisions. Conversely, patients felt they could not access information presented by clinicians, especially at conferences, due to the medical language used.



### 2. What is the intervention?

An HS patient association was formed for HS patients, and eventually went on to collaborate with several associations for rare diseases, to present an annual conference.

How long has it been running?

The annual conferences have been running since 2011.

What do they do?

The association started by offering patients peer support. Members met – and continue to meet – monthly, to discuss their experience. However, with regards to wider activities, the size of the association was a limiting factor, as it was for several other associations in the area. To address this, the KOL put the various associations in touch with one another, with the aim of encouraging collaboration, and thus fostering the ability to plan activities and events that they might not be able to manage singly.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Patient association (Germany) (2/2)



### 3. What are the next steps?

The associations started to work together in 2010 to put on a joint conference, where patients presented to clinicians on what they felt were salient issues in HS. The speakers share opinions on treatment, self-care and other topics. In this way, they have a chance not only to raise awareness, but also to collate learnings from different disease areas.

The attendee population has grown over the years, with ~1,200 attendees in 2016. The population make-up has altered too, moving from a clinician majority to a patient majority. Notably, the conferences are now also attended by national politicians of some rank – an indication of the lobbying power of the collaboration.



### 4. What are the benefits and how are they measured?

The conference started as a way to present to clinicians, but has evolved to encompass other arenas. It is now attended by politicians representing various departments of Government. It is hoped that this evolution will continue as the reputation of the conference grows, and that it will attract a wider and more influential range of attendees.



### 5. What are the lessons for other centres in implementing this intervention?

#### Setting up an association

- Ensure funding is in place to establish initial operations

#### Cross-association collaboration

- Consider regionally appropriate methods to introduce and connect groups.
- Ensure adequate staff support until group is self-sufficient. In this case study, the KOL facilitated the collaboration of associations in the first instance.
- Consider disease areas requiring representation in your own region.

EXECUTIVE SUMMARY  
Follow up / ongoing



# Standardising HS care (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

An application to standardise the delivery of HS care across 18 European countries



### 1. What was the challenge?

The quality of HS care provision across Europe is highly variable.

Patients have to travel internationally to attend a centre such as Städtisches Klinikum, as the care they require is not always available in their own country of residence.



### 2. What is the intervention?

A potential collaboration between 42 centres, across 18 European countries, to standardise care delivery across the region.

How long has it been running?

The intervention is not yet underway.

What do they do?

Prof Zouboulis is in conversation with the German government, highlighting the treatable nature of HS, with a view to gain high-level support.

EXECUTIVE SUMMARY  
Treatment



## Standardising HS care (2/2)

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### 3. What are the next steps?

Next steps are not applicable as the intervention is currently in development.



### 4. What are the benefits and how are they measured?

As the project has not yet commenced, there are no success measures. The desired outcome is to improve access to high-quality care across Europe.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify staff member(s), preferably with an interest in HS, to drive the initiative.
- Identify centres in and around your region, to collaborate with.
- Ensure adequate funds and resources are available to convene for discussion and development of care standards.
- Success will depend in part on successful lobbying for support at national and international levels. Centres may wish to involve strong spokespersons as well as strong clinicians when garnering support.

EXECUTIVE SUMMARY  
Treatment



# Community dermatology care (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

A dermatology clinic in the community addresses mild HS patients and ongoing wound care, allowing the hospital clinic to focus on the more severe cases



### 1. What was the challenge?

Dealing with mild HS or ongoing wound care was limiting hospital clinicians' capacity to address more serious cases.

They therefore decided to work in tandem with a dermatology clinic in the community.



### 2. What is the intervention?

The community clinic deals with simple cases and ongoing care, only referring those requiring surgery to the hospital clinic.

**How long has it been running?**

The collaboration has been in place since 2012.

**What do they do?**

The community clinic accepts referrals and treats all cases where surgery is not required. The clinic also provides care for several of the patients released back into primary care after treatment at Städtisches Klinikum. The close working relationship between the two settings is a result of Dr Altenburg, the community clinic head, having trained at Städtisches Klinikum.

EXECUTIVE SUMMARY

Follow up / ongoing



## Community dermatology care (2/2)

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### 3. What are the next steps?

Changes are not planned at present as the collaboration is working effectively.



### 4. What are the benefits and how are they measured?

Clinicians note that patients receive high-quality care as each clinic focuses on their particular stage of need. Patients returning to community care find the transition is a smooth one.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify potential clinics to partner with. Where pre-existing relationships do not exist, evaluate which centres to approach.
- Develop and maintain clear communication channels between the clinics. In Saxony-Anhalt, there is an effective information transfer system in place between the two clinics which allows patient data to flow down from hospital to community clinic easily. Consider how data will be passed quickly and safely between centres in your region.
- Jointly agree transfer protocols, so that centres have confidence in referrals being made correctly.

EXECUTIVE SUMMARY  
Follow up / ongoing



# Tissue viability nurses (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

The centre has collaborated with a university to develop a course to train tissue viability nurses



### 1. What was the challenge?

Patients have extensive wound management needs but these do not necessarily need clinician management.

Tissue viability nurses (TVNs) can help to advise on pain management, appropriate dressings and general self-care. However, this specialty was not available in the region. The department surgeon, Dr Wild, therefore approached the Dessau University of Applied Sciences with a proposal for developing a training course for TVNs.



### 2. What is the intervention?

A TVN course aimed at training nurses with expertise wound care.

How long has it been running?

The course will be launched in September 2016.

What do they do?

The university provides the vocational course, which has been developed in conjunction with Dr Wild.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Tissue viability nurses (2/2)

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### 3. What are the next steps?

N/A. The course is yet to be launched.



### 4. What are the benefits and how are they measured?

Patients have access to high quality wound care via nurses with expertise in the field. At the same time, clinicians' capacity is positively impacted, allowing them to focus on providing care to patients requiring relatively complex treatment.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify appropriate institutions to partner with and present a clear case for the mutual benefit associated with developing the offering.
- Consider presenting a business case to local funding bodies such as local authorities and charities.
- Ensure that course content reflects the regional needs whilst being comprehensive enough to allow TVNs to work across various settings.

EXECUTIVE SUMMARY  
Follow up / ongoing



# Treatment algorithm (Germany) (1/3)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

The centre lead has collaborated with other HS experts to produce a treatment algorithm based on the European guidelines



### 1. What was the challenge?

The limited clinician awareness of HS resulted in ineffective treatments and poor understanding of treatment options.

Primary care clinicians in particular would not attend first line treatment at all, instead referring patient immediately



### 2. What is the intervention?

The algorithm outlines a detailed process flow for the optimal treatment options of HS, both surgical and medical.

What do they do?

The algorithm builds on the findings of the European guidelines and provides guidance on medical and surgical treatment for HS.

EXECUTIVE SUMMARY  
Treatment



# Treatment algorithm (Germany) (2/3)

## Proposed actualisation of the European guidelines for the treatment of HS<sup>1</sup>

Active (inflammatory) disease		
Mild	Moderate	Severe
Topical clindamycin	<b>Conventional systemic therapy</b> Clindamycin + Rifampicine / Tetracycline / Acitretin  <b>Biologic therapy</b> Adalimumab (registered) Infliximab (off-label)	

Inactive (non-inflammatory) disease		
Hurley I	Hurley II	Hurley III
No surgery	Deroofing, lasers, local excision	Radical surgical excision (with secondary wound healing)
<b>Adjuvant therapy</b> Weigh loss and tobacco abstinence (essential) Pain management Treatment of superinfections		



### 3. What are the next steps?

The proposed actualisation will evolve as new findings emerge over time.

EXECUTIVE SUMMARY  
Treatment

Notes

- Posterpreis, 5. International Konferenz des European Hidradenitis Suppurativa Foundation e.V., 2016



## Treatment algorithm (Germany) (3/3)

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### 4. What are the benefits and how are they measured?

The algorithm takes in to account any major new findings (it is based on the European guidelines, which in turn drew on a literature review on the Medline database for the period 2013-2015 under the term 'hidradenitis'). As such, it provides treatment guidance in line with the latest findings, and validated by HS experts.



### 5. What are the lessons for other centres in implementing this intervention?

- Disseminate information across a range of platforms to clinicians who may not receive this otherwise.
- Train clinicians as to how to follow the algorithm and potentially combine with wider HS training awareness programme.
- Track the use of the algorithm in patient population to ensure the guidelines are properly followed.

EXECUTIVE SUMMARY  
Treatment



# European guidelines (1/2)



## Centre: Städtisches Klinikum, Dessau, Germany

Centre lead: Prof Christos C. Zouboulis – president of the European Hidradenitis Suppurativa Foundation (EHSF)

The centre lead has worked with several other HS specialists to draw up European guidelines for the diagnosis, classification and treatment of HS



### 1. What was the challenge?

The quality of HS care was widely varied, with patients often having to travel to other countries to get help.

This was a result of a lack of clinician recognition of HS as well as uncertainty about appropriate treatment for the disease.



### 2. What is the intervention?

The guidelines lay out diagnostic criteria, staging tools and treatment options.

How long has it been running?

The guidelines were published in 2015

What do they do?

The guidelines provide:

- information on the nature and epidemiology of HS
- diagnosis criteria for both primary and secondary settings, with the latter divided into obligatory and additional criteria. It also highlights the importance of examination by the naked eye, rather than simply asking the patient about their lesions<sup>1</sup>
- information on differential diagnoses
- options for diagnostic imaging
- options for severity classification
- assessment of anti-inflammatory treatment effectiveness
- information on comorbidities.

EXECUTIVE SUMMARY  
Diagnosis

#### Notes

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015



## European guidelines (2/2)



### 3. What are the next steps?

The guidelines will evolve as new findings emerge over time.



### 4. What are the benefits and how are they measured?

The guidelines present a collective expert opinion which both primary and secondary clinicians can draw upon to improve diagnosis and treatment. Increased use of the guidelines across settings is also likely to improve standardisation of the quality of HS care.



### 5. What are the lessons for other centres in implementing this intervention?

- Where possible, draw on material that has already been created, such as these guidelines.
- If creating own, work together with experts in the region



# Patient association (France) (1/4)



## Centre: Clinique du Val d'Ouest, Lyon, France

Centre lead: Dr Phillippe Guillem – surgeon

Solidarité Verneuil promotes HS awareness, provides funding and clinician advice, and offers pastoral support to members



### 1. What was the challenge?

Hélène Raynal, the founder, was keenly aware of the multiplicity of issues faced by HS sufferers and the lack of support for the same.

She has an active interest in identifying clinicians and regions offering high-quality care, and sharing information on these with fellow sufferers and local clinicians.



### 2. What is the intervention?

Solidarité Verneuil is an association consisting of 250 paid members and ~700 unpaid ones.

How long has it been running?

The association was set up in 2009 when Hélène and two other sufferers met each other through visiting the same clinic. The three quickly decided to form an association, setting up a Facebook page as well as a website.

### What do they do?

Clinician recommendations

Members share information online and in person about clinicians and centres they have found to be providing high-quality care. This internal advertising meant that over 2006-2009, Clinique Val d'Ouest found that 46% of their referrals came through the association<sup>1</sup> (as well as one other, longer-running association that Hélène was also a member of). As a result, the centre saw several HS patients, leading to a raised profile in the disease area, and prompting an increase in referrals from other clinicians.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing

Notes:

1. Guillem P, presentation at Verneuil network Scientific Day, 2015



## Patient association (France) (2/4)

Main sources of referrals of HS patients to Val d'Ouest<sup>1</sup>



### Provide financial advice

The association offer general advice to patients likely to apply for extra funding for costs not covered by the healthcare system, e.g. encouraging them to take photos before and after treatment. They also advise patients who are appealing rejected applications for extra funding to cover costs not covered by Securite Social – something that can happen reasonably regularly in areas where doctors are unfamiliar with HS, and therefore fill in the form requesting extra funding poorly<sup>2</sup>.

### Provide pastoral and psychological support

The centre and association work very closely; all new patients are asked on their registration form if they would like to speak to an association member. Those that agree are visited by the members, both in hospital and at home, and offered comfort and support.

Patients who find themselves having to be admitted for surgery unexpectedly are helped by local members who put together and provide packs with basic necessities such as toothbrushes.

### Raising awareness

Solidarité Verneuil work to raise awareness in several ways, including:

- information leaflets: 13 association sector heads across France visit doctors and pharmacists to provide information leaflets for patients. These materials are designed by Solidarité Verneuil and note that recurrent boils and abscesses might indicate HS
- collating data on patient views to evidence the need for HS education and appropriate treatments; for example, the executive committee designed a patient survey which was completed by 202 patients and evaluated how they perceive their health care pathway<sup>3</sup>
- working with the KOL to organise awareness days for patients. The first of these was held in 2013, with:
  - the KOL presenting on HS management to nurses
  - a dermatologist, plastic surgeon and general surgeon speaking about treatment to patients.
  - patients with expertise in specific related fields, e.g. social insurance, advising patients on how to approach these.

### Notes

1. Guillem P, presentation at Verneuil network scientific day, 2015.
2. HS does not feature on the primary list of recognised diseases requiring extra funding in France. It does appear on the longlist, which means that funding may be available, but needs to be applied for by the treating clinician.
3. Guillem P and Raynal H, The health care pathway encountered by patients with hidradenitis suppurativa; Results of a self-built self-reported questionnaire from the French patient organisation 'Solidarité Verneuil', 2016.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



# Patient association (France) (3/4)



### 3. What are the next steps?

#### Information leaflets

Solidarité Verneuil would like to customise their information leaflets for GPs, nurses and pharmacists. They are currently limited from doing this by funds. The KOL also notes that the efficacy of these leaflets might be heightened if they were distributed as part of a larger programme, where the pharmacists and GPs were educated about HS by expert clinicians.

#### Awareness days

The next event is planned for 2017. The KOL hopes to involve other centres, and possibly pharmaceutical companies, with the aim of distributing the administrative and financial burden.



### 4. What are the benefits and how are they measured?

#### Clinical recommendations

Patients can discuss care and seek out the doctors who provide the best care.

#### Pastoral and psychological support

Patients often suffer alone, but the association means there is a support network of understanding individuals available to help.

#### Financial advice

Patients benefit from the experience of those who have already learnt how to navigate the funding system. Of the patients advised by Solidarité Verneuil when appealing a funding decision, ~50% win their appeal.

#### Raising awareness

##### HS leaflets

Association members note that it is difficult to measure the impact of this intervention, which has been running for seven years.

##### Collating patient views

Clinicians have access to a proactive body that presents patient views, and can refer to these when designing centre protocols.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



# Patient association (France) (4/4)



## 5. What are the lessons for other centres in implementing this intervention?

### Forming the association

- Aim to bring together individuals with skills across several areas e.g. accounting, marketing and public speaking, in order to create a sustainable and effective association. Encourage members to share skills so that operations can continue smoothly during any absences.

### Clinician recommendations and financial advice

- Ensure an appropriate platform is available to share views and collate experiences.

### Pastoral and psychological support

- Keep in mind that the level of in-person support that can be offered depends on the number of patients willing and able to contribute their time. Consider what level will be feasible in your setting.

### Information leaflets

- Consider where the greatest gaps in knowledge are in your given region in order to determine leaflet content.
- Consider modes of dissemination – not all associations may wish to visit in person.
- Where patients have limited time, or are unsure about layout design and information selection, they may wish to consider liaising with associations who have already created materials and are willing to share these.

### Data collation

- Consider what data would be useful to collect, and how the centre and the association can collaborate to collect it.

### General

- A centre must be willing to work closely with the association in order to gain full benefit. Val d'Ouest offers all new patients the choice to meet with an association member, and liaises closely with Solidarité Verneuil to ensure that such meetings occur. Where it is not possible to organise meetings at the centre, consider introducing patients to association members, to allow direct coordination of meetings.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



## Hospital mini-registry (1/2)



### Centre: Edouard-Herriot, Lyon, France

Centre lead: Prof Denis Jullien – dermatologist

New patient details are recorded to facilitate both clinical trials and treatment without the need for a registry



### 1. What was the challenge?

Edouard-Herriot run clinical trials as well as treating patients, and need appropriate data to conduct both successfully.

However, they were finding it very time consuming to collect one set of details for treatment and another for trials. Additionally, staff capacity did not allow for filling in patient registries, some of which could take up to 30 minutes to complete (per patient).



### 2. What is the intervention?

A 'mini-registry' at the hospital that is completed by an intern with the patient, just prior to the patient seeing the clinician.

How long has it been running?

The system was installed in 2015.

What do they do?

All new patients' details are entered on to a comprehensive form that records:

- Lifestyle factors that may impact HS, such as smoking
- HS-related health concerns such as Crohn's disease
- Treatment history, both medical and surgical
- Lesions' type, placement and severity.

Additionally, patients' DLQI scores are also recorded.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Hospital mini-registry (2/2)



### 3. What are the next steps?

The intervention is relatively new, so there are no current plans to amend it. However, more generally, the centre are in discussions with the university about amending the medical curriculum so that more focus is placed on HS than is currently the case.

Whilst the centre does not have plans to deliver any awareness programmes, it notes that there is much merit in HS experts approaching organisers of conventions of GPs, surgeons etc. and presenting on HS in such settings.



### 4. What are the benefits and how are they measured?

- The centre minimises time spent on data collection, meaning that more time is available for understanding the disease and identifying the correct treatment.
- Over time, it is hoped that both the types and the volume data collected will start to show patterns across patients, the recognition of which will facilitate improved handling.

As the intervention is still very new, quantitative data is not yet available for either of these.



### 5. What are the lessons for other centres in implementing this intervention?

- Consider whether patient volume at your centre is large enough to yield meaningful data (Edouard-Herriot currently has ~170 patients).
- Identify staff available to undertake the data collection.
- Ensure that the clinic timetable is designed so as to incorporate the data collection.
- Where a centre already subscribes to a registry, or where clinical trials are not conducted, evaluate whether the intervention is necessary.
- Edouard-Herriot implemented this 'mini-registry' at a time when there was a hospital-wide patient file software update, asking the visiting I.T. staff if they would help to build it. Interviewees note that this access to staff with the necessary expertise is a crucial factor. Where it is not available, centres wishing to replicate the system may wish to consider hiring such staff in.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Multi-disciplinary team (France) (1/4)



### Centre: Clinique du Val d'Ouest and Edouard-Herriot Hospital, Lyon, France

Centre leads: Dr Phillipe Guillem – surgeon; Professor Denis Villani and Dr Axel Villani – dermatologists

Clinique Val d'Ouest and Edouard-Herriot hospital act as a single unit to provide HS treatment across surgery, dermatology and psychology as well as ancillary support (for diet and addiction)



### 1. What was the challenge?

Dr Guillem felt that care provision was disjointed, as patients were speaking to several specialists, but specialists were not necessarily speaking to each other.

This observation arose from conversations with patients as well as from noting the number of referrals from Edouard-Herriot's dermatology department.



### 2. What is the intervention?

Clinical and support treatment is provided by the centre in conjunction with Edouard-Herriot, to ensure holistic treatment. MDT meetings are also held to discuss difficult cases.

#### How long has it been running?

The two centres have been aligning provision to work as one unit since 2012. Whilst they have informally discussed patients during this time, their first official MDT meeting was held in December 2015, and will be held two to three times per year to start.

#### What do they do?

Patients visiting either centre are screened for comorbidities and lifestyle factors that may aggravate the disease (e.g. obesity and smoking). Depending on the needs flagged during this screening, patients are treated not just for HS but for any comorbidities.

A distinctive feature in this setting is the additional treatment offered for psychological and lifestyle support. All patients are offered support from:

#### Psychologists

Dr Guillem noted that a large proportion of patients were impacted psychologically by HS and suffered social isolation, self-disgust and depression, which in some cases was severe enough to incite suicide. For this reason, he felt that the provision of psychological support was of high importance.

#### EXECUTIVE SUMMARY

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## Multi-disciplinary team (France) (2/4)

Two psychologists are therefore available to help patients to work through negative emotional states and the triggers for these. The service has been offered at the centre since 2010, with Dr Guillem formalising psychologist involvement since 2012. Patients in France are eligible to receive psychological support for up to three months after surgery, and multiple appointments are available for those patients who are willing and able to take them.

In February 2015, Dr Guillem presented a paper at the European Hidradenitis Suppurative Foundation (EHSF) conference, on the psychologists' exploration of HS patients' emotional states, inter- and intra-personal relationships, and pre-existing traumas<sup>1</sup>.

### Dietician

HS patients have an above-average prevalence of obesity. Additionally, a growing body of data suggests that HS symptoms are aggravated by obesity. A dietician is therefore available for a one-off meeting with patients. As she does not get to see these patients on a recurrent basis and remind them of healthy eating habits, the dietician has created a booklet which outlines these. The booklet notes which foods should be reduced or cut out in order to reduce gut inflammation, and provides a sample meal plan for breakfast, lunch and dinner.

### Addictologists

Since 2003, patients visiting Clinique Val d'Ouest are offered the option to meet with an addictologist, with a view to encouraging smoking cessation. The practitioner may be either a doctor or a nurse with a specialism in addictology. Patients who decline the offer of a meeting are offered a second chance as the addictologist visits the centre once they have been admitted. In the vast majority of cases, patients agree to the appointment at this second opportunity.

The addictologists work in a coaching capacity so that patients can decide that they would like to stop smoking, rather than being told that they must do so. The team also acknowledge the difficulties that HS patients have with smoking cessation, given that smoking provides distraction from their significant pain burden. This helps patients realise that they are not being judged, and by extension, helps them understand that smoking cessation is being suggested to improve their quality of life.

“It is...key... that patients know that stopping smoking will make them more comfortable in their life.”

Dr Sophie Arnaud-Reveau, addictologist



### 3. What are the next steps?

#### MDT meetings

The KOL, along with the head of dermatology at Edouard-Herriot, will shortly be meeting with dermatologists working in Lyon, to inform the clinicians of the MDT offering that they provide. This is likely to increase volumes of patients with severe disease. At this point, the MDT meetings will be held more frequently.

Notes

1. Hauet et al, Psychological support for patients with hidradenitis suppurativa, 2016.

EXECUTIVE SUMMARY

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## Multi-disciplinary team (France) (3/4)

### Psychologists

The psychologists would like to repeat their studies with a larger cohort, to see if the severity of trauma and of HS are correlated. They would also like to get a scientific researcher to do this full time.

### Dietician

The dietician would like to performed a statistical study on the effects of the dietary treatment she advises, but currently doesn't have the means as she only sees the patients once.

### Addictologists

The team are currently working to develop a system whereby they measure the average number of addictology sessions a patient attends, and correlating success with smoking cessation.



## 4. What are the benefits and how are they measured?

### Psychologists

Anecdotally, the psychologists noted that patients who felt calmer often reported a reduction in pain and flares as well.

### Dietician

The dietician is not able to measure the success of her intervention with the patients due to the limited nature of their interaction.

### Addictologists

As mentioned, the addictologists are in the process of developing outcome measures to gauge the success of their intervention. Anecdotally, they note that:

- patients realise the impact of smoking on HS symptoms, and are therefore more inclined to stop
- patients feel empowered, knowing that there is support available if they do make this choice.



## 5. What are the lessons for other centres in implementing this intervention?

### Psychologists

- Consider funding requirements for engaging mental health staff.
- Ensure that these staff receive adequate information about HS so as to be able to address patients' needs.

#### EXECUTIVE SUMMARY

Treatment (p.12)  
Treatment (p.13)  
Follow up / ongoing



## Multi-disciplinary team (France) (4/4)

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### Dieticians

- Consider whether funding will allow dietician involvement, especially when measuring outcomes may be difficult.

### Addictologists

- Employ specialised staff, with an understanding of addiction, and the most effective techniques to help overcome it.
- Ensure that adequate time is scheduled for interaction with the patient. Appointments take 30-40 minutes per patient, and shortening the sessions may end up reducing their efficiency.
- Consider the longer term timelines involved. Interviewees note that it may take several visits, over several months, for any discernible impact to show.
- In countries where funding is available through charities, consider approaching these.

EXECUTIVE SUMMARY

Treatment (p.12)

Treatment (p.13)

Follow up / ongoing



# Hyperbaric chamber (1/3)



## Centre: Edouard-Herriot Hospital, Lyon, France

Centre lead: Dr Thierry Joffre – hyperbaric oxygen therapist

Post-surgery patients attend sessions in the hyperbaric chamber to reduce pain and accelerate healing time



### 1. What was the challenge?

Patients experience long healing times with high levels of associated pain when recovering from surgery.

A hyperbaric chamber was already installed at the centre, and the spare capacity could therefore be employed for HS patients.



### 2. What is the intervention?

Hélène Raynal, the head of the patient association, became aware of a clinician in Marseille, France, who was using a hyperbaric chamber in the treatment of HS. Due to the strong relationship between the association and Clinique Val d'Ouest, she requested and was granted the opportunity to invite the clinician to come and speak about the technique to the practitioners treating HS in Lyon. The doctors felt that this would be a powerful intervention to adopt and formed an agreement with the hyperbaric team to send patients to the chamber. Currently, approximately fifteen of the 200-300 patients using the hyperbaric chamber annually are HS patients.

#### How long has it been running?

The chamber has been used for HS patients since 2008.

#### What do they do?

Patients attend sessions in an eight-person hyperbaric chamber for two reasons:

#### Pain reduction

Patients attend daily session for five to six days in order to reduce pain levels after smaller surgeries.

EXECUTIVE SUMMARY

Follow up / ongoing (p.14)

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## Hyperbaric chamber (2/3)

### Wound healing

Patients attend 24–40 sessions – more are required for those patients who are smokers. The first 20 sessions are sequential; sessions after this run at three sessions a week, so as to prevent oxygen damage.

Exterior and interior of hyperbaric chamber



Each patient seat is equipped with an individual gas mask and patients get a cocktail of gas appropriate to their specific needs; so several different conditions can be treated during a single session. The cocktail is controlled automatically, with a hyperbaric nurse overseeing the readings for safety.



### 3. What are the next steps?

Alterations are not currently planned as the technique is working efficiently.



### 4. What are the benefits and how are they measured?

The centre does not compile its own records on the efficacy of treatments, but a range of literature from the last 20 years shows that hyperbaric chamber use is effective for wound healing.

“I was one of the first to try [the hyperbaric chamber]. It's difficult because you have to go every day, but it is great. I usually take two months to recover [after surgery], but with the chamber, I took one.”

Hélène Raynal, patient (translated)

EXECUTIVE SUMMARY  
Follow up / ongoing (p.14)  
Follow up / ongoing (p.15)



## Hyperbaric chamber (3/3)

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### 5. What are the lessons for other centres in implementing this intervention?

- Explore infrastructure available in your locality. In regions where hyperbaric chambers are available, centres may wish to form relationships with the infrastructure owners, as these chambers represent a significant investment.
- If there are no local hyperbaric chambers, draw on relevant research to form a robust business case for investment.
- Consider patient selection criteria, keeping in mind distance from treatment centre and willingness to attend daily in the first instance. This is especially relevant if the hyperbaric ward does not have any beds.

EXECUTIVE SUMMARY  
Follow up / ongoing (p.14)  
Follow up / ongoing (p.15)



# Patient care meetings (1/2)



## Centre: Clinique du Val d'Ouest, Lyon, France

Medical director: Dr Jean-Paul Varichon

A meeting of the Commission Relation avec les Usagers (CRU) brings together centre staff and patient representatives to discuss and optimise patient care



### 1. What was the challenge?

All medical facilities in France have a legal requirement to form CRUs. This intervention was embraced by Clinique Val d'Ouest, which has a strong focus on listening to the patient – an attitude that comes from the top down.

The centre treats a lot of conditions that require multiple specialism input. As such, they are used to multi-disciplinary working, and in fact embrace it, continually considering how they can treat the whole patient, and incorporate patient views. An example of this is the centre successfully applying for funding to develop a training day and informational material on appropriate diet, for parents of child patients with cleft palates.

“ [We] are here to give patient care, and to listen.  
When you listen to patients, you provide a good service.”

Dr Jean-Paul Varichon, medical director



### 2. What is the intervention?

A quarterly meeting involving two patient representatives and four hospital staff representing medicine, surgery, care and quality. The director's assistant also attends. How long has it been running?

The meetings are a legal requirement, and have run quarterly since the centre's inception.

What do they do?

The group discuss:

- patient complaints and claims
- any current litigation action
- satisfaction ratings. This includes scores from Scope Santé, a national tool used to measure patient satisfaction
- any other currently relevant matters, e.g. events on patient care, or upcoming investment decisions.

EXECUTIVE SUMMARY  
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## Patient care meetings (2/2)

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### 3. What are the next steps?

There are no formal plans for effecting changes, as the meetings are working well. However, the point of the meetings is to continually amend practice, so next steps for improving patient care arise naturally as a result of the process.



### 4. What are the benefits and how are they measured?

The director feels that care is optimised as patients' views are incorporated into hospital operations and funding decisions.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify staff and patient representatives who are willing and able to evaluate patient care on a regular basis.
- Ensure that centre schedules and timetables allow staff attending such meetings to do so with minimal disruption to their regular duties.
- Where a patient association does not exist, consider how patient representatives will be selected.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Nurse HS course (1/2)



### Centre: Clinique du Val d'Ouest, Lyon, France

Centre lead: Dr Phillippe Guillem – surgeon

A centre nurse visits a local nursing college to deliver HS education



### 1. What was the challenge?

An operative nurse at the centre became increasingly aware that no HS education was provided during nurses' training.

The awareness was particularly heightened when clinicians enquired about how much of the disease was discussed at nursing college.



### 2. What is the intervention?

A one-day training session is run every year. It is delivered by the nurse at her former alma mater to educate trainee nurses about HS.

**How long has it been running?**

The programme has run since 2013.

**What do they do?**

The staff member initially approached her former lecturer, with whom she was still in contact, with the idea of introducing HS training at the college. The existing relationship and the obvious benefit of expanding the trainees' knowledge meant that the college were willing to progress with the idea. The nurse therefore developed a curriculum plan, incorporating information about HS symptoms, and care for HS patients, with a specific focus on post-operative care.

EXECUTIVE SUMMARY  
(First symptoms, diagnosis)



## Nurse HS course (2/2)

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### 3. What are the next steps?

Crystal is currently in conversation with another college, and hopes to introduce the course in the new setting too. Additionally, Dr Guillem has contacted other nursing schools with the offer of expanding this training into their settings.



### 4. What are the benefits and how are they measured?

Anecdotally, the nurse notes that there is already a growing awareness and understanding of HS amongst trainees. She has delivered the training to two cohorts to date. The first cohort did not have any knowledge of the disease. However, a 'trickle-down effect' meant that the second cohort came in to the course with some prior knowledge of HS.



### 5. What are the lessons for other centres in implementing this intervention?

- Nursing staff may consider getting in touch with the institutions that they trained at, as the personal connection can act as a strong incentive to the college.
- Asking a patient to co-deliver the training can be a powerful way to make the disease come alive for the trainees. The staff member in this case study has done this, and noted that the impact appears to be much higher than that achieved through photos alone.

EXECUTIVE SUMMARY  
(First symptoms, diagnosis)



# Follow-up wound care specialists (1/3)



## Centre: Cica+, Lyon, France

Centre lead: Vincent Lagrange – wound care nurse

Expert wound care nurses support home care nurses in caring for patients in their homes after surgery



### 1. What was the challenge?

Home care nurses are generalists and do not necessarily have expertise in wound care.

As a result, they may not always be sure about the appropriate dressings and treatments to use, the exact application procedure, and the wound progression that should be occurring.



### 2. What is the intervention?

Cica+ is a small company comprising eight staff, three of whom are nurses. The establishment supports home nurses who are visiting patients who have returned to their homes after surgery and are being seen to for wound care.

**How long has it been running?**

The company has been operating since 2013.

**What do they do?**

Cica+ have a simple business model whereby they purchase wound care supplies in bulk in order to gain a discount, and then offer these at a price covered by the healthcare system. In this way, there is no extra cost to the payer in using Cica+.

They also have a series of value-add activities across a range of areas.

Personal support

Cica+ nurses accompany the home nurse every eight days to:

- evaluate the patient's progress, and determine whether dressings and medication need to be changed
- support the home nurses with any queries on treatment or symptom changes. This largely eliminates the need for clinician involvement.

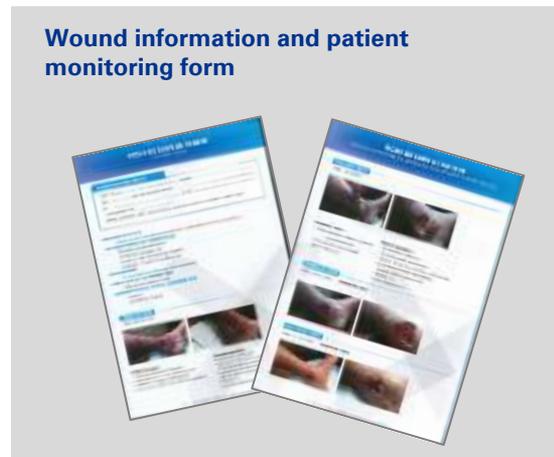
EXECUTIVE SUMMARY  
Follow up / ongoing



# Follow-up wound care specialists (2/3)

## Training and information materials

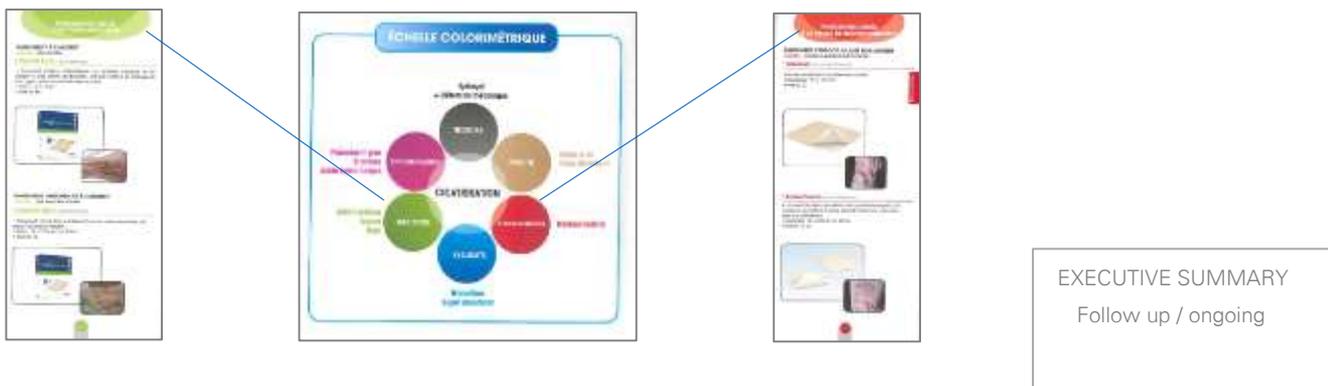
- The company runs training afternoons for home care nurses where they go over the different types of wounds typically seen, and the appropriate treatment for each.
- An abbreviated version of this information is made available in leaflet form, and customised for doctors and nurses.
- Patient monitoring forms are also available for nurses, for a range of wound types. These list features such as likely reasons for the wound, the average patient type, and what the home nurses should expect the wound to look like, from first to last visit.



## Supplies

- Cica+ assemble and deliver supplies to the patient’s home, so that home nurses attending them are equipped with the materials appropriate to the specific wound and stage of healing. They provide enough materials for seven days, visiting in person on the eighth to determine whether to continue the regimen or update it.
- The company provide materials that help nurses choose appropriate medication and bandages. Cica+ produce a booklet that colour-codes materials according to the stage of healing.

**The colour-coded catalogue facilitates choosing materials for a given stage of wound healing.**





## Follow-up wound care specialists (3/3)



### 3. What are the next steps?

Cica+ currently serve Lyon, but are exploring ways to grow their offering to other areas, either through expansion or through a joint venture with other businesses.



### 4. What are the benefits and how are they measured?

Whilst there is not documented evidence, the company notes that the provision of effective wound care speeds up healing time, reducing patients' pain as well as the cost and capacity burden on the healthcare system.

Additionally, home care nurses feel less obliged to contact a clinician as they can get support from Cica+, who provide an expert evaluation on whether concerns need to be escalated. They have rarely found this to be necessary. Clinicians therefore find their capacity for dealing with new cases positively impacted.



### 5. What are the lessons for other centres in implementing this intervention?

- The system is most suited to countries where there is a healthcare system covering a certain level of costs. Where this is not the case, consider whether the business model needs to be adapted.
- Similarly, evaluate whether this intervention needs to be amended to work in regions where home nurses are not the norm, for example considering whether the wound care nurses might be the only source of home support.
- Identify staff with appropriate expertise to deliver wound care.

EXECUTIVE SUMMARY  
Follow up / ongoing



# National review of HS (1/2)



## Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

A structured national review of HS to consider disease treatment



### 1. What was the challenge?

There is low awareness of the disease at a governmental level.

As a result, reimbursement for medical treatment is limited, a factor which means hospitals can struggle to provide treatment for patients requiring costly medication such as biologics.

The limited awareness also means that the route for patients to gain financial support is poorly developed – a large problem given that many patients are unable to continue working as their symptoms worsen.



### 2. What is the intervention?

Prof Jemec, the centre lead, has lobbied the Danish Health Authority with the ultimate objective of raising the profile of HS in hospitals, thereby improving treatment of, and reimbursement for, the disease.

**How long has it been running?**

The lobbying campaign started approximately two years ago, in 2013.

**What do they do?**

A structured review process has been undertaken in order to consider:

- the prevalence of HS
- the physical and psychological impact of HS, and the resulting impact on patients' QoL and functional ability
- whether appropriate provision is in place to support effective treatment.

EXECUTIVE SUMMARY  
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## National review of HS (2/2)



### 3. What are the next steps?

Reimbursement improvements have also been initiated at a hospital level. Currently, departments are remunerated with a one-off sum per patient – a system that encourages maximising throughput. However, many HS patients require several repeat visits and iterative treatment, which may need to be jointly agreed by different specialisms. Therefore, it has been requested that the case mix be considered when allocating funding, so that departments are not dis-incentivised from treating patients requiring follow-up treatment and multi-disciplinary input.



### 4. What are the benefits and how are they measured?

As a result of the review, HS will now appear in national policy documents on disease areas of special interest. This recognition means that higher levels of reimbursement will be available for drugs to treat the disease.



### 5. What are the lessons for other centres in implementing this intervention?

- Consider the long-term objective, and then tailor centre strategy to support this. For example, significant work has been carried out at Roskilde Sygehus on HS prevalence, and this work has ultimately supported the national review.
- Where it is not feasible to carry out the research in your own setting alone, consider collaborating with agencies involved in such research work.

EXECUTIVE SUMMARY  
Treatment



## HS awareness day (1/2)



### Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof. Gregor Jemec – dermatologist

An annual awareness day to share information and address patient queries



### 1. What was the challenge?

Patients had limited awareness of their disease and so were ill-equipped to cope with it.

Additionally, several patients had spent a considerable period of time visiting clinicians who were unable to diagnose or treat them. As a result, these patients were somewhat mistrustful of the professionals, and not always inclined to follow their suggestions.



### 2. What is the intervention?

An annual HS awareness day is run by the dermatology department to provide structured education, foster relationships and address any specific patient queries.

#### How long has it been running?

The awareness days were started in 2009.

#### What do they do?

#### Organisation

The awareness days are organised by a staff member who works solely with patient involvement and education.

They are attended by the organiser and the centre lead, as well as one other doctor from the centre. Those nurses and research students with an interest in the disease also attend.

#### Patient attendees

Patients who sign up at the centre to receive information about HS are invited. Doctors in other settings are also made aware of the intervention and tell their patients about the meeting. Those patients expressing an interest are then contacted by the organiser. Additionally, the event is advertised on the hospital web page and on the patient association's Facebook page and website.

EXECUTIVE SUMMARY  
Treatment



## HS awareness day (2/2)

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### Content

The course organiser aims to structure the day to:

- provide information that is deemed mandatory for the patients to hear. This is usually done through a series of presentations
- respond to patient concerns and queries. For this part of the day, audience questions are noted down, and the speakers and organisers then aim to answer these.

Speakers include both clinicians and other patients. The latter speak about their own experience of HS, and of treatment options such as biologics and surgery.



### **3. What are the next steps?**

The programme is to be run more frequently from summer 2016, becoming bi-annual rather than annual.



### **4. What are the benefits and how are they measured?**

No quantitative data has been collected on the impact of the intervention. However, staff anecdotally note that since the advent of the awareness days, the patients appear more empowered, and show an increased ability to accept their condition. This in turn allows them to proactively find ways to minimise its impact.



### **5. What are the lessons for other centres in implementing this intervention?**

- Identify the main gaps in knowledge that need to be addressed in your area, and tailor a programme to address these.
- Involve patients as co-presenters rather than as audience members only
- Consider the staffing, funding and logistic capacity in your setting when deciding on how to structure a similar intervention.

EXECUTIVE SUMMARY  
Treatment



## Multi-disciplinary team (Denmark) (1/3)



### Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

Multiple specialisms' input is co-ordinated and offered in order to optimise medical, surgical and psychological treatment.



### 1. What was the challenge?

Patients had multiple needs and required input from several specialisms.

These needs were not only with regards to medical and surgical treatment, but also encompassed lifestyle factors and psychological concerns.



### 2. What is the intervention?

Clinical and support treatment is provided by the centre to ensure holistic treatment. MDT meetings are also held to discuss difficult cases.

How long has it been running?

Dermatology-plastic surgery MDT: 2003

Lifestyle counselling: ~18 months (set up in 2014)

Psychiatrist input: ~two years (since 2014)

What do they do?

Patients visiting the centre are screened for comorbidities and lifestyle factors that may aggravate the disease (e.g. obesity and smoking).

Clinician collaboration

Those with comorbidities are treated by the dermatology department in conjunction with other appropriate departments.

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## Multi-disciplinary team (Denmark) (2/3)

A formal weekly meeting is held between dermatology and plastic surgery to discuss patients cases where input from both departments is required. Collaboration with other specialisms is on an informal basis, and initiated as and when required. The size of the centre and the country facilitates this ad-hoc interaction. Additionally, the mode of operation is necessary, as the current funding system in the region works by paying a one-off sum per patient, meaning that no extra funds are available to provide the additional support – such as MDT meetings – that more complicated cases require.

### Lifestyle counselling

A distinctive feature in this setting is the additional treatment offered to improve lifestyle factors. All patients are offered the opportunity to attend five 30-minute sessions with a nurse. The sessions focus on patients' long term objectives, and what steps the patients can take to reach these. As such, it is a motivational methodology; the nurse is diligent not to stigmatise the patient for their lifestyle, but rather to support them to recognise that a healthier one may improve their quality of life. In addition, patients are given specific information about the effect of smoking and obesity on HS symptoms, rather than a generic message on the benefits of weight reduction and smoking cessation.

### Psychiatric support

HS can have a significant psychological impact, with patients experiencing social isolation, self-disgust and depression. These are not only concerns in themselves, but can also leave patients incapable of altering lifestyle factors that aggravate symptoms. In this way, a vicious cycle is set up.

For this reason, the centre aims to provide psychiatric support. A psychiatrist is available for a half-day every week. Patients are referred to the psychiatrist if:

- their initial screening highlights a need (e.g. very low DLQI score)
- the clinician at the initial consultation feels that it is required
- the nurse in the lifestyle counselling clinic feels that the patient needs further support.



### 3. What are the next steps?

#### Clinician collaboration

Other than MDT meetings with plastic surgery, collaboration is likely to remain informal until there is a change in the funding structure.

#### Lifestyle counselling

Doctors will start recommending the session to patients who they feel might benefit from these. It is hoped that this will motivate patients who may not be willing to sign up on the encouragement of the nurse alone.

Staff would like to see the lifestyle counselling sessions complemented by access to a dietician, although finances do not currently allow this.

#### Psychiatric support

Staff would also like to offer more psychiatric support, as there are currently more patients requiring support than can be seen in one afternoon per week. Again, limited resources mean that this is not presently feasible.

#### EXECUTIVE SUMMARY

Treatment (p.12)

Treatment (p.13)

Follow up / ongoing



# Multi-disciplinary team (Denmark) (3/3)



## 4. What are the benefits and how are they measured?

### Clinician collaboration

Staff note that patients receive holistic care, with all the involved clinicians having knowledge of the treatment being administered to the patients by their colleagues in other settings. This results in improved patient satisfaction.

### Lifestyle counselling

The nurse notes that of the three attendees that she sees, one has lost 5 kilos over the last year. However, as there are currently very few participants, it is difficult to quantify benefits in a statistically meaningful way. The nurse running the sessions is currently looking to develop a system to measure the benefits of the intervention. This will involve identifying appropriate outcome measures.

### Psychiatric support

Staff would also like to offer more psychiatric support, as there are currently more patients requiring support. Anecdotally, patients feel better equipped to deal with their condition and its attendant concerns.



## 5. What are the lessons for other centres in implementing this intervention?

### Clinician collaboration

- Consider the operational style that will work best for your setting, whether this be formal MDT meetings, ad-hoc interaction, or a combination of both. Keep in mind the funding regimen in your area, as this will influence the breadth of attendees, and the number of meetings that can be held.

### Lifestyle counselling

- Gauge patients' willingness to sign up. Roskilde Sygehus has found that whilst many patients supported the idea of the counselling sessions, very few were ready to join in themselves. This was due to their having a plethora of concerns – physical, mental and financial – which put changing their lifestyle low on their list of priorities.
- Consider whether funding will allow for the intervention, especially when measuring outcomes may be difficult.

### Psychiatric support

- Consider funding requirements for engaging mental health staff.
- Ensure that these staff receive adequate information about HS so as to be able to address patients needs.

EXECUTIVE SUMMARY

Treatment (p.12)

Treatment (p.13)

Follow up / ongoing



# Develop outcome measures (1/2)



## Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

The research programme includes the refinement and development of clinical and quality of life (QoL) outcome measures for HS



### 1. What was the challenge?

There is a lack of robust QoL outcome measures, whilst severity measures are geared to clinical trials rather than treatment.

The absence of standardised, evidence-based measures that are meaningful to patients can result in an inability to gauge the type and degree of need accurately. It can also result in difficulties with comparing results of studies undertaken across different settings.



### 2. What is the intervention?

A PhD student at the centre is assessing the reliability of current scores as well as looking to develop new ones.

How long has it been running?

The PhD started recently, in 2015, and research has been running for six months.

What do they do?

Development of a new QoL measure

The research will assess the reliability of current scores – likely through a one-day workshop with 25 patients and six dermatologists – to investigate which elements are agreed on as important by all attendees. Those that are agreed on will go into a new score, which will also be added, again through testing with patients and clinical experts.

Development of a new clinical score

The research will assess the reliability of current scores – likely through a one-day workshop with 25 patients and six dermatologists – to investigate which elements are agreed on as important by all attendees. Those that are agreed on will go into a new score, which will also be added, again through testing with patients and clinical experts.

EXECUTIVE SUMMARY  
Treatment



## Develop outcome measures (2/2)

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### 3. What are the next steps?

The research is in its initial phases, so new activity is not yet planned. Eventually, consideration would need to be given to gaining international agreement on using the measures across all settings.



### 4. What are the benefits and how are they measured?

It is hoped that the study will make it easier to measure HS severity and patient QoL, so that the effect of interventions – in both clinical trials and in the hospital setting – can be accurately gauged.

It is also hoped that the research will assist in ensuring standardisation across trials and clinics.



### 5. What are the lessons for other centres in implementing this intervention?

- Collaborate with institutions that are undertaking similar work. The centre is working together with the International Dermatology Outcome Measures (IDEOM) group, as the latter have expertise in developing and validating outcome measures in dermatology.
- Match the external collaboration with internal. Working together with colleagues such as psychologists and biostatisticians will help to ensure that the outcome measures cover a wide range, and are robust.

EXECUTIVE SUMMARY  
Treatment



# Patient association (Denmark) (1/4)



## Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

Patientforeningen HS is an association that provides support for patients and has engaged in a high-profile awareness raising campaign



### 1. What was the challenge?

Staff at the centre noted that there was no forum available for HS patients to speak to each other, despite a strong desire for this amongst the sufferers.

This heightened their social isolation, which was often significant to start, given the lack of awareness of HS amongst the general public, and even amongst some clinicians.



### 2. What is the intervention?

A small group of patients in the local area, with a larger following on Facebook, work together to raise awareness of HS and to support each other. The group was set up with the support of the patient engagement and education officer at Roskilde Sygehus, who initially introduced members.

How long has it been running?

The association was set up three years ago, in 2012.

What do they do?

Public awareness campaign

The association members actively try to educate those that they meet, e.g. speaking to practitioners about the association website when visiting settings where HS is not widely known about, such as general wound clinics.

More recently, Patientforeningen HS ran a more structured operation to raise awareness. This took the form of a nationwide campaign, titled 'Shh!', to highlight how little HS is known or spoken about. The campaign was launched in October 2015 with funding support from an industry partner, AbbVie. It presented information on symptoms, prevalence and the patient experience. This was done through hand-outs, social media and web pages.

The campaign also included a photography exhibition of HS patient photos in the centre of Copenhagen during the European Academy of Dermatology and Venereology (EADV) congress. The exhibition raised the profile of HS amongst visiting dermatologists and the public alike.

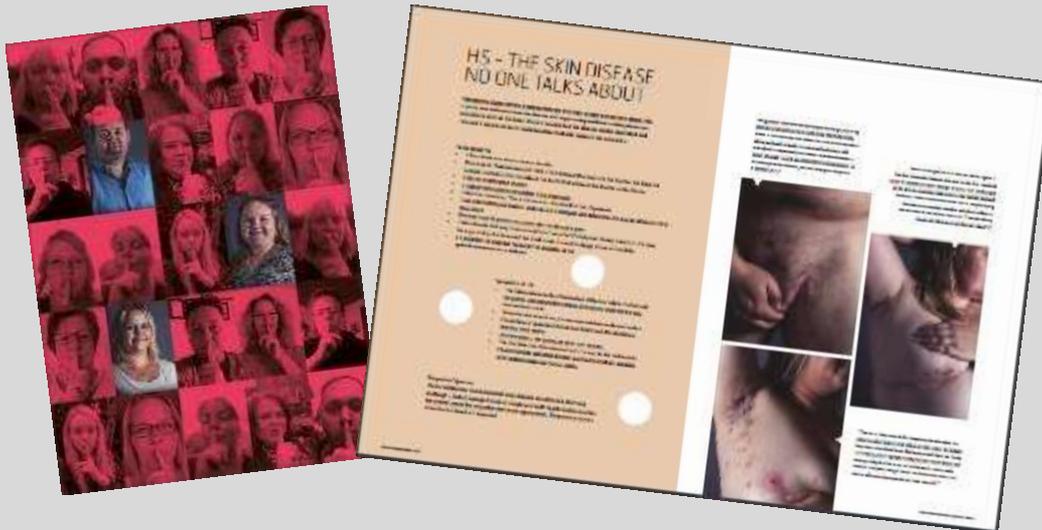
Patientforeningen HS also had a booth at the congress, to represent patient views to the clinicians.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



# Patient association (Denmark) (2/4)

## Excerpts from the Shh! campaign handout



As part of the Shhh! campaign, Patientforeningen created information leaflets for patients to share with their GPs, schools, employers and relatives. The leaflets are tailored to the audience, in order to make them easily accessible.

## Information leaflets are available for employers, relatives, healthcare workers and schools



EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



## Patient association (Denmark) (3/4)

### Pastoral and psychological support

Patients provide each other with support and advice through the Facebook page. At the time of writing this report, there were only seven patients who resided closely enough to meet face-to-face, whereas there were ~300 members on the Facebook page.

The association works closely with national and international bodies in order to provide support and raise awareness. They have worked with AbbVie and the European Hidradenitis Suppurativa Foundation (EHSF) to develop the website, 'Voices of HS'. The website:

- provides links to individual countries' HS pages.
- presents information about the disease for both patients and clinicians
- allows patients to complete a simple online test that indicates whether their symptoms might be indicative of HS.



### 3. What are the next steps?

Patientforeningen HS is considering how they might facilitate regional meetings in different parts of Denmark – the ones they are currently held in Roskilde are too far for several members to get to. They are exploring the option of using free local spaces such as library rooms.

They are also exploring ways in which they can arrange social advice, as many patients lose their jobs or have limited ability as a consequence of the disease.

The association plan to build on their successful Shh! campaign by having a famous personality champion the cause in a follow-up advertising campaign.

Finally, they are considering potential collaboration with other patient groups outside Denmark. e.g. the Italian patient group, which is seeking to form a European patient association.



### 4. What are the benefits and how are they measured?

Patients comment that they do not feel alone once they have joined the association. Staff note that they have seen an increase in the numbers of patients since the campaign. This is due both to increased clinician awareness and referrals, and to members of the public hearing about the symptoms and realising that they have a treatable disease.

“I saw two patients who didn't know that they had this disease till the saw [the Shh! campaign] on TV. And I don't see many of the HS patients.”

Linnea Thorlacius, PhD student

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



## Patient association (Denmark) (4/4)

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### 5. What are the lessons for other centres in implementing this intervention?

- When looking to set up a patient association, consider having a staff member facilitate this at the outset, and step back once initial operations are established.
- Draw on social media. The ex-chair of the association notes that setting up a Facebook page is easy, and gives instant access to a wide region.
- Approach industry bodies for funding for specific campaigns.
- Use materials that have already been created by other associations to spread awareness in your own area, ensuring that you have sought owner permission. Patientforeningen HS are happy to be contacted for permission to use their materials.
- If creating your own materials, draw on the strengths of your specific association. The photography exhibition put on by Patientforeningen HS was initiated by an association member who was a photographer and so had a interest in and ability for promoting awareness through photographs.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Follow up / ongoing



## CO<sub>2</sub> laser surgery (1/2)



### Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

Where extensive excision is not required, diseased tissue is surgically removed using a CO<sub>2</sub> laser.



### 1. What was the challenge?

It was difficult to determine the delineation between diseased and healthy tissue by using imaging techniques.

This meant that surgeons needed to make deep excisions in order to ensure that all diseased tissue was removed, and to prevent symptom recurrence. This resulted in lengthy healing times, during which patients experienced significant pain and mobility reduction.



### 2. What is the intervention?

Whilst severe cases are operated on by plastic surgery, others are dealt with by dermatology, where two of the clinicians are able to perform CO<sub>2</sub> laser surgery.

**How long has it been running?**

The laser has been in use since 2009.

**What do they do?**

The laser surgery technique works by vaporising a single layer of tissue at a time. Removing tissue in this way gives the clinicians a chance to visually inspect the area after each layer removal, and gauge if all diseased tissue has been eliminated.

Once the operating clinician deems this to be the case, they remove a small, extra precautionary layer before concluding the surgery.

EXECUTIVE SUMMARY  
Treatment



## CO<sub>2</sub> laser surgery (2/2)

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### 3. What are the next steps?

Changes are not currently planned for the procedure.



### 4. What are the benefits and how are they measured?

There has not been any study directly comparing the efficacy of the traditional surgical method with that of the laser surgery. Staff at the centre use the latter technique as they feel it provides more control during the surgery, and allows for procedures such as de-roofing with relative ease. This results in reduced times to healing and mobility which, as well as being beneficial to the patient, also has a positive impact for the hospital, in the form of reduced bed days.



### 5. What are the lessons for other centres in implementing this intervention?

- The surgery is impacted by the patients' weight and level of tobacco use. Evaluate whether patients in your setting have the resources to control these factors prior to the operation.
- Where a CO<sub>2</sub> laser is not already available, consider how a business case may be framed in the absence of comparative studies.
- Look at approaching other departments in your setting if they already own the equipment; they may be able to share this if capacity allows.

EXECUTIVE SUMMARY  
Treatment



# Motivational support (1/2)



## Centre: Roskilde Sygehus, Roskilde, Denmark

Centre lead: Prof Gregor Jemec – dermatologist

Nurses are trained by a senior nurse to use a motivational methodology to empower HS patients



### 1. What was the challenge?

HS places a significant psychological burden on sufferers, which can incapacitate them so that they are unable to make empowered choices.

Patients struggle with social isolation, self-disgust, pain and financial concerns. Many suffer depression, which strips them of their ability to optimise self-care.

A significant number of patients have low levels of education and are unaware of the level of impact that can be achieved by taking ownership of their condition.



### 2. What is the intervention?

The nurses aim to use Den Motiverende Samtale, a motivational methodology originally designed to support those fighting alcoholism, and since adapted for use in other areas. The approach focuses on encouraging patients to think about their aspirations, and what steps they might take to reach these. In this way, it aims to foster a desire to effect lifestyle changes from within, rather than instructing patients to change.

#### How long has it been running?

The intervention is a recent one, initiated in 2015 and running for six months to date.

#### What do they do?

A member of the nursing staff was interested in the methodology, and approached the centre with a request for time and funding to gain a diploma in the area.

On completing her training, the staff member felt other nurses would also benefit from the instruction. In conjunction with the centre lead, she organised for an external instructor to visit the centre and deliver a day-long training session on Den Motiverende Samtale. Attendees were given a handbook on the methodology, containing extensive information, much of which was not easily accessible given the brevity of the training. The staff nurse therefore designed a programme which built on the training session, to support the staff in using the methodology. To facilitate use, she split the methods into nine modules. Key points from each were made available on flashcards. This made it possible for nursing staff to choose one area to focus on, and keep key information on this area to hand.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Motivational support (2/2)

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The staff nurse therefore designed a programme which built on the training session, to support the staff in using the methodology. To facilitate use, she split the methods into nine modules. Key points from each were made available on flashcards. This made it possible for nursing staff to choose one area to focus on, and keep key information on this area to hand.

Once they felt confident in delivering that specific type of support, they could choose to switch to another module.



### 3. What are the next steps?

The initiating staff member has noted that nurses often lack the confidence to employ the methodology, as they worry about patients' response, and their own ability to deliver the support effectively. She is considering identifying a receptive patient group for them to approach, to ameliorate concerns about how patients will react.



### 4. What are the benefits and how are they measured?

The initiating staff member notes that the technique empowers patients and encourages them to take ownership of their disease.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify staff member to drive the initiative.
- Ensure time is set aside at regular intervals for 'top-up' training and monitoring; staff note that it is easy for the intervention to be forgotten during the course of everyday demands.
- Be willing to adapt the intervention as needs dictate.

EXECUTIVE SUMMARY  
Follow up / ongoing



# Multi-disciplinary team (Canada) (1/2)



## Centre: Sunnybrook Health Sciences Centre – Toronto, Canada

Centre lead: Dr Neil Shear – head of dermatology

Sunnybrook and St Michael's hospital collaborate to provide holistic care in the absence of a formal MDT



### 1. What was the challenge?

HS patients are high-need individuals requiring input from several specialisms.

Surgeons were not always willing to treat HS patients, as they required repeat treatment which impacted volumes and therefore financial recompense. In addition the nature of the disease rendered it an unpleasant one to treat. Additionally, patients with infected wounds were seen as a risk to other in-patients.



### 2. What is the intervention?

Sunnybrook liaises with St Michael's, a local hospital, in order to give patients access to surgeons, wound care and psychological treatment.

How long has it been running?

The collaboration was initiated in 2015

What do they do?

AbbVie initiated introductions between Sunnybrook and the surgery department at St Michael's at a time when Sunnybrook were finding it difficult to identify surgeons willing to take on HS referrals. St Michael's voiced a concern about finding themselves taking on referrals where surgery was not in fact required, but rather where patients had been passed on as the original centre was unsure how to help them. To ameliorate this concern, the two centres worked jointly to draw up referral criteria.

Establishing this partnership led to referrals not just from dermatology to surgery, but the other way around as well; as the surgeons grew more familiar with HS, they were able to recognise the HS patients that had been referred to them (by centres other than Sunnybrook) whose staging could be addressed medically rather than surgically.

The partnership was then extended to include the wound care clinic at St Michael's, a services that was not offered at Sunnybrook.

EXECUTIVE SUMMARY  
Referral  
Treatment



## Multi-disciplinary team (Canada) (2/2)



### 3. What are the next steps?

Sunnybrook would like to offer patients educational support of the kind that they offer to their psoriasis patients. The centre currently runs a multi-media information session for psoriasis patients, to educate them on the disease and on self-care. They feel that a similar model would be desirable in HS, but are currently limited from setting this up due to financial and time constraints.



### 4. What are the benefits and how are they measured?

The collaboration on protocol assures surgeons that Sunnybrook will only refer cases where there is a genuine need. The KOL notes that patients requiring surgery are now seen quickly where before they faced long delays. Conversely, patients incorrectly referred to surgery can be sent to Sunnybrook for treatment.

The staff feel that holistic treatment improves the patients' QoL, by giving them tools to deal with the physical and mental impact of the disease.



### 5. What are the lessons for other centres in implementing this intervention?

- Be practical about how the relationship will work; overloading a partner specialism with patients may result in the relationship becoming unsustainable. Where possible, try to partner with several centres in order to spread the load.
- Identify an appropriate centre / centres to collaborate with or refer to, e.g. surgery, psychiatry, dieticians, addictologists.
- Initiate and maintain clear communication channels between the parties wishing to collaborate.
- Ensure there is an effective framework to capture various patient needs.
- Provide regular training to develop and maintain staff awareness of the multiple needs of HS patients.

EXECUTIVE SUMMARY  
Referral  
Treatment



# Dedicated dermatology nurses (1/2)



## Centre: Sunnybrook Health Sciences Centre – Toronto, Canada

Centre lead: Dr Neil Shear – head of dermatology

The centre have employed a team of five nurses who help the doctors with providing care for patients



### 1. What was the challenge?

The centre doctors' capacity was often taken up with tasks that did not necessarily require a doctor's input. The nursing staff reduce the burden on the doctors by taking on some of their tasks.

This allows the doctors to focus their efforts on the remaining tasks, thereby providing higher quality care for the patients.



### 2. What is the intervention?

The nurses support the doctors by undertaking

- oversight of biologic delivery
- wound care
- day to day tasks such as biopsies
- dealing with first line patient queries via a nurse line. This is a phone line and email address that patients can contact if they have a concern or query. The line is not constantly manned but nurses pick up voicemails and emails in the mornings, answering these and arranging appointments when the issue warrants it.



### 3. What are the next steps?

When time and funding capacity allows, the centre would like to be able to engage the nurses in a more educational capacity, so that they support patients comprehensively, providing information about HS treatment and care.

They are also hoping to expand capacity by employing another nurse this year.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Dedicated dermatology nurses (2/2)

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### 4. What are the benefits and how are they measured?

Centre staff note that patients display satisfaction with the overall care that they receive, and display confidence in their treatment choice.



### 5. What are the lessons for other centres in implementing this intervention?

- Ensure adequate funding is available to employ nursing staff. Unlike the centre in this case study, other settings may be bound by legislation ruling their wider organisation. In such cases, it is worth considering whether the nursing team will have the freedom to provide the planned services.
- Implement standardised protocols that nurses can use when educating patients on self-care or treatment options.
- Provide regular training for nurses in treatment option features, and on how to advise patients.

EXECUTIVE SUMMARY  
Referral  
Treatment



## HS awareness training (Spain) (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

A training session to raise HS awareness amongst both primary and secondary clinicians



### 1. What was the challenge?

Patients were often mis-referred, resulting in their being seen by secondary care practitioners (SCPs) who were unable to provide diagnosis or treatment.

As a result, several patients returned to primary care without a diagnosis. ASENDHI, the HS patient group, note that it can take up to 15 years for patients to get HS diagnosis and appropriate treatment. In most of the cases, patients do not see a dermatologist whilst in secondary care.



### 2. What is the intervention?

Patients can contact their clinicians on multiple platforms for simple questions as and when required.

How long has it been running?

Dr Martorell started presenting the training four years ago to primary care providers (PCPs) across the catchment area.

What do they do?

The training focuses on how to diagnose, prevent and treat HS. It is targeted at primary care but is also available for specialists.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Referral



## HS awareness training (Spain) (2/2)



### 3. What are the next steps?

The centre is currently developing training courses specifically tailored to general practitioners and general surgeons, and plan to deliver these on a regular basis. They have also recently completed a visual atlas of HS, and aim to distribute this to practitioners, to aid the early detection of HS.



### 3. What are the benefits and how are they measured?

By sharing the training materials with PCPs, the centre hopes to increase the diagnosis rate. However it is still too early for this to be tracked.

A rise in referrals has been seen by the centre in recent years, which they have attributed to both the training programme and their rising reputation.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify personnel with HS experience to coordinate and conduct training.
- Identify primary care champions who will advocate the training on your behalf.
- Consider adopting a train-the-trainer format, thereby increasing the reach of the training.
- The funding requirement for such an initiative may need to be factored in when setting the centre budget.
- The PCPs selected as initial champions were well known to the centre. Where such relationships do not already exist, it may be worth developing these, to ensure PCP commitment.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Referral



## Tele-health (1/2)

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### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

The HS unit provides a tele-health service to all of their patients, who can email, call, and send text messages to the clinicians



#### 1. What was the challenge?

Patients spent much of their time visiting the hospital, often presenting with issues that required relatively simple treatment.

Both the patients and dermatologists therefore found much of their time taken up unnecessarily.



#### 2. What is the intervention?

An interactive, two-module presentation designed to raise HS awareness amongst both primary and secondary practitioners.

*How long has it been running?*

Dr Martorell started presenting the training 4 years ago to Primary Care Providers (PCPs) across the catchment area.

*What do they do?*

Where there is no discernible clinical concern, patients are reassured that what they are experiencing is normal. In many cases, this is all the intervention that is required.

Patients who report moderate issues are given a phone appointment with a dermatologist for the same day, in order to speak through management options.

For patients reporting a notable change in symptoms, an in-person appointment is organised within 24 hours.



## Tele-health (2/2)

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### 3. What are the next steps?

The centre is working to offer an online self-assessment programme which allows patients to list symptoms, and which offers suggestions for next steps based on the patients' inputs.



### 3. What are the benefits and how are they measured?

Clinicians working in the centre find that patients now only contact them for relevant information and that this has reduced the number of unnecessary appointments.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify clinicians willing to participate.
- Pilot programme across a disease area and track volume of interaction.
- Train clinicians to understand data protection and governance to regulatory compliance.
- Ensure IT systems allow for secure patient data transfer and comply with data protection and governance regulations.
- Hospital Manises has embraced the culture of close, regular contact with patients across a range of platforms. In settings where clinicians are concerned about similar communications being burdensome, it may be useful to identify champions and pilot the initiative on a small scale, before rolling out more widely.



## Multi-disciplinary team (Spain) (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

An established MDT comprising dermatology, gastroenterology, plastics, rheumatology, psychology, topography and other specialisms meets regularly to discuss a range of inflammatory disease cases



### 1. What was the challenge?

An MDT allows the team to address HS and comorbidities holistically, and to potentially identify any common underlying factors.

HS, Crohn's, arthritis and other inflammatory diseases are often jointly present in patients, suggesting to staff that they may have a shared cause.



### 2. What is the intervention?

MDT meetings are held to discuss all HS cases. Holistic treatment is provided by a number of specialisms working closely with each other to address the disease and its comorbidities.

How long has it been running?

The MDT has been in place since 2012.

What do they do?

MDT meeting

A weekly meeting is held with the core team, to review all HS patients. Members such as the topography engineer may not attend every meeting, joining instead where there is a particular need for their expertise.

Rapid holistic treatment

Patients presenting to a specialist and reporting comorbidity symptoms are seen on the same day by the appropriate related clinician.

EXECUTIVE SUMMARY  
Treatment



## Multi-disciplinary team (Spain) (2/2)



### 3. What are the next steps?

The centre is working to create an annual international meeting of multi-disciplinary teams.



### 3. What are the benefits and how are they measured?

- Of the 91 new patients<sup>1</sup> seen at the HS unit since its inception, only three have needed biologics, with the rest managed successfully on antibiotics.
- The KOL notes a reduction in the number of HS surgical procedures required since the introduction of the MDT, although exact numbers were not available.
- The high number of patients referred from other catchment areas (60% of all current patients) highlight the success and strong reputation of the centre.



### 5. What are the lessons for other centres in implementing this intervention?

- Create a business case identifying potential savings and benefits from an MDT to present to clinical leads at your centre.
- Identify the key influencers in each specialism, and focus on gaining their buy-in.
- The dermatology team at Hospital Manises is part of a larger inflammatory team, a set-up that facilitates collaboration. In more traditional settings where departments work independently of each other, consider how collaboration may be initiated and maintained.

EXECUTIVE SUMMARY  
Treatment



## Ultrasound imaging (Spain) (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

Ultrasound is used to determine disease stage accurately



### 1. What was the challenge?

The inflammatory process occurs subcutaneously and is difficult to diagnose accurately without invasive treatment.

The visible areas of the body do not necessarily give a clear indication of whether fistula or abscess formation is underway.



### 2. What is the intervention?

Ultrasound is therefore used to understand the disease severity more effectively, in particular the extent of fistula and abscess formation.

**How long has it been running?**

The intervention has run since the establishment of the HS unit, in 2009.

**What do they do?**

Ultrasound is used to gain an accurate picture of disease stage, allowing for effective treatment plan decisions, and reduced invasive treatments and surgeries.

EXECUTIVE SUMMARY  
Treatment



## Ultrasound imaging (Spain) (2/2)



### 3. What are the next steps?

A multi-centre study to validate the technique is currently in development.



### 4. What are the benefits and how are they measured?

The efficacy of ultrasound is currently under review. However the centre attributes the following to it:

- of the 91 new patients<sup>1</sup> seen at the HS unit since its inception, only three have needed biologics, with the rest managed successfully on antibiotics
- the KOL notes a reduction in the number of HS surgical procedures required since the introduction of the MDT, although exact numbers were not available.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify staff members with expertise in disease and technology.
- Develop measures to track the benefits of using the technology, in order to develop a robust business case for investment.
- Consider roll-out methods including specialist training or technician recruitment. Conducting ultrasound requires expert knowledge of its application and interpretation. If this does not exist in your centre consider a training programme to upskill staff, and visiting one of the leading centres to understand the process better.
- Link technology use throughout the pathway, such as with tele-health imaging.

EXECUTIVE SUMMARY  
Treatment

#### Notes

1. The centre segments patients into new and follow-on patients.



## Patient association (Spain) (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Silvia Lobo – HS patient and President of the society

A patient association promoting the welfare of HS patients and providing a support network for them



### 1. What was the challenge?

The association founder noted that patients experience dejection when considering a future with a chronic condition, and confusion about handling their care.

Asociación de Enfermos de Hidrosadenitis (ASENDHI) was therefore created to provide a support network to 5,000 HS patients across Spain.



### 2. What is the intervention?

An association of HS patients, focused on lobbying Government, developing local and national HS awareness and disseminating scientific information to patients.

**How long has it been running?**

The association was founded in 2008.

**What do they do?**

**Patient-clinician interaction**

ASENDHI has a large Facebook network in Spain, with 1,044 patients and 15 dermatologists from across 15 different centres in Spain.

They organise an annual conference which is attended by patients, dermatologists, gastroenterologists and other interested parties.

They have also set up Whatsapp groups which include key GPs, HS patients (mainly association leaders) and KOLs.

The association has close, regular contact with the Spanish Academy of Dermatology and Venereology (AEDV).

EXECUTIVE SUMMARY  
Follow up / ongoing



## Patient association (Spain) (2/2)

### Lobbying

ASENDHI has strong relationships with the Ministry of Health, Social Services and Equality.

### Patient support

The association organises bi-monthly HS meeting groups in Madrid in order to provide patients with an opportunity meet with other sufferers and discuss their experiences with clinicians, treatments and self-care.



### 3. What are the next steps?

ASENDHI are now looking to expand their offering into Mexico, and have already initiated contact with clinicians treating HS in that country.

The association has also recently hired a (non-patient) manager to oversee public relations, government relations, patient database and other administrative concerns such as funding and sponsorship.



### 4. What are the benefits and how are they measured?

According to the President of the association, the biggest indicators of success are:

- the constant increase in membership, which stood at 1,044 in February 2016.
- the increasing commitment of the Spanish Ministry of Health to HS provision.



### 5. What are the lessons for other centres in implementing this intervention?

- Understand the needs of your community and design the service offering accordingly.
- Identify lead experts in your region to help provide information for your group and develop links to clinicians.
- Identify key sources of funding to ensure long-term sustainability.
- Build a strong social media following to reach younger patients.
- Spain is a large country but with strong transport links, which allow for a widely spread community to meet in person easily. Where population size is small and unsupported by a robust transport network, consider partnering with other groups via digital platforms.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Topographical skin records (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

3D imaging tracks HS lesions over time



### 1. What was the challenge?

Patient symptom severity is difficult to assess over the long term.

Patients may not notice symptom deterioration if it is gradual enough. Reporting of symptoms may therefore be inaccurate. Assessing symptom progression and the associated treatment plan changes can therefore be correspondingly difficult to assess.



### 2. What is the intervention?

3D images of HS lesions are created and recorded in order to track the swelling of lesions over time.

How long has it been running?

Topographical records database started in September 2015.

What do they do?

A topography engineer photographs patients' lesions every time the latter visit the centre. This results in a photographic record which allows Hospital Manises to assess how the lesions are responding to treatment plans, and to alter these plans where a positive impact is not apparent.

EXECUTIVE SUMMARY  
Follow up / ongoing



## Topographical skin records (2/2)

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### 3. What are the next steps?

Staff are currently looking at ways to develop an integrated model to optimise the patient's follow up by drawing on the topographical skin records.



### 4. What are the benefits and how are they measured?

This is a novel approach in this field and the work is currently being evaluated with an aim to publish findings of the approach.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify an engineer to construct technology or identify technology solution. An engineer was engaged to ensure the technology worked with the centre's I.T. system, and to train clinicians to use the programme. Where financial constraints do not allow this, consider identifying existing products to use rather than aiming to develop new ones.
- Ensure capability to run technology exists and if not, train staff accordingly.
- Ensure supporting process are in place, e.g. communication with primary care.
- Develop a patient-centred approach to empower patients to manage their diagnoses.
- To encourage early adoption of the technology, consider incentivising and tracking usage.

EXECUTIVE SUMMARY  
Follow up / ongoing



## HS patient registry (Spain) (1/2)



### Centre: Hospital Manises, Valencia, Spain

Centre lead: Dr Antonio Martorell – dermatologist and HS lead

An HS registry collecting patient data information across their treatment pathway.



### 1. What was the challenge?

HS is poorly understood and patient data for analysis is limited

Tracking patient data will drive innovations in care across the patient pathway. This is a particularly useful consideration at a centre such as Hospital Manises, with its focus on novel treatments.



### 2. What is the intervention?

A full-time data manager oversees the data collection and management for a registry tracking patients with the aim of improving clinician understanding of HS.

How long has it been running?

Data collection was started in 2015.

What do they do?

Data is mainly collected during HS appointments and includes details on age, weight, height, family history, previous treatment, interventions and staging.

EXECUTIVE SUMMARY  
Follow up / ongoing



## HS patient registry (Spain) (2/2)

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### 3. What are the next steps?

The centre is developing retrospective and prospective epidemiological and clinical studies based on the registry data.



### 4. What are the benefits and how are they measured?

The aim is to use database information to recognise disease patterns, thereby improving understanding of patient needs and of treatment impact.

Additionally, the database may also evidence the success of interventions across the hospital.



### 5. What are the lessons for other centres in implementing this intervention?

- Hospital Manises has both a large population of HS patients, and a number of treatments that data can be collected for. Centres with smaller HS patient pools or treatment options may consider having a combined database which includes patients with similar or comorbid diseases.
- Identify process components along the patient pathway for tracking.
- Build a database and engage personnel with the required skill to manage this, and provide analysis.
- Establish appropriate governance and data protection processes to ensure your data safety.

EXECUTIVE SUMMARY  
Follow up / ongoing



# HS awareness programme (Canada) (1/3)



## Centre: NewLab Clinical Research – St John’s, Canada

Centre lead: Dr Wayne Gulliver – leadership of dermatology network

A training programme designed to raise awareness of HS amongst both primary and secondary clinicians



### 1. What was the challenge?

A lack of HS awareness amongst clinicians led to extensive delays in diagnosis and referrals.

The long diagnostic delay for HS – an average of seven years<sup>1</sup> – resulted, for some, in symptoms deteriorating to the point where surgery was required.



### 2. What is the intervention?

A training programme consisting of three modules delivered via a PowerPoint presentation.

How long has it been running?

The pack will be shared for the first time at the National Emergency Physicians’ conference, in summer 2016.

What do they do?

The modules present information across a number of areas, and are accessible by non-dermatology clinicians across primary and secondary care.

The areas explored are:

Clinical presentation

- Clinical presentation
- Symptoms
- Timeline of symptoms, highlighting chronic pattern of the inflammatory and suppurative process
- Presentation by gender, and body areas affected
- Typical presentation profile

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Referral

Notes

1. Zouboulis et al, Hidradenitis Suppurativa / Acne Inversa: criteria for diagnosis, severity assessment, classification and disease evaluation, 2015



# HS awareness programme (Canada) (2/3)

## Epidemiology

- Symptoms
- Timeline of symptoms, highlighting chronic pattern of the inflammatory and suppurative process
- Presentation by gender, and body areas affected
- Typical patient profile

## Pathogenesis and etiology

- Causes of HS, including sequence of pathogenic events
- Factors contributing to HS development

## Diagnosis

- Factors supporting diagnosis
- Diagnostic challenges
- Differential diagnoses

## Assessment tools

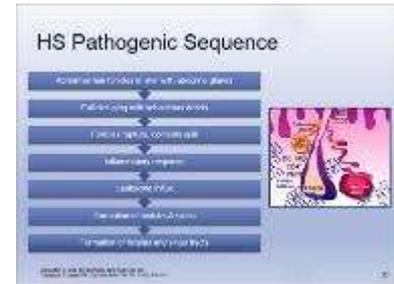
- Description and relative merits of
  - Hurley’s Clinical Staging
  - Sartorius Score
  - HS-PGA
  - HS Severity Index

## Holistic treatment

- Comorbidities
- Burden of disease and patient quality of life

## Current treatments

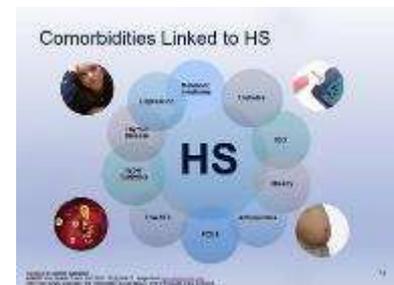
- Medical
- Surgical
- Considerations for adopting one or the other
- Local wound care
- Pain control



HS pathogenic sequence

Tool Name	Description	Purpose
Hurley's Clinical Staging	Divides HS into four stages based on the extent of disease and the presence of sinus and tracts.	To determine the extent of disease and to guide treatment decisions.
Sartorius Score	A 10-item questionnaire that assesses the impact of HS on a patient's quality of life.	To measure the impact of HS on a patient's quality of life.
HS-PGA	A 10-item questionnaire that assesses the impact of HS on a patient's quality of life.	To measure the impact of HS on a patient's quality of life.
HS Severity Index	A 10-item questionnaire that assesses the impact of HS on a patient's quality of life.	To measure the impact of HS on a patient's quality of life.

Overview of assessment tools



Overview of comorbidities

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
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## HS awareness programme (Canada) (3/3)



### 3. What are the next steps?

The training has recently been developed, and will be presented for the first time at the National Emergency Physicians' Conference (summer 2016).



### 4. What are the benefits and how are they measured?

There is anecdotal evidence that sharing the training materials with course organisers for discussion has already resulted in an increase in referrals for HS to the centre.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify a leader for project, ideally a specialist with an interest in HS, who is willing to coordinate the project.
- Collaborate with non-dermatology specialities to develop training material. St John's is a small region and collaboration between specialities is relatively straightforward. In larger areas, where there is less ease of access, looking to identify partners early and obtaining buy-in may help in spreading information.
- Identify appropriate platforms to disseminate training. In large regions you may want to consider digital dissemination or presenting at existing teaching sessions or symposia.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Referral



# Treatment algorithm (Canada) (1/3)



## Centre: NewLab Clinical Research – St John’s, Canada

Centre lead: Dr Wayne Gulliver – leadership of dermatology network

An algorithm outlining HS treatment, defining optimal treatment plans, sympathetic to the Canadian Healthcare landscape



### 1. What was the challenge?

The limited clinician awareness of HS resulted in ineffective treatments and poor understanding of treatment options.

Primary care clinicians in particular would not attend first line treatment at all, instead referring patient immediately.



### 2. What is the intervention?

The algorithm outlines a detailed process flow for the optimal treatment options of HS, both surgical and medical.

How long has it been running?

The algorithm was published in 2016 and is based on the European guidelines for HS.

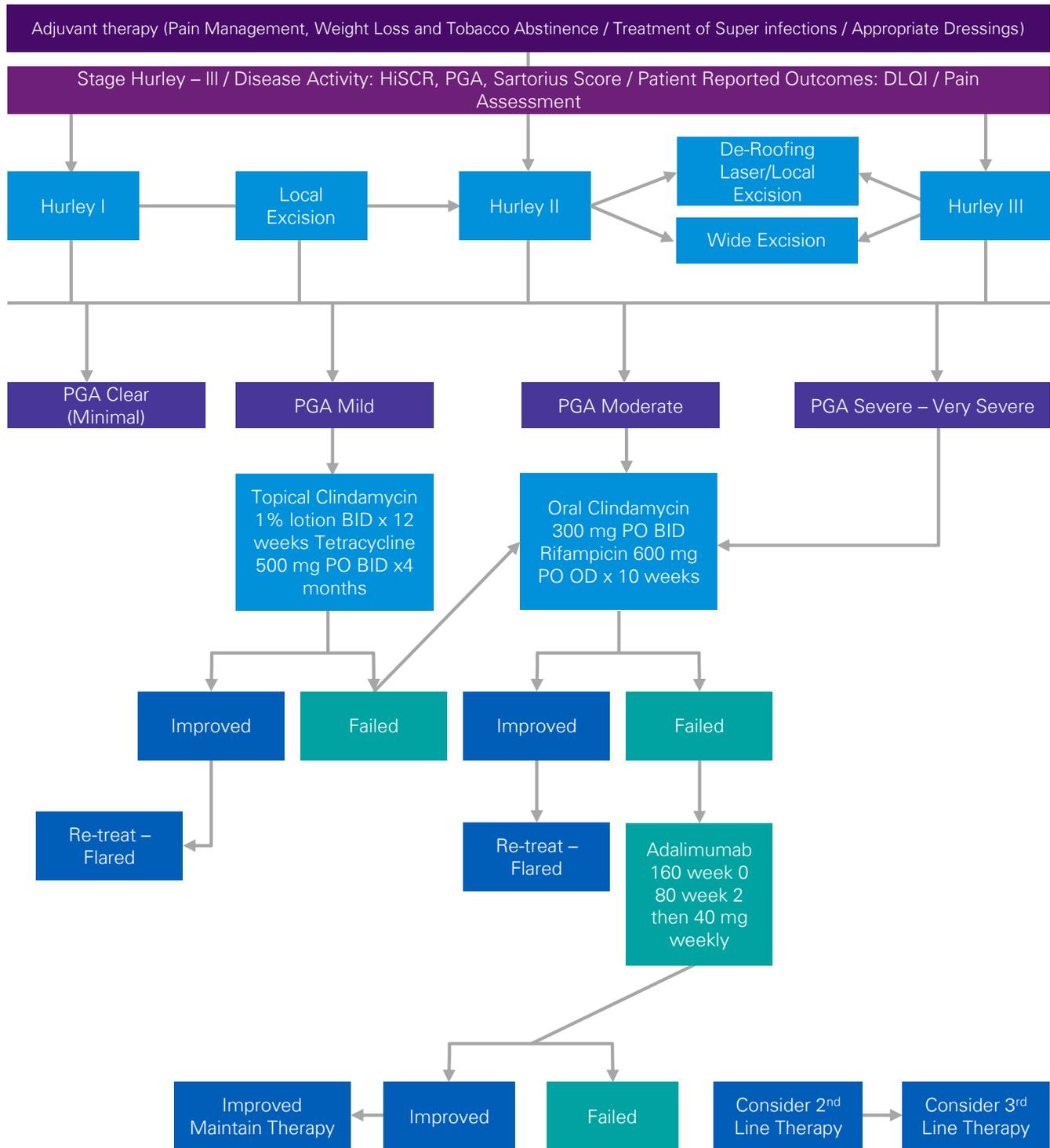
What do they do?

The algorithm appears in a paper titled ‘Evidence-based approach to the treatment of hidradenitis suppurativa / acne inversa, based on the European guidelines for hidradenitis suppurativa’. The algorithm is presented overleaf.

EXECUTIVE SUMMARY  
Treatment



# Treatment algorithm (Canada) (2/3)



EXECUTIVE SUMMARY  
Treatment

Notes:

1. Algorithm from: Gulliver et al, Evidence-based approach to the treatment of hidradenitis suppurativa/acne inversa, based on the European guidelines for hidradenitis suppurativa, 2016



## Treatment algorithm (3/3)

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### 3. What are the next steps?

No further actions are currently planned, as the algorithm has been published recently (at the time of writing this report).



### 4. What are the benefits and how are they measured?

The paper has been very recently published, so data on its impact is still to be gathered. However, construction of the algorithm has been based on a systematic review of data and therefore the algorithm should provide evidence-based benefits to patients.

Additionally, it is hoped that the algorithm will give non-dermatology clinicians the confidence to administer first-line treatment before referring patients. This will allow for earlier determination of whether further treatment is required.



### 5. What are the lessons for other centres in implementing this intervention?

- Disseminate information across a range of platforms to clinicians who may not receive this otherwise.
- Train clinicians as to how to follow the algorithm and potentially combine with wider HS training awareness programme.
- Track the use of the algorithm in patient population to ensure the guidelines are properly followed.

EXECUTIVE SUMMARY  
Treatment



## HS patient registry (Canada) (1/2)



### Centre: NewLab Clinical Research – St John’s, Canada

Centre lead: Dr Wayne Gulliver – leadership of dermatology network

The centre subscribes to an HS patient registry whereby patients currently under medical care are tracked



### 1. What was the challenge?

HS as a disease is poorly understood and therefore there is opportunity to improve patient care significantly.

It is hoped that tracking data of patients will drive innovations in diagnoses and referrals, and improve treatments for patients and their ongoing care.



### 2. What is the intervention?

The centre registers its patients to a registry. Details are updated by an administrative staff member after every visit.

The centre also subscribes to a database that tracks HS patients in Newfoundland and Labrador.

#### How long has it been running?

The registry has been running for 18 months, having opened in 2014. NewLab has subscribed to the registry since its inception.

#### What do they do?

Patients aged 18 years or older with HS, who are currently under medical care (regardless treatment type, if any), are followed as per standard of care for four years<sup>1</sup>.

The data is collected through physician office visits, medical charts and patient-reported outcomes are entered into an electronic data capture system. Variables collected include demographic characteristics, clinical signs and symptoms, methods of diagnosis, prior and current treatments for HS, concurrent conditions and concomitant medications, patient-reported outcomes, clinical assessments of patient status, disease severity and disease-related events<sup>1</sup>.

EXECUTIVE SUMMARY  
Follow up / ongoing

#### Notes

1. AbbVie H13-147 Hidradenitis Suppurativa (HS) Disease Registry Site Survey.



## HS patient registry (Canada) (2/2)

The centre also contributes to a database held at the Newfoundland and Labrador Centre for Health Information (NLCHI). NLCHI is able to identify and track HS patients based on International Classification of Diseases (ICD) 9 and 10 diagnostic codes, as well as hospital discharge diagnosis.



### 3. What are the next steps?

The centre would like to subscribe to as large and as global a registry as is available. Clinicians in Norway are currently considering how a global registry may be developed. Scandinavia, Italy and Europe also have registries for their own regions.

A research study has been proposed that would involve NLCHI working in collaboration with dermatologists, plastic surgeons, GPs and ER clinicians, to study of a cohort of 200-500 patients with 10-year retrospective data as well as prospective data. Research is ongoing and preliminary data has been identified. In a recent meeting of dermatologists, plastic surgeons and general surgeons, GPs and ER clinicians, at least 200 cases of HS were confirmed.



### 4. What are the benefits and how are they measured?

The centre feel that adding to the pool of knowledge about HS increases awareness of its prevalence and presentation, and allows for pattern recognition across patients, thereby improving understanding of patient needs and of treatment impact.



### 5. What are the lessons for other centres in implementing this intervention?

- Develop the required processes and paperwork/software for data capture.
- Establish appropriate governance and data protection processes to ensure your data is captured safely.
- Monitor upload of data on to the system to ensure regular entries and amendments.

EXECUTIVE SUMMARY  
Follow up / ongoing

#### Notes

1. AbbVie H13-147 Hidradenitis Suppurativa (HS) Disease Registry Site Survey.



# Multi-disciplinary wound clinic (1/3)



## Centre: NewLab Clinical Research – St John’s, Canada

Centre lead: Dr Tracy Brown-Maher – dermatologist, wound clinic lead

A general wound care clinic led by a dermatologist and plastic surgeon is run weekly in the community and attended by a variety of patients, including those suffering from HS



### 1. What was the challenge?

Local hospital surgeons often found their time taken up with managing ongoing care of wounds, which limited their capacity for new surgeries.

It was therefore decided to set up a wound clinic in the community, where a surgeon could assist on a multi-disciplinary team.



### 2. What is the intervention?

A weekly wound clinic, based out a local hospital, for general wound care, including HS wounds.

**How long has it been running?**

The clinic was set up 25 years ago.

**What does it do?**

#### Clinical organisation

The dermatologist is joined weekly by support staff – one wound care nurse, one community health nurse and trainees. Every four weeks, she is also joined by a plastic surgeon from the local hospital, who is able to see to several potential surgical cases at once, rather than through individual consultations. As the dermatologist and nurses have often seen these patients for several weeks before this, they are able to comment on specific indications suggesting the need for surgical intervention.

#### Patient care

There is a high focus on patient involvement and treatment decisions are made jointly wherever possible, in order to maximise adherence.

EXECUTIVE SUMMARY  
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## Multi-disciplinary wound clinic (2/3)

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Nurses provide patients with general information on self care, so that they can make themselves comfortable between visits. They also provide ad-hoc advice specific to the patient's situation, e.g. suggesting methods to ensure water was made safe to use in wound cleaning, to a patient working in remote areas where clean water was not always available.

### Research

The centre engages in several studies, both medical and those on patient QoL. This allows them access to new and innovative ideas, which inform their treatment.



### 3. What are the next steps?

The wound clinic will shortly be supplemented by a multi-disciplinary HS clinic at NewLab. At this clinic, a vascular, plastic and general surgeon will attend on a rotating basis, so as to address the full spectrum of surgical needs.



### 4. What are the benefits and how are they measured?

Interviewees state that patient concordance is high due to clinicians taking the time to discuss treatment options, and thereby helping patients own the treatment decision. Patients are also better able to manage their care at home as a result of the clinic. Where the treatment is not working for them, patients are able to articulate the situation clearly to the staff.

In addition, the dermatologist and surgeon have built a stronger relationship, allowing for smooth collaboration between the two parties. For example, the dermatologist is able to advise the surgeon on the best topical treatment to use after surgery on a specific wound type.



### 5. What are the lessons for other centres in implementing this intervention?

- Identify patient need in the area in order to determine clinic services offered.
- Identify a suitable facility to host the clinic. In order to cover the catchment, multiple wound care clinics in the community may be required.
- Create a business case identifying potential savings from the intervention.

EXECUTIVE SUMMARY  
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## Multi-disciplinary wound clinic (3/3)

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- Recruit a dermatologist, surgeon and multi-disciplinary team to run clinic. In larger regions, co-ordination is likely to require senior leaders from the centres.
- Where there is a wide range of surgical needs, consider having a plastic, general and vascular surgeon on rotation at the clinic. This also eases the time burden on each.

EXECUTIVE SUMMARY  
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## GP education (1/2)



### Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

A team of dermatologists run an HS training session for general practitioners (GPs) in their region



### 1. What was the challenge?

There is low awareness of the disease amongst GPs.

As a result, patients often do not get referred correctly, or referred at all, as the GPs do not realise that the symptoms displayed are indicative HS.



### 2. What is the intervention?

The team provide annual training to GPs in their region for various dermatology conditions.

**How long has it been running?**

The campaign started a year ago, in 2015. At this first session, GPs were educated in psoriasis.

**What do they do?**

Three of the dermatologists from the hospital will provide a day-long session training in September 2016, highlighting

- the symptoms of HS
- common mis-diagnoses made
- how to differentiate HS from conditions with similar symptoms
- the ways in which the hospital can help HS patients that are referred to them.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
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## GP education (2/2)



### 3. What are the next steps?

NA; the HS training is to take place in September 2016.



### 4. What are the benefits and how are they measured?

It is hoped that the training will equip GPs to better recognise HS and drive up referrals as a result. It is also hoped that, in recognising and referring mild cases, the GPs will facilitate the centre in providing early treatment, which the centre feel is more efficacious than late stage treatment.



### 5. What are the lessons for other centres in implementing this intervention?

- In countries where there is a national body that holds the details of all GPs, consider approaching the body in order to develop a mailing list.
- Approach funding bodies where available in order to finance the intervention.
- Consider running the training on a weekend or during a quiet period so that
  - it is easy for GPs to attend
  - several members of the HS team can deliver the training together.
- Use images wherever possible to show symptoms.
- Identify and target new GPs who are actively willing to learn about little known conditions.

EXECUTIVE SUMMARY  
First symptoms, diagnosis  
Referral



## Secondary clinician education (1/2)



### Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

Dermatology staff deliver annual training to practitioners from other specialties in the hospital



### 1. What was the challenge?

Staff across the hospital were seeing common conditions such as pressure ulcers and needed support in understanding how to deal with these.

As a result, a decision was made by hospital management to provide training for the staff.



### 2. What is the intervention?

An annual training day is run by Dermatology staff for other practitioners.

**How long has it been running?**

The awareness days were started in 2006.

**What do they do?**

Dermatologists from the hospital will provide a day-long session training, highlighting

- the symptoms of HS
- common mis-diagnoses made
- how to differentiate HS from conditions with similar symptoms
- the ways in which the hospital can help HS patients that are referred to them.

EXECUTIVE SUMMARY

First symptoms, diagnosis  
Referral



## Secondary clinician education (2/2)



### 3. What are the next steps?

NA; the HS training is to take place after September 2016.



### 4. What are the benefits and how are they measured?

It is hoped that the training will equip clinicians to better recognise HS and drive up referrals as a result. It is also hoped that, in recognising and referring mild cases, the clinicians will facilitate the centre in providing early treatment, which the centre feel is more efficacious than late stage treatment.



### 5. What are the lessons for other centres in implementing this intervention?

- Consider approaching management with a case for providing training, as their buy-in is crucial to making the intervention financially viable.
- Consider running the training on a weekend or during a quiet period so that
  - it is easy for practitioners to attend
  - several members of the HS team can deliver the training together.
- Use images wherever possible to show symptoms.

EXECUTIVE SUMMARY  
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## Multi-disciplinary team (Italy) (1/2)



### Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

Multiple specialisms' input is co-ordinated and offered in order to optimise medical, surgical and psychological treatment



### 1. What was the challenge?

Patients had multiple needs and required input from several specialisms.

These needs were not only with regards to medical and surgical treatment, but also encompassed lifestyle factors and psychological concerns.



### 2. What is the intervention?

The centre are looking to move from the current informal style of collaboration, to set up a multi-disciplinary team (MDT) with a range of members.

**How long has it been running?**

NA. The centre are in the process of setting up the MDT.

**What do they do?**

#### Current set-up

**Surgery:** Dermatology work closely with one **proctologist** for any major anal or rectal surgery. Working with Plastic Surgery is difficult as the latter are a very busy team. Minor surgical procedures are undertaken by one of the Dermatologists.

**Other:** Where patients need input from a **psychologist** and/or **nutritionist**, this is offered. The department uses the hospital's internal referral system to refer any interested patients.

EXECUTIVE SUMMARY  
Treatment



## Multi-disciplinary team (Italy) (2/2)

### Planned

The department are in the process of expanding their network to include a

- surgeon with expertise in operating in the mammary region (priority)
- psychologist
- nutritionist
- endocrinologist
- gastroenterologist
- Gynaecologist.

Once the department have established an agreement for collaboration, they aim to hold MDT meetings.

- Meetings will be called as and when a case requiring multi-disciplinary input arises.
- Each meeting will focus on one specific patient/case.
- Attendees will depend on the needs of the case in question.



### 3. What are the next steps?

Once the MDT is fully established, the team will consider holding more longer, more regular meetings, where they can discuss several cases that have broadly similar requirements in terms of specialists' involvement.



### 4. What are the benefits and how are they measured?

Patients will receive holistic care, with all the involved clinicians having knowledge of the treatment being administered to the patients by their colleagues in other settings. This results in improved patient satisfaction.



### 5. What are the lessons for other centres in implementing this intervention?

- Prioritise involvement of clinicians who can address the symptoms most commonly seen in your setting.
- Schedule and run meetings in the manner best suited to your setting and team type; a smaller team may be able to call meetings with little notice, whereas a large one may prefer to have set dates in the diary.

EXECUTIVE SUMMARY  
Treatment



# Laser imaging (1/2)



## Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

A laser scanner is used to create a topographic record of lesion and wound evolution



### 1. What was the challenge?

It was difficult to track lesion evolution and therefore treatment efficacy

It was difficult for both patients and clinicians to gauge whether a lesion differed slightly from how it had appeared at the last visit.



### 2. What is the intervention?

A laser scanner is used to gain a topographic image of the lesion.

How long has it been running?

The laser scanner has been used since 1999.

What do they do?

A small, hand-held laser camera is used approximately once every 4 weeks to photograph the lesion. The image uploads immediately to the clinician's computer, where they manually draw on the outline to delineate the area to be measured. The software then calculates lesion perimeter, area and maximum depth.



### 3. What are the next steps?

No further evolution of the intervention is currently planned.

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Treatment



## Laser imaging (2/2)



### 4. What are the benefits and how are they measured?

Clinicians are able to track even minor changes to the lesion size and depth, and therefore determine whether a given treatment is working, or whether it needs to be changed.

Where a post-surgical wound is being monitored, quick identification allows for rapid treatment change, resulting in improved recovery time and pain minimisation.



### 5. What are the lessons for other centres in implementing this intervention?

- Prepare for the initial investment; enter conversations with budget decision makers early in order to give enough time to weigh up the purchase decision.
- Ensure staff are shown how to use the hardware and software, and that all computers are updated with the software, to avoid inconsistency in image recording.

EXECUTIVE SUMMARY  
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## Ultrasound imaging (Italy) (1/2)



### Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

An ultrasound machine is to gain dermal and sub-dermal images of lesions and wounds



### 1. What was the challenge?

It was difficult to assess disease severity from topographic measurement alone.

This meant that clinicians were unable to track sub-dermal tissue changes, or to gauge how deep the diseased tissue ran.



### 2. What is the intervention?

**An ultrasound machine is to gain images of the skin and soft tissue of lesions and wounds**

#### How long has it been running?

The ultrasound has been used since 2012.

#### What do they do?

An ultrasound image is taken every 3-4 weeks with a high frequency 20 MHz machine. Comparing images over time allows the centre to track the state of the tissue under the lesion/wound, and to therefore ensure that any deterioration is identified and treated.



### 3. What are the next steps?

The centre are currently trialling the use of higher MHz ultrasound scanners, which can:

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## Ultrasound imaging (Italy) (2/2)

- Create much higher resolution pictures therefore allowing clinicians to identify features such as fistulas up to 5mm deep.
- Measure blood flow in the region, thereby allowing clinicians to gauge whether the patient is having an inflammatory response, This may allow for altering treatment plans towards or away from anti-inflammatory drugs as required.



### 4. What are the benefits and how are they measured?

Clinicians are able to track dermal and sub-dermal changes and therefore determine whether a given treatment is working, or whether it needs to be changed.

Where a post-surgical wound is being monitored, quick identification allows for rapid treatment change, resulting in improved recovery time and pain minimisation.

A study is currently being run to measure the benefits of using the newer ultrasound machines over the ones currently in place. The study looks at a patient group with eczema and psoriasis on the palms, as the two conditions are difficult to tell apart. Images are taken with both scanners in order to see if clinicians are better able to differentiate the conditions when using the more powerful machinery.



### 5. What are the lessons for other centres in implementing this intervention?

- Seek management buy-in early as the tool is an expensive one.
- Staff will need training to use the machinery; make sure that this is accounted for.
- Keep in mind that the wand size means that building up a picture of large areas will be time consuming.

EXECUTIVE SUMMARY  
Treatment



## HS assessment tool (1/2)



### Centre: Ospedale Santa Chiara – Pisa, Italy

Centre lead: Dr Marco Romanelli - dermatologist

A new assessment tool to measure HS severity has been proposed



### 1. What was the challenge?

Current staging methods are either imprecise or time-consuming.

They have been developed either for general dermatological conditions, specifically for another condition, or to measure therapeutic responses (and are therefore not always sensitive enough to pick up on mild HS).



### 2. What is the intervention?

One of the staff members is first author on a paper proposing a new disease severity assessment tool.

How long has it been running?

NA. The paper was published in 2015 but the tool is not yet used in the setting.

What do they do?

An HS-tailored, composite, dynamic score, named the Acne Inversa Severity Index (AISI) was designed to include a physician-rated assessment that considers the type of lesions occurring and the affected body sites.<sup>1</sup>

Additionally, a 0-10 visual analog scale (VAS), named Illness-VAS, was created to assess a patient's pain, discomfort, and disability due to HS.<sup>1</sup>

The authors compared AISI with other validated measurements, namely the Hurley staging classification, modified Sartorius score, and the Dermatology Life Quality Index (DLQI), and was found to be correlated to these.<sup>1</sup>

EXECUTIVE SUMMARY  
Treatment

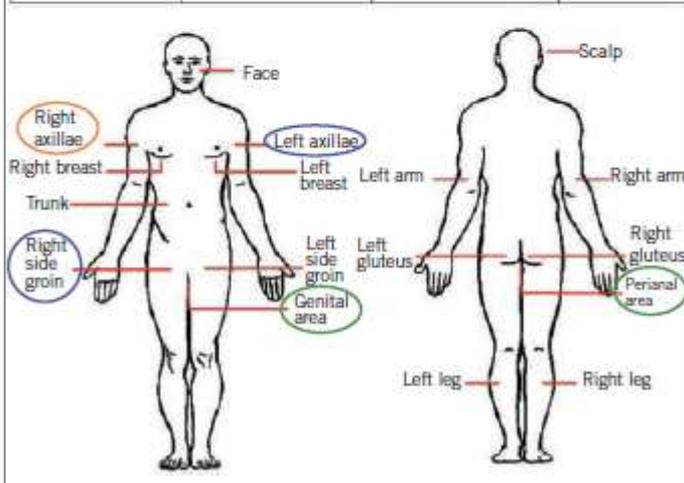
#### Notes

1. Chiricozzi et al, AISI: A New Disease Severity Assessment Tool for Hidradenitis Suppurativa, 2015



# HS assessment tool (2/2)

A.I.S.I.	If observed	Multiplied by the overall number of sites where the lesion occurs	Subtotal
Comedonic lesion	1 point		
Abscess / Inflammatory nodule	2 points	2	4
Sinus tract	3 points	2	6
Keloid, fibrotic adherence	4 points	1	4
Fibrosclerotic inflammatory plaque	5 points		
Illness-VAS (pain-discomfort-disability)	0-10	///////	6
<b>Total</b>	///////	///////	<b>20</b>



The AISI proposes assigning a score to different features of HS (e.g. 2 points to nodules, 3 points to sinus tracts). The score is then multiplied by the number of sites where the lesion occurs, and the scores are added together, along with the illness VAS.



### 3. What are the next steps?

The KOL feels that the communication between specialties is somewhat disjointed, and that this will become more of a problem as the number of HS patients grows, not least as the specialties are based at different locations and do not have any meetings together. For this reason, the centre would consider the feasibility of having surgeons, psychologists and dieticians on-site down the line, either employed by the dermatology department, or attending regular clinics.



### 4. What are the benefits and how are they measured?

The range of treatments improves the patients' QoL and gives them tools to deal with the physical and mental impact of the disease.



### 5. What are the lessons for other centres in implementing this intervention?

- Initiate and maintain clear lines of communication with other specialists involved in the treatment of HS.

EXECUTIVE SUMMARY  
Treatment



## Multi-disciplinary team (Dubai) (1/2)



### Centre: Rashid Hospital – Dubai, UAE

Centre lead: Dr Anwar Al-Hammadi - dermatologist

The department works with surgeons, dieticians and psychologists to provide holistic support



### 1. What was the challenge?

HS patients require input from a range of specialties to address their different needs.

These needs can be medical, surgical, psychological and / or dietary.



### 2. What is the intervention?

The centre refers patients to other hospital departments as well as other centres in order to give patients access to surgeons, wound care, dietary advice and psychological treatment.

**How long has it been running?**

N/A. There is no formal programme.

**What do they do?**

#### Internal collaboration

Dermatologists refer to the hospital's plastic surgery and psychology department, and with their wound care clinic, to arrange for the provision of their services to HS patients who require them.

#### External collaboration

Rashid Hospital also refer to a local centre that is not part of the hospital, but that can provide dietician support, as this is not available at the hospital.

EXECUTIVE SUMMARY  
Treatment



## Multi-disciplinary team (Dubai) (2/2)



### 3. What are the next steps?

The KOL feels that the communication between specialties is somewhat disjointed, and that this will become more of a problem as the number of HS patients grows, not least as the specialties are based at different locations and do not have any meetings together. For this reason, the centre would consider the feasibility of having surgeons, psychologists and dieticians on-site down the line, either employed by the dermatology department, or attending regular clinics.



### 4. What are the benefits and how are they measured?

The range of treatments improves the patients' QoL and gives them tools to deal with the physical and mental impact of the disease.



### 5. What are the lessons for other centres in implementing this intervention?

- Initiate and maintain clear lines of communication with other specialists involved in the treatment of HS.

EXECUTIVE SUMMARY  
Treatment



# Appendix

## 6.2 Centre details



## 6. Centre details

### 6.1 NewLab Research Lab, Canada



#### 6.1.1 Centre Overview



##### Key information



St John's, Canada  
Lead KOL: Dr Wayne Gulliver

##### Practitioners

###### A total of 11 clinics, served by:

- eight dermatologists
- five plastic surgeons
- 20 general surgeons, one of whom supports extensively with HS care.

##### Centre features

There is **strong collaboration across the dermatology care providers in St John's**, with 11 clinics working closely together. The clinic profile is:

- one hospital-based clinic
- eight private clinics
- two dermatology based surgery clinics which may be used for minor surgical procedures in HS patients

Of the constituent clinics, NewLab Research Centre is headed by Dr Wayne Gulliver and other dermatologists who have a specific interest in HS.

##### Patient pool

- 50 HS patients, cohort growing.
- 550k surgery patients.
- 300k dermatology patients.

##### Catchment area

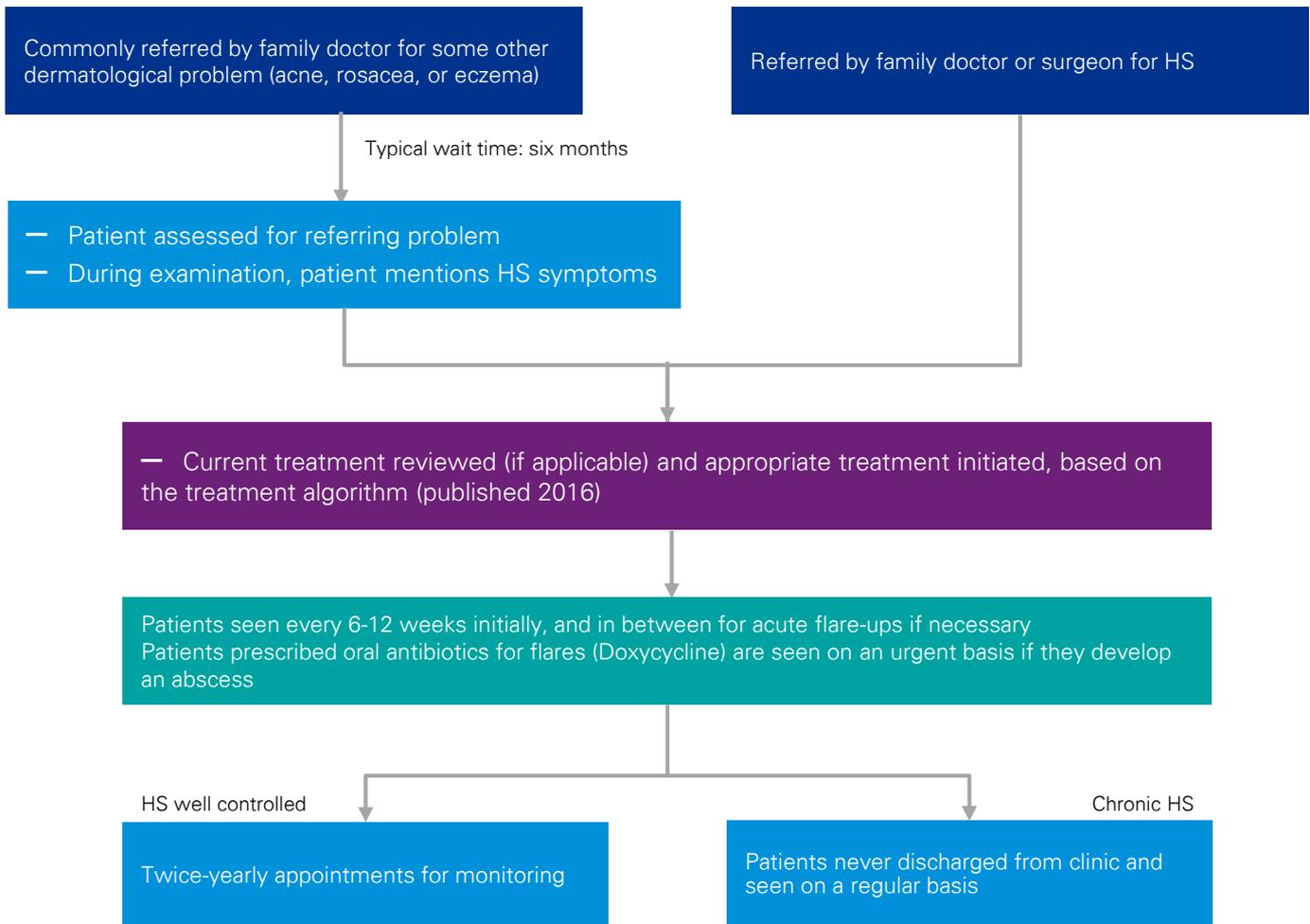
- East coast of Newfoundland.
- Population: ~300k.



**Estimated referral routes**

- Patients referred specifically for HS treatment:
  - family doctor: 80%
  - surgeons: 20%.
- The majority of patients who end up being seen for HS are initially referred for other issues such as eczema, rosacea or acne. On the first visit, many do not mention HS symptoms as they are unaware that the dermatologist understands and treats the disease.
- Referrals from other dermatologists in the network are rare, as all of these are familiar with HS, and can diagnose and treat it with confidence. However, NewLab is in the process of setting up a dermatology surgery clinic. Once this is running, they expect to start receiving referrals from other dermatologists who do not have surgical facilities in their own settings.

**Typical patient journey**





## 6.1.2 Challenges, interventions and benefits



We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these

	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	(1) Delayed presentation to medical practitioners due to lack of patient awareness of symptoms or patient embarrassment	(1) Delay in diagnosis due to: - limited clinician recognition of HS - diagnosis criteria and guidelines not shared widely amongst clinicians	(1) Lack of, and inappropriate referrals resulting in patient delays for up to seven to eight years (2) Limited transfer of patient history causing delays in commencing treatments	(1) Primary care attempt minimal treatment plans (2) Access to specialists and treatments for specific cohorts is limited due to financial constraints	(1) Hospital capacity reduced from wound follow-up demand (2) Low patient concurrence to medical treatment and lifestyle choices (3) HS leads to wider patient psycho-social issues affecting patient happiness
Interventions		(1) HS awareness training programme for clinicians	(1) HS awareness programme for clinicians	(1) A treatment algorithm designed by HS experts (3) HS registry to track disease	(1) Multi-disciplinary wound clinic in the community
Stated benefits		(1) Improved speed of referrals due to quicker diagnosis from clinicians (1) Administration of initial treatment by primary care practitioners (PCPs) leading to quicker understanding of treatment response	(1) Condition stabilised early through quicker referral to specialists for treatment management	(1) Improved access resulting in the patient not requiring to travel to a specialist (3) Research leading to improving treatment through data capture and analysis	(1) Improved hospital efficiency, with focus only on operative surgery (1) Improved access for patients



## 6.1.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**



### HS awareness programme

Work with specialists in comorbidity and co-treatment fields to develop training materials; identify channels to present training through.

### Treatment algorithm

Adapt algorithm to suit regional needs and preferences, and share with clinicians via training and online platforms.

### HS patient registry

Ensure resource and time is available to capture data accurately and update registry regularly.

### Multi-disciplinary wound clinic

Observe similar clinics in settings where these exist, in order to develop an understanding of operational requirements.



## 6.2 Sunnybrook Health Sciences Centre, Canada



### 6.2.1 Centre Overview



#### Key information



Toronto, Canada  
Lead KOL: Dr Neil Shear

#### Practitioners

- Nine dermatologists, ~six of whom will see HS patients
- Five nurses

#### Centre features

- Premises are only rented from the hospital, allowing the department a high degree of decision-making freedom
- One of the centre dermatologists, has a **specific interest in HS**.
- HS **research focuses on both physical and mental issues associated with HS**, and allows the centre to better provide holistic care.
- The senior administrator is also an HS sufferer, and her **first-hand understanding** enables her to provide ad-hoc support to patients contacting the centre.
- There is a **strong team ethos**; all interviewees commented on being able to rely on colleagues.
- Centre staff are **willing to try bold treatments**, including innovative treatment mixes. The relatively large number of dermatologists with HS experience allows for regular discussion around treatments.

#### Patient pool

- Approximately 40,000 patients overall per annum.

#### Catchment area

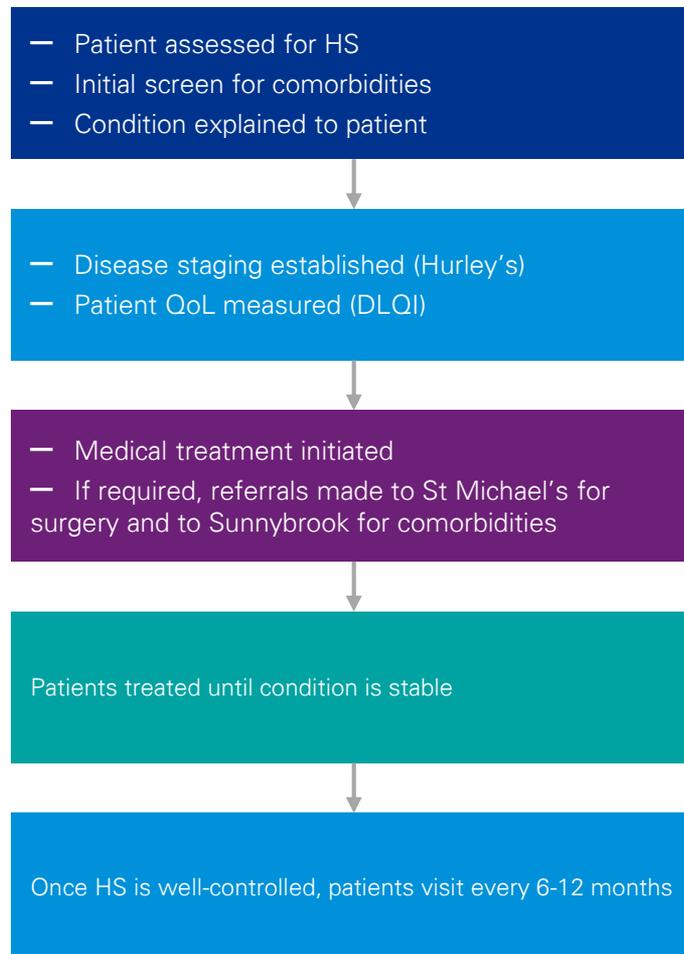
- Greater Toronto area.
- Population: 5m – 6m.



### Estimated referral routes

- Family doctors: 70%
  - Of these referrals, a growing number are now specifically for HS rather than undiagnosed or misdiagnosed ones. The KOL feels that this is driven by patients finding out about HS more easily on the internet as information on the topic grows.
- Surgeons from surgeon-dermatologist network: 15%
- Other dermatologists: 15%

### Typical patient journey





## 6.2.2 Challenges, interventions and benefits

We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these.



	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	<p><b>Patients stigmatised</b> when presenting with initial symptoms</p>	<p><b>Delayed time to diagnosis</b> due to limited clinician recognition of HS</p>	<p><b>(1) Incomplete history</b> of disease in many patients  <b>(2) Clinicians sometimes reluctant to deal with HS patients</b></p>	<p><b>(1) Disease mechanism poorly understood</b>, with correct treatment difficult to identify  <b>(2) High patient expectations</b>, with sufferers expecting a cure  <b>(3) Funding for biologics</b> difficult to obtain due to unclear payer / insurer criteria  <b>(4) Ancillary treatment</b> such as laser hair removal <b>not always covered</b> by payers / insurers</p>	<p><b>(1) Patients' quality of life impacted</b> by physical and mental impact of HS</p>
Interventions			<p><b>(1,2) Multi-disciplinary working</b>, with surgeon-dermatologist network to refer patients quickly</p>	<p><b>(2) Dedicated dermatology nursing</b> care team</p>	<p><b>(1) Multi-disciplinary working</b>, including addressing ongoing wound care and psycho-social needs</p>
Stated benefits			<p><b>(1,2) Timely access to surgery</b> for patients requiring this  <b>(1,2) Referral to dermatology</b> for patients incorrectly directed to surgery  <b>(1,2) Improved treatment administration</b> due to fuller picture of disease being captured</p>	<p><b>(2) Increased patient satisfaction, and confidence</b> in treatment administered</p>	<p><b>(1) Improved physical and mental comfort</b> as patients empowered to deal with ramifications of HS</p>



## 6.2.4 Key replication lessons for other centres

---

**We asked the interviewees to identify the key factors for the successful replication of the interventions.**



### Multi-disciplinary working

Design working practices that work with involved parties' budgets and the region's reimbursement procedures. Consider formalising interactions where large centres are involved.

### Dedicated dermatology nurses

Work within regulatory and funding constraints to develop nursing staff who can offer high quality dermatology care.



### 6.3 Roskilde Sygehus, Denmark



#### 6.3.1 Centre Overview



##### Key information



Roskilde, Denmark  
Lead KOL: Professor  
Gregor Jemec

##### Practitioners

- HS nurses
- One project nurse
- Approximately ten dermatologists, of whom
  - two to four are HS specialists
  - one is dedicated to HS patients and responsible for the laser surgery procedures for these.

##### Centre features

- There is a **strong culture of research** at the centre; there are several doctoral and post-doctoral candidates working under the centre lead, with a number focusing specifically on HS.
- **Residents offer comprehensive clinical support** to the doctors, including having their own patient list at each HS clinic. This allows for shorter waiting lists, and each patient gets to spend more time with their clinician, thereby fostering deeper understanding and trust.
- Staff have a **good understanding of patients' wider needs**.
  - Clinicians provide informal education sessions during patient visits, using posters to indicate areas that may be affected. Patients are also given informational leaflets which have been created at the centre.
  - They also discuss treatment options, keeping in mind patients' preferences and budgets, and prescribing those medicines that patients will be able to afford. Anecdotally, it is noted that this positively impacts adherence.
  - One staff member has developed a template on which the prescription drug and methods of use can be noted, and handed to patients (patients are not handed the actual prescription as these are directly and electronically transmitted to pharmacies). The method is helpful for patients who are unsure about whether they have had the same drug before, and again is felt to encourage compliance with the treatment plan.
- The centre **focuses on maximising patient satisfaction and engagement**, with a staff member dedicated to the role. In conjunction with their research work, this allows them to conduct surveys, ranging from single patient interviews to focus groups and questionnaires.
- The centre sees an **unusually large number of patients outside the average age bracket for HS**, including children, and adults past middle age. This is possibly due to the centre's reputation for HS treatment, and the relatively high level of disease awareness in the region.



**Patient pool**

- Total patients (2015): 4,100 active patients.
- HS patients (2015): 370 active patients (~9% of total dermatology patients).

**Catchment area**

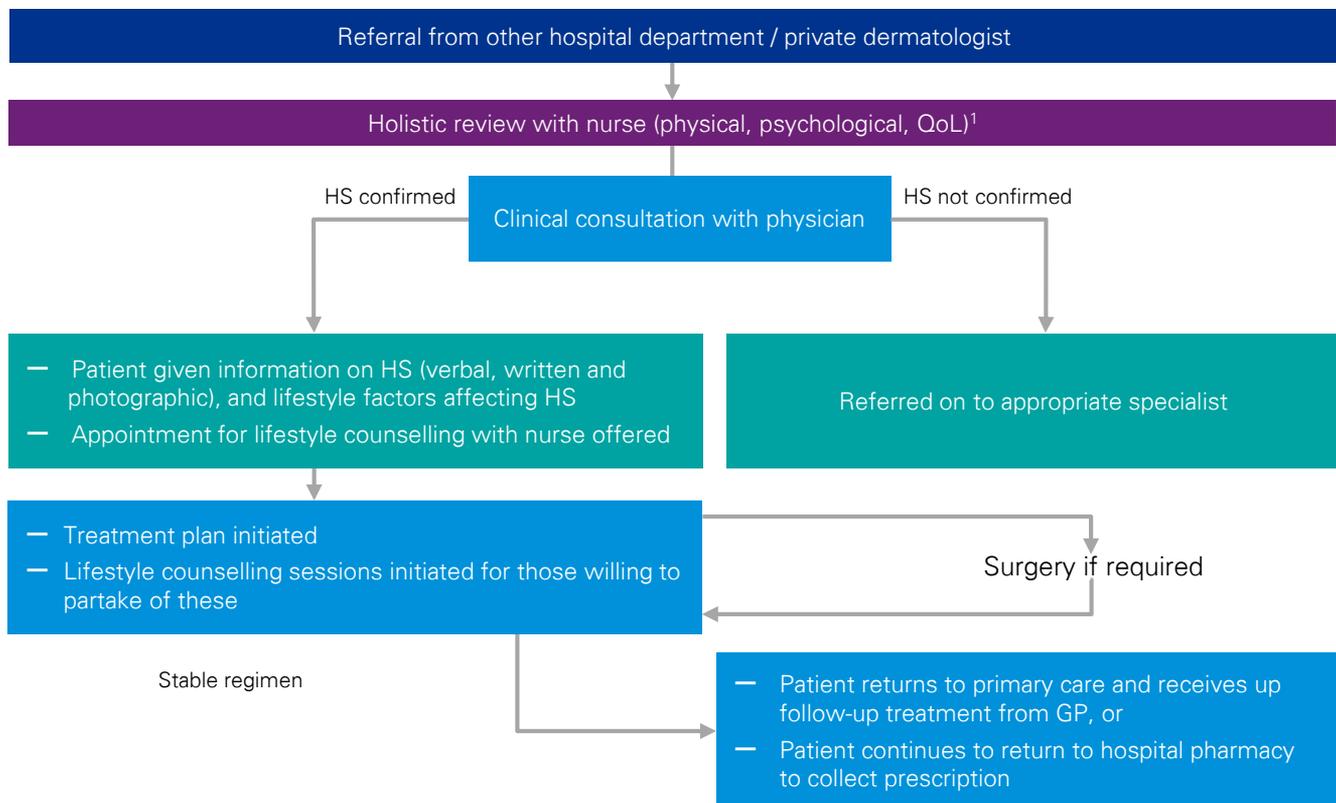
- Roskilde Sygehus serves all of Denmark.

**Referral routes**

- Other hospital departments: 70%.
- Private dermatologists: 28%.
- GPs: 2%.

The unusual ratios arise as Roskilde Sygehus works within a system where the bulk of the referrals accepted are from other hospitals.

**Typical patient journey**





## 6.3.2 Challenges, interventions and benefits

We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these.



	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	(1) <b>Patient reluctance to approach clinicians</b> due to embarrassment or unawareness	(1) <b>Delayed time to diagnosis</b> due to limited clinician recognition of HS	(1) <b>Multi-modal treatment</b> difficult to coordinate under certain reimbursement regimens	(1) Lifestyle choices lead to <b>delays in surgery</b> (2) <b>Psychological impact of HS</b> leaves patients poorly equipped to optimise self-care (3) <b>Lack of robust, outcome-based measures</b> for clinicians due to data gaps (4) <b>Patients' lack of awareness, and mistrust of healthcare system</b> can cause reluctance in complying with treatment plans	(1) <b>Financial constraints</b> on patients due to difficulty in maintaining jobs (2) Need for <b>repeat treatment impacts clinician capacity</b> for new cases (3) Some <b>patients discontinue treatment</b> once symptoms improve, resulting in flares (4) <b>Long recovery period</b> due to deep surgical excision
Interventions	(1) <b>Patient association</b> awareness campaign		(1) <b>Multi-disciplinary team (MDT)</b> , employing a mix of formal and formal collaboration	(1,2) <b>MDT</b> , offering lifestyle counselling and psychiatric support (2) <b>Motivational support</b> to patients by nurses (3) Research to <b>develop</b> clinical and Quality of Life (QoL) outcome <b>measures</b> (4) <b>HS awareness days</b> to educate patients and build trust	(1,2) <b>National review of HS</b> to raise disease profile across hospitals and improve reimbursement (3) <b>Treatment plans designed with patients</b> , after conversation about their preferences ( <i>no case study</i> ) (4) <b>CO<sub>2</sub> laser surgery</b> to minimise excision
Stated benefits	(1) <b>Increased referrals</b> due to improved HS recognition		(1) <b>Holistic patient treatment</b> improving HS patients' QoL	(1,2,3,4) Increased patient trust and understanding, resulting in <b>improved effort at adherence and lifestyle changes</b> (2) Nurses better equipped to provide <b>high-quality support care</b> (3) Improved ability to <b>track and monitor outcomes</b>	(1,2) <b>Improved care</b> resulting in higher QoL (3) Increased patient trust and understanding, resulting in <b>improved effort at adherence</b> (4) <b>Reduced pain and time to mobility</b> for patients after surgery



## 6.3.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**



### National review of HS

Maintain persistence, and work towards developing data that supports the case for change.

### Annual HS awareness day

Develop a programme that addresses local needs, keeping in mind staffing and funding requirements.

### Multi-disciplinary team (MDT)

Consider the operational style that will work best for your setting, and keep in mind the funding regimen in your area, as this will influence the breadth of attendees and meeting regularity.

### Develop outcome measures

Collaborate both internally and externally with colleagues engaged in similar or complementary work in order to develop outcomes that are robust and universally applicable.

### Patient association

Support set up at the centre by identifying and introducing potential members. Approach industry bodies to help fund campaigns.

### CO<sub>2</sub> laser surgery

Explore options to jointly use equipment with other departments. Consider how to develop a business case in the absence of comparative studies.

### Motivational support

Identify staff members to oversee initiative and ensure sustainability by following up initial training with 'top-up' sessions and monitoring.



## 6.4 Rashid Hospital, Dubai



### 6.4.1 Centre Overview

#### Key information



Dubai, UAE  
KOL: Dr Anwar Al-Hammadi

#### Practitioners

- 15 dermatologists.
- Six nurses.

#### Centre features

- The centre is a **tertiary body of Rashid hospital, a local public university hospital.**
- Hospital management trust the clinicians' prescription decisions. The centre has **fast, easy access** to even the most expensive medication, and clinicians are **permitted to prescribe off-label** drugs.
- **All patients are made familiar with their treatment plan**, including potential future steps, should the current treatment fail. This improves adherence as patients are confident that their treating physician will move on to another treatment once the current one has been evaluated.
- Nurses at the centre provide wound care for minor wounds. Significant wounds are seen to at Rashid hospital.

#### Patient pool

- ~20k patients seen at centre in 2015, of which ~1% we HS patients.

#### Catchment area

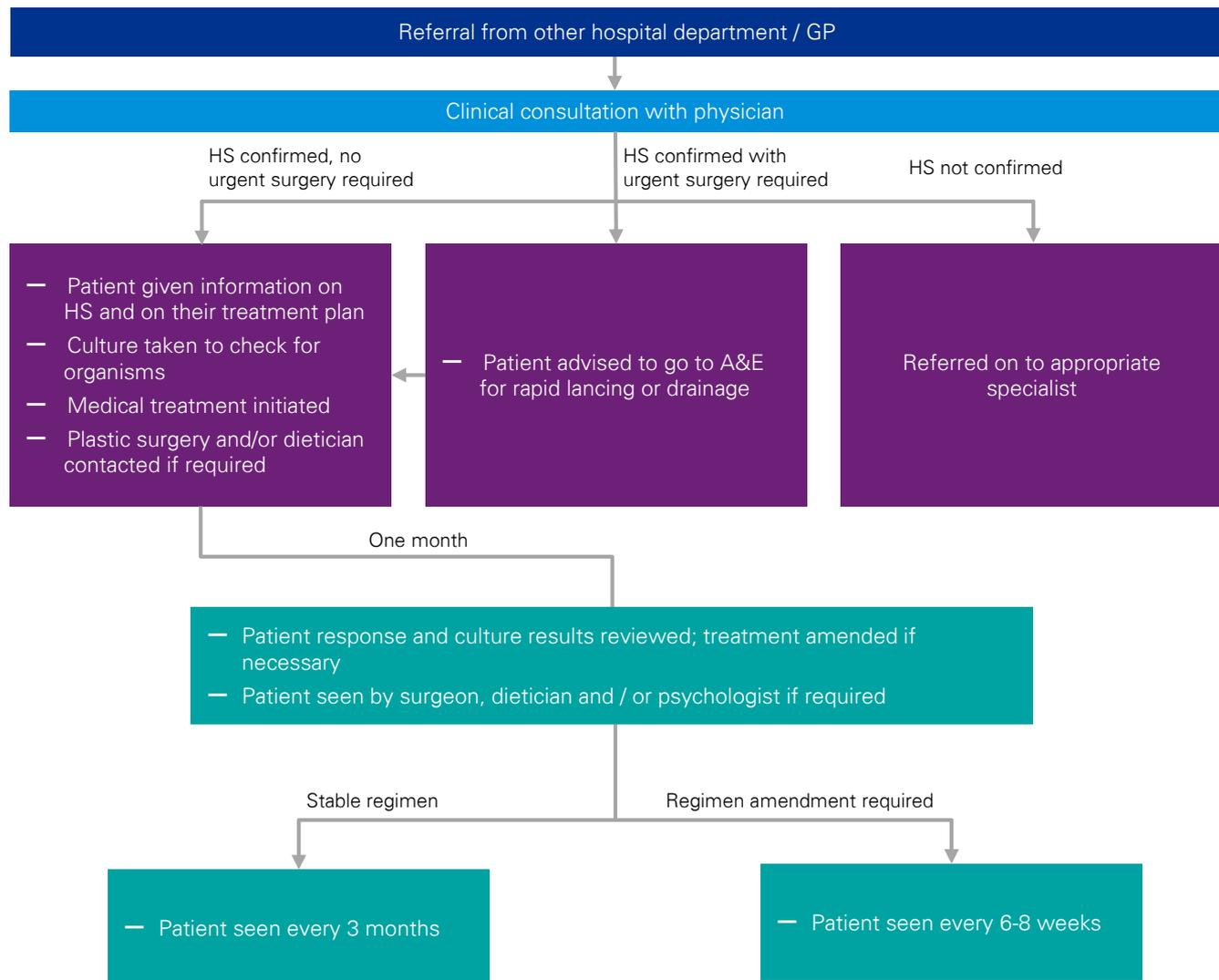
- The centre serves Dubai, which has a population of ~2.5 million.



**Estimated referral routes**

- GP: 40%.
- Emergency department: 40%.
- Surgery: 10%.
- Gynaecology: 10%.

**Typical patient journey**





## 6.4.2 Challenges, interventions and benefits

We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these.

	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	(1) <b>Delayed presentation</b> to clinicians due to patient embarrassment or unawareness	(1) <b>Delayed time to diagnosis</b> due to limited clinician recognition of HS	(1) <b>Clinicians reluctant to treat</b> given unpleasant disease nature and high time demands (2) <b>Limited communication between specialists</b> dealing with HS patients	(1) Delayed presentation <b>limits treatment efficacy</b>	(1) <b>Difficult to forecast pattern</b> and extent of disease spread (2) <b>High levels of smoking and obesity</b> in the region (3) <b>Extreme heat</b> in the region <b>exacerbates disease</b>
Interventions			(1) <b>Cross-discipline referrals</b> to other hospital departments and external settings		
Stated benefits			(1) <b>Holistic patient treatment</b> improving HS patients' QoL		



## 6.4.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**

### Cross-discipline referrals

Initiate and maintain clear lines of communication with other specialists involved in the treatment of HS.



## 6.5 Clinique Val d'Ouest and Hospital Edouard-Herriot, France



### 6.5.1 Centre Overview



#### Key information



Lyon, France  
Lead KOL:  
Dr Philippe Guillem

#### Clinique Val d'Ouest - surgery

- One surgeon.
- 15 anaesthetists.
- Two psychologists.
- One dietician.
- ~ 20 nurses.

#### Hospital Edouard-Herriot - Dermatology

- Two dermatologists.
- Hyperbaric chamber.

#### Centre features

- Clinique Val d'Ouest is a **private hospital** with c.120 private doctors.
- Over the last three years, there has been **close collaboration between the Clinique Val d'Ouest and Hospital Edouard-Herriot**, which is part of the central university hospital of Lyon, and the largest hospital in the Rhone-Alpes region. The collaboration was instigated by Dr Guillem, and the two centres now aim to function as one single body in terms of HS treatment provision.
- The staff at Clinique Val d'Ouest – clinical and otherwise – have a **strong understanding of the disease's physical and psychological impact** on patients. This knowledge is driven by Dr Guillem's interest in HS. As a result, all staff, including administrative staff, take time to make patients feel supported and heard.
- The centre offers **extensive holistic support**, with every patient offered the opportunity to work with psychologists, dieticians and addictologists as well as clinicians treating comorbidities.
- The **patient association work very closely with the centre**. The strong relationship has resulted in numerous referrals to the centre through association members' recommendations.

#### Patient pool

- ~700 HS patients at Clinique Val d'Ouest.
- ~170 at Hospital Edouard-Herriot

#### Catchment area

- The Rhone-Alpes region in France.
- 27% of Val d'Ouest patients seeking HS treatment come from parts of France outside the local Rhone-Alpes area.



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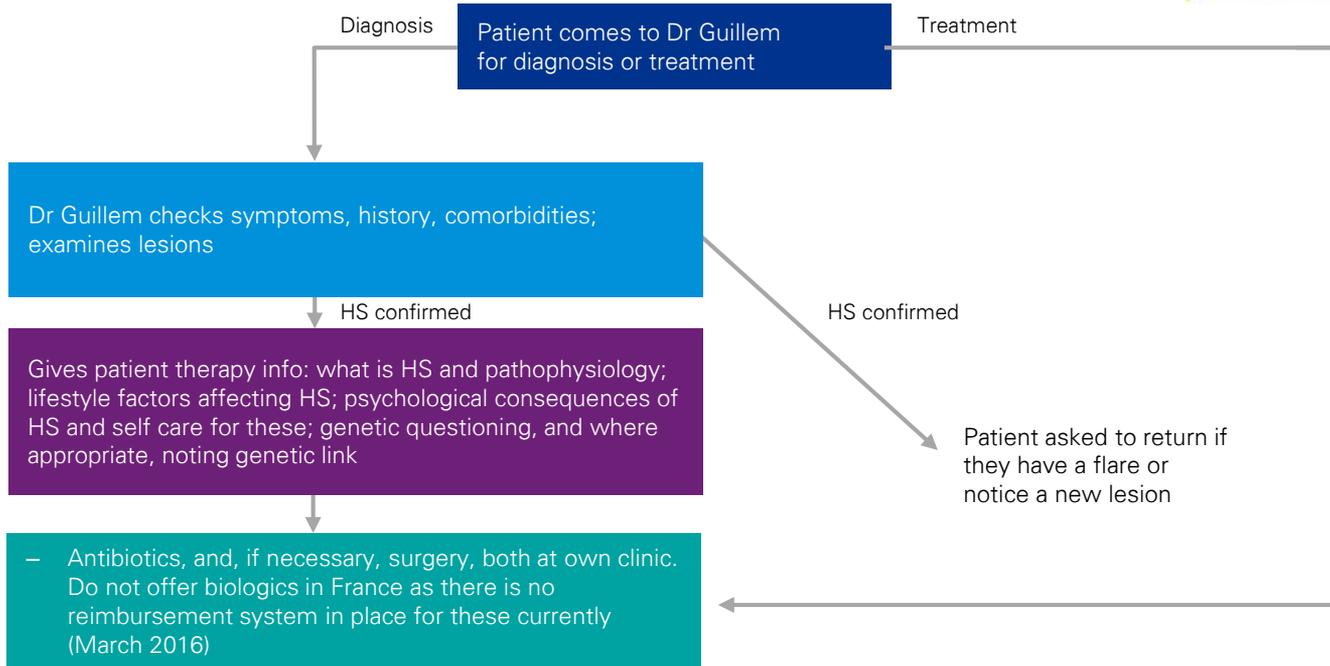
### Referral routes



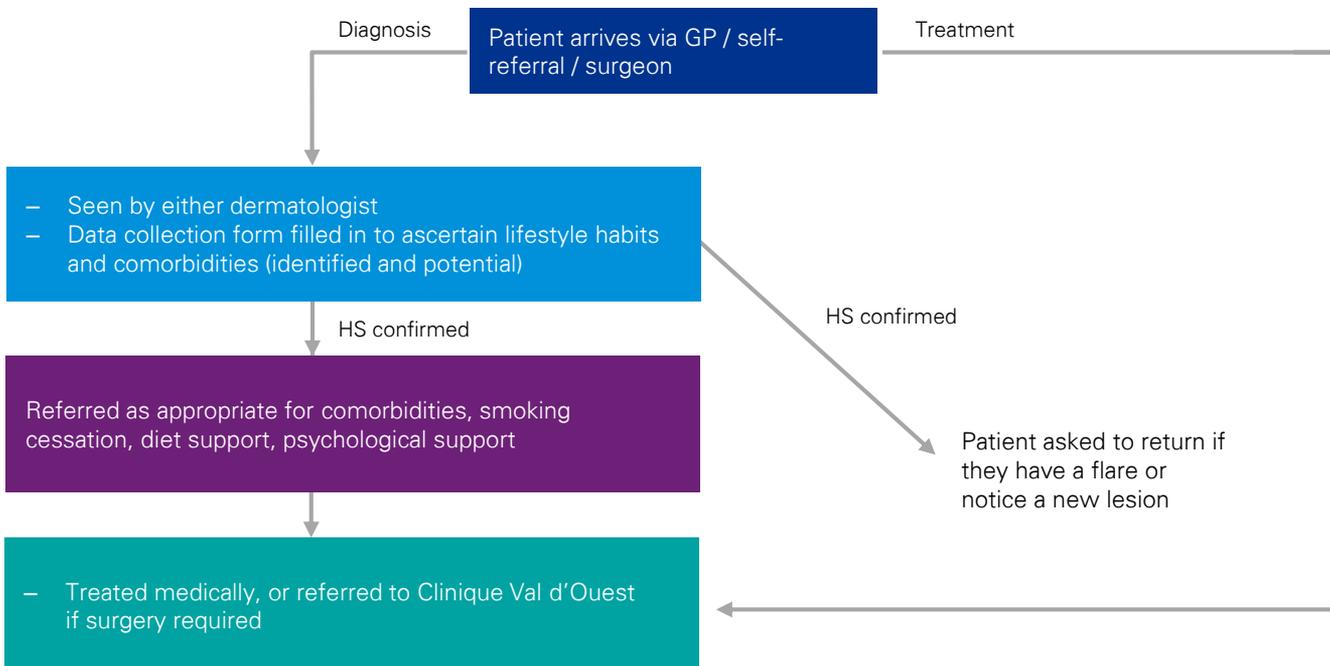
- Patient association: 32%.
- Non-university dermatologists: 13%.
- GPs: 10%.
- Emergency departments: 8%.
- Internet: 8%.
- University dermatologists: 6%.
- Friends/family/word of mouth: 6%.
- Digestive surgeons: 6%.
- Gynaecologists: 3%.
- Independent nurses: 2%.
- Consultations for other disease: 2%.
- Staff at Clinique Val d'Ouest@ 1%.
- Urologists: 1%.
- Plastic surgeons: 0.4%.
- Other: 1%.



**Typical patient journey at Clinique Val d'Ouest**



**Typical patient journey at Hospital Edouard-Herriot**





## 6.5.2 Challenges, interventions and benefits



	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	<p>(1) <b>Patient reluctance to approach clinicians</b> due to embarrassment</p>	<p>(1) Difficulty in <b>capturing useful data</b> in a timely manner  <b>(2) Delayed time to diagnosis</b> due to</p> <ul style="list-style-type: none"> <li>a) limited clinician recognition of HS</li> <li>b) patients not seeking second opinion if own GP is unable to diagnose</li> </ul>	<p>(1) <b>Surgeons reluctant to operate</b> given unpleasant disease nature and high time demands  <b>(2) Limited communication between specialists</b> dealing with HS patients</p>	<p>(1) <b>Long recovery period</b> due to deep surgical excision  <b>(2) Patient voice unheard</b> leading to frustration  <b>(3) High levels of patient isolation</b>  <b>(4) Lifestyle choices</b> difficult to change, aggravating physical and psychological well-being  <b>(5) Variable treatment</b> across regions due to lack of practitioner knowledge of HS  <b>(6) Patients used to self-medicating for pain</b></p>	<p>(1) <b>Homecare nurses inexperienced</b> in follow-up wound care  <b>(2) Reduced mobility following surgery</b>  <b>(3) Variability in funding application acceptance rate</b> across different regions</p>
Interventions	<p>(1) <b>Patient association</b> to raise awareness of disease</p>	<p>(1) <b>Hospital mini-registry</b> to record data for effective treatment and clinical trials  <b>(2a) Patient association HS information leaflets</b> for clinics and pharmacies</p>	<p>(1) <b>Patient association</b> advise on where to find willing and able clinicians  <b>(2) Multi-disciplinary team (MDT)</b></p>	<p>(1) <b>Hyperbaric chamber</b> for swifter healing and pain reduction  <b>(2) Patient association</b> to ensure patient views are heard  <b>(2) Patient care meetings</b> to improve patient care  <b>(3,4) MDT</b>, including support from psychologists, dietician and addictologists  <b>(5) Nurse HS course</b> at nursing college  <b>(6) Clinicians aim to incorporate patient preferences</b> into pain management routine <i>(no case study)</i></p>	<p>(1,2) <b>Follow-up wound care specialists</b> offer expert support and training for home nurses  <b>(3) Patient association</b> advise on how to track disease and appeal rejections</p>
Stated benefits	<p>(1) <b>Patients empowered</b> to approach clinicians</p>	<p>(1) Data available for both treatment and clinical trials  <b>(2a) Increased awareness of HS</b> resulting in <b>faster and more accurate referrals</b></p>	<p>(1) Patients have <b>improved access</b> to care</p>	<p>(1) <b>Reduced pain and time to mobility</b> for patients after surgery  <b>(2,5) Patient preferences incorporated</b> into treatment decisions  <b>(3,6) Improved psychological state</b> leading to <b>improved QoL</b>  <b>(4) Improved patient treatment across a range of settings</b></p>	<p>(1) <b>Improved recovery time</b> for patients with correspondingly <b>lower cost and capacity demand</b>  <b>(3) High rate of successful appeals</b> results in access to <b>appropriate treatment and follow-up care</b></p>



## 6.5.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**



### Patient association

Use online platforms to draw patients together. Upskill each other so that the team can function efficiently even in the case of certain team members' absences.

### Hospital mini-registry

Consider what data your specific centre needs to collect when designing content fields. Ensure that appropriate personnel are available to develop the I.T. infrastructure required.

### Multi-disciplinary team (MDT)

Design working practices that work with involved parties' budgets and the region's reimbursement procedures. Consider formalising interactions where large centres are involved.

### Hyperbaric chamber

Draw on existing infrastructure where possible. Where a chamber is to be installed, draw on data on the use of a hyperbaric chamber for pain relief and wound healing, to build a business case.

### Patient care meetings

Ensure senior buy-in in order to effectively implement the meetings outcomes.

### Nurse HS course

Foster existing relationships with potential host centres. Consider delivering training in conjunction with a patient presenter.

### Follow-up wound care specialists

Develop a follow-up wound care programme that works within the healthcare funding regimen in your region.



## 6.6 Städtisches Klinikum, Germany



### 6.6.1 Centre Overview

#### Key information



Dessau, Germany  
Lead KOL: Prof  
Christos Zouboulis

#### Key information

- Five dermatologists (three dermatology surgeons).
- One surgeon.
- ~Five researchers.
- ~20 nurses in clinic; ~five in out-patient support

#### Departments providing regular support

- Physiotherapy (two physiotherapists assist regularly).
- Gynaecology.
- Gastroenterology.

#### Centre features

- The centre is part of Städtisches Klinikum, Dessau, which is the **teaching hospital** for the Martin Luther University in Halle, Germany.
- There is a **strong research focus** in the department, driven in part by the centre lead's interest in academia and education. On-site clinical and experimental laboratory facilities also assist research.
- There is **regular collaboration for research** with other dermatology departments globally.
- There is also **strong collaboration between the clinic's own departments**; clinicians regularly confer with colleagues from other specialisms in order to confirm diagnoses and jointly decide on treatment.

#### Patient pool

- ~12,000 dermatology patients.
- ~60 HS patients being seen for chronic care.

#### Catchment area

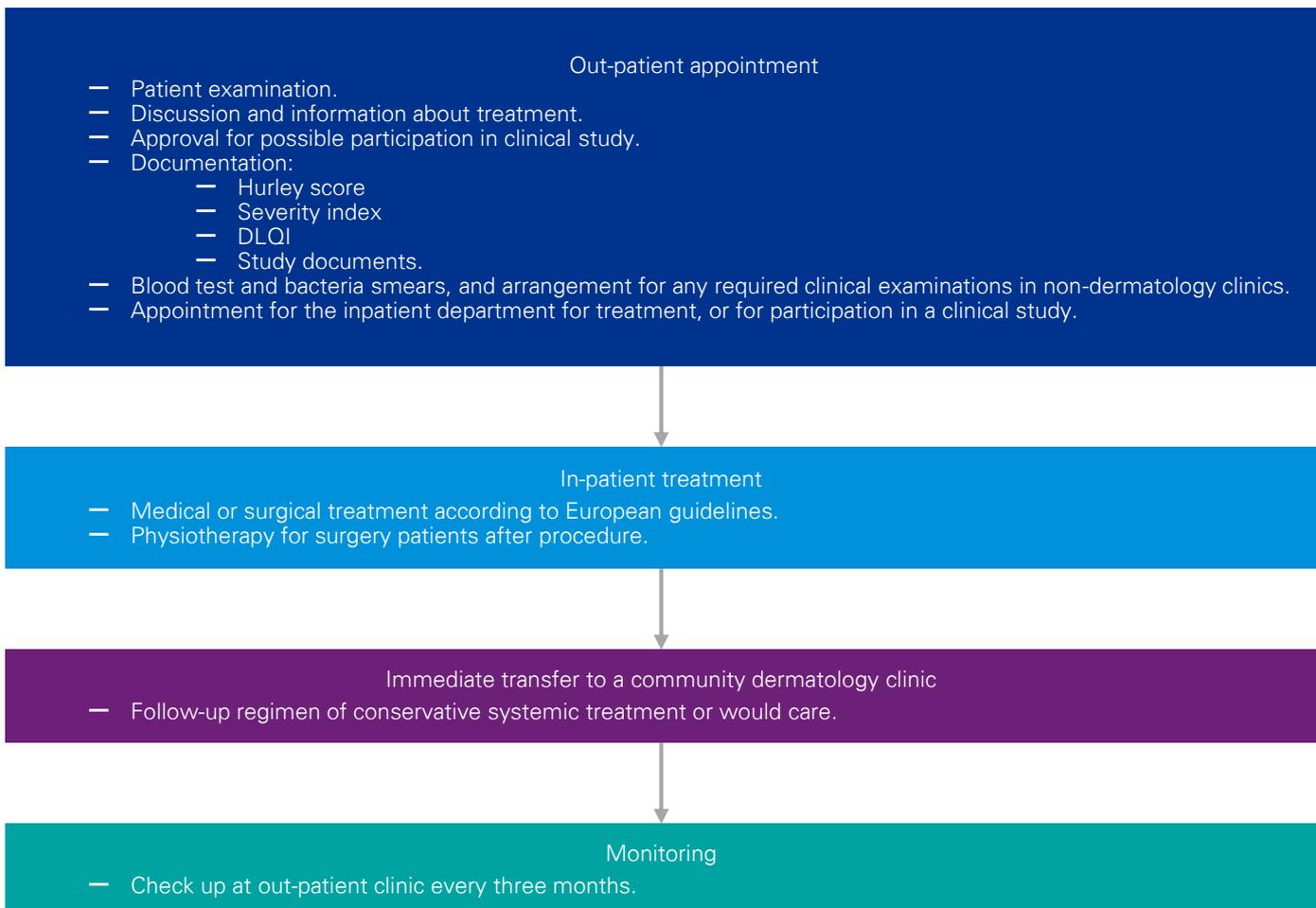
- The clinic serves the region of Anhalt of the state of Saxony-Anhalt.
- A number of patients seeking HS treatment also visit from other parts of Germany, as well as from other countries.



### Referral routes

- Dermatologists, gynaecologists, urologists, general physicians and surgeons (across Germany): 50%.<sup>1</sup>
- Other clinicians (Saxony-Anhalt): 20%.
- Dermatology departments (German and European hospitals): 15%.
- Other departments (Germany): 5%.
- Self referrals with permission from patient's country health authorities: 5-7%.
- Self-funded self referrals: 2-3%.

### Typical patient journey



### Notes

1. A number of these referrals are made to Städtisches Klinikum on the patients' request



## 6.6.2 Challenges, interventions and benefits

	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	<p>(1) <b>Patients reluctant to approach clinicians</b> due to embarrassment about symptoms</p>	<p>(1) <b>Limited knowledge sharing</b> due to lack of clinician networks                      (2) <b>Delayed time to diagnosis</b> due to limited clinician recognition of HS                      (3) <b>Difficulty in differentiating HS</b> from other conditions</p>	<p>(1) <b>Delayed patient information transfer</b> between primary and secondary care resulting in late treatment</p>	<p>(1) <b>Reduced mobility following surgery</b> due to rapid tissue healing                      (2) <b>Extensive excision required</b> to ensure surgery effectiveness                      (3) <b>Multiple patient needs</b>, requiring input from different specialisms                      (4) <b>Patient voice unheard</b> by clinicians due to lack of a platform                      (5) <b>Variable quality of care</b> between countries</p>	<p>(1) <b>Patients travel long distances</b> to access follow-up wound care                      (2) <b>Hospital capacity reduced</b> from wound follow-up demand                      (3) <b>Preventing flares</b> is difficult                      (4) High impact on <b>patients' quality of life</b></p>
Interventions		<p>(1) ESHF affiliation to support <b>regional HS networks'</b> formation and learning</p>	<p>(1) <b>State-wide information sharing system</b> giving clinicians immediate access to hospital notes on own patient</p>	<p>(1) <b>Physiotherapy programme</b> following surgery                      (3) <b>Multi-disciplinary working</b> to diagnose / treat HS                      (4) <b>Patient-led conference</b> for clinicians                      (5) <b>Standardising HS care</b> across Europe</p>	<p>(1,2) <b>Community dermatology care</b> addressing early disease and follow-up needs                      (2) Course to train <b>tissue viability nurses</b></p>
Stated benefits		<p>(1) Clinicians get <b>global information access</b> whilst addressing local needs</p>	<p>(1) <b>Smooth patient transition</b> on return to primary care</p>	<p>(1) <b>Reduced pain and time to mobilise</b> for patients after surgery                      (3) <b>Ease of access</b> for patients                      (4) <b>Patient preferences heard and incorporated</b> into treatment decision                      (5) <b>Improved coordination</b> of care</p>	<p>(1,2) <b>Improved access</b> for patients                      (1,2) <b>Hospital capacity</b> freed up for treatment of serious cases</p>



## 6.6.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**

### Regional HS network

Ensure teams have adequate national and local support in order to function sustainably.

### Information sharing system

Secure management buy-in for this large intervention, which may have high funding and IT requirements.

### Multi-disciplinary team (MDT)

Design working practices that work with involved parties' budgets and the region's reimbursement procedures. Consider formalising interactions where large centres are involved.

### Patient-led conference

Consider how clinicians or centre staff might support the initiative in the first instance, until it gains momentum.

### Standardising HS care (in development)

Initiate contact with other medical centres and jointly lobby health authorities across the regions.

### Community dermatology care

Develop and maintain lines of communication between primary and secondary setting.

### Tissue viability nurses

Identify training institutions, and approach these with a clear case for course development.



## 6.7 Hospital Santa Chiara, Italy



### 6.7.1 Centre Overview

#### Key information



Pisa, Italy  
Lead KOL:  
Dr Marco Romanelli

#### Practitioners

- 35 staff, comprised of:
  - four govt. salaried dermatologist<sup>1</sup>
  - four university salaried dermatologists<sup>1</sup>
  - seven dermatology nurses
  - one project nurse
  - six residents
  - medical and nursing students.

#### Centre features

- Santa Chiara is a **major referral centre** for dermatology across Tuscany, along with two other hospitals in Florence and Siena.
- It is a **university hospital**, and one of two major hospitals in Pisa.
- The department **focuses on wound management**. The centre lead is the chair of the World Union of Wound Healing Societies (WUWHS) conference in 2016, where HS is discussed on the agenda with reference to wound care.
- The centre regularly trials **innovative treatments for wound management**, e.g. injecting fistulas with antiseptic gel.
- There is a **focus on concurrent medical and surgical treatment** where both are needed, without interrupting the medical regimen in the lead up to, and post-surgery.
- There is also **healthy collaboration between dermatology and the pathology lab**, to understand the immuno-biological aspect of HS and other conditions.

#### Patient pool

- ~180 general dermatology patients per week.
- ~200 sub-specialty patients per week.
- HS patient numbers unknown at time of report (2016).

#### Catchment area

- East Tuscany region (Tuscany is divided into three macro-regions: East, West and South, served by hospitals in Pisa, Florence and Siena respectively).

#### Notes

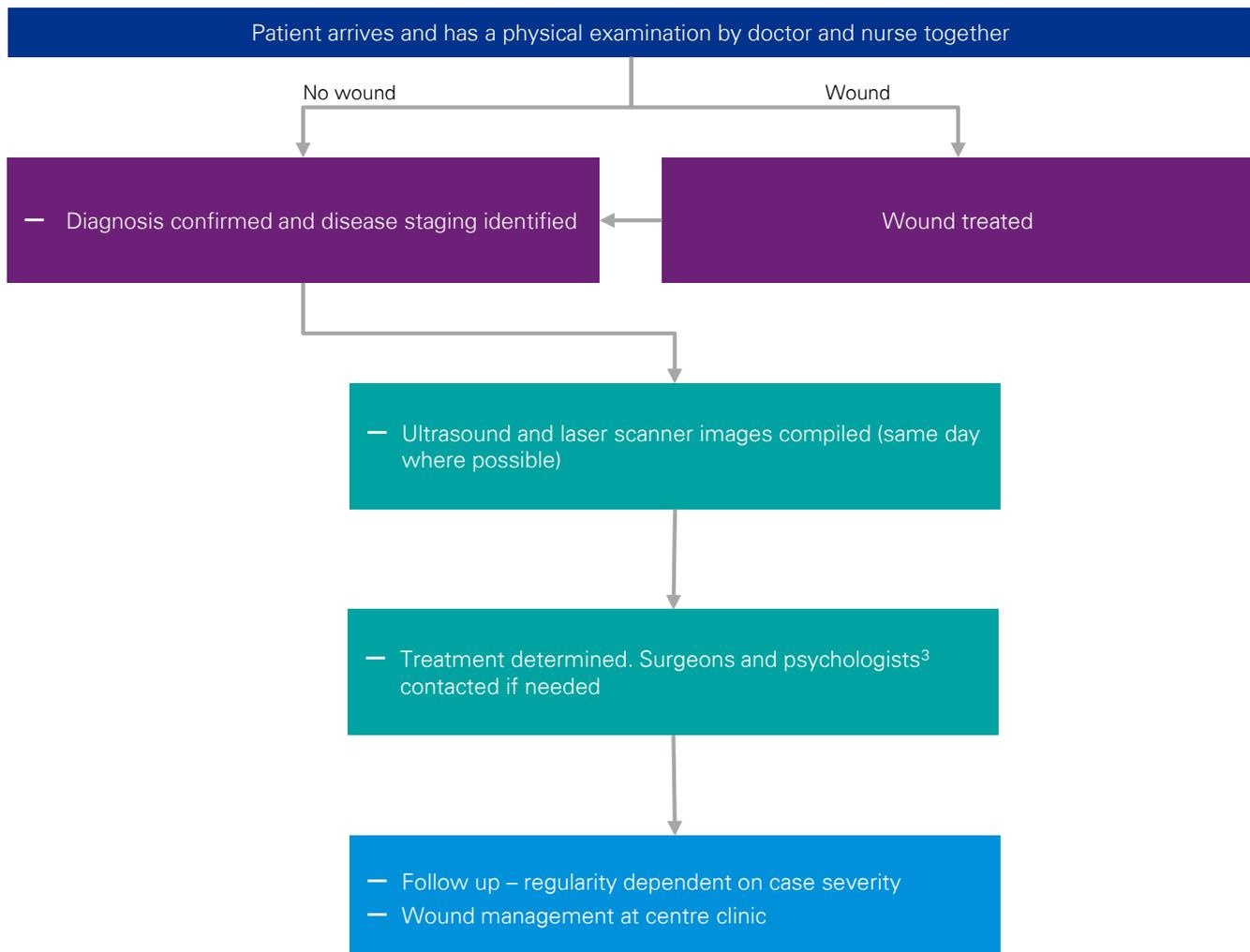
1. Two of the staff are able to perform minor surgeries e.g. derroofing, and one is able to perform surgery on HS patients



### Estimated referral routes

- General practitioners: ~40%.
- Emergency department: ~20%<sup>1</sup>.
- Other dermatology units in the East Tuscany macro-region: ~20%<sup>2</sup>.
- Other specialisms, e.g. general surgery, proctology: ~10%.
- Other regions in Tuscany: ~10%.

### Typical patient journey



#### Notes

1. The referees refer patients as cases requiring some dermatology input – they do not recognise HS specifically.
2. These are usually severe cases, referred because the treatment is likely to be costly.
3. Psychologist involvement in ~40% of cases.



## 6.7.2 Challenges, interventions and benefits

We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these

	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	(1) <b>Patient reluctance to approach clinicians</b> due to unawareness	(1) <b>Delayed time to diagnosis</b> due to limited clinician recognition of HS	(1) Clinicians can aim to <b>treat HS either with surgery alone, or with medicine alone</b> (2) <b>Multiple comorbidities</b> and patient needs	(1) <b>Difficulty in tracking lesion evolution</b> and treatment efficacy (2) <b>Difficulty in identifying disease severity</b> (3) <b>Assessing staging is time consuming</b> , with tools not fine-tuned to HS	(1) <b>Patient adherence</b> low (2) <b>Patient isolation</b> (3) Heavy <b>financial burden</b> on patient
Interventions		(1) <b>GP education</b> (1) <b>Secondary clinician education</b>	(1,2) <b>Multi-disciplinary team (MDT)</b> , to share expertise and develop treatment plan that covers all patient needs	(1) <b>Laser imaging</b> to track lesion evolution (1,2) <b>Ultrasound imaging</b> to assess sub-dermal tissue (3) <b>Developing assessment tools</b> geared to HS	(2) <b>MDT</b> to provide psychological and nutritional support
Stated benefits		(1) <b>Increased referrals</b> (1) <b>Improved treatment efficacy</b> resulting from quicker diagnosis	(1) <b>Holistic patient treatment</b> improving HS patients' quality of life	(1) Improved ability to <b>track and monitor treatment efficacy</b> (2) Potential for more <b>targeted treatment</b> (2) <b>Increased precision</b> in surgical excision (3) <b>Quicker identification of disease staging</b>	(2) <b>Holistic patient treatment</b> improving HS patients' QoL



## 6.7.4 Key replication lessons for other centres

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### **We asked the interviewees to identify the key factors for the successful replication of the interventions**

#### GP education

Work with clinicians at the start of their career, who are eager to learn and innovate.

#### Secondary clinician education

Consider approaching management with a case for providing training, as their buy-in is crucial to making the intervention financially viable.

#### Multi-disciplinary team (MDT)

Prioritise involvement of clinicians who can address the symptoms most commonly seen in your setting.

#### Laser imaging

Create a robust business case to justify the initial expenditure.

#### Ultrasound imaging

Create a robust business case to justify the large initial expenditure. Train staff fully to ensure they are able to use the machinery appropriately.

#### HS assessment tool

Collaborate with other clinicians to jointly agree definitions used (e.g. what is a 'nodule', and is everyone calling it such).



## 6.8 Hospital Manises, Spain



### 6.8.1 Centre Overview

#### Key information



Valencia, Spain  
Lead KOL:  
Dr Antonio Martorell

#### Practitioners

- Six dermatologists.
- Five plastic surgeons.
- 12 general surgeons.

#### Centre features

- Hospital de Manises has integrated its clinical workforce to work as **one cohesive inflammation team**, tackling a range of conditions including HS. The team includes specialists from dermatology, gastroenterology, plastic surgery and rheumatology, amongst others.
- **Monthly group meetings** between staff and patients are held and any new symptoms reported are quickly dealt with. This allows clinicians to pick up early on conditions that benefit from early recognitions, such as arthritis.
- The multi-disciplinary nature of the team allows for a **variety of clinical perspectives** on the needs of the patient.
- The centre has a **strong focus on innovation**, and uses several original methods of diagnosis and data tracking in an effort to optimise patient care.
- The team attends **a bi-weekly review of patients** across specialties, including conditions such as HS and Crohn's disease.

#### Patient pool

- 285 HS patients, cohort growing.
- 5,162 surgery patients.
- 22,713 dermatology patients (13,700 new visits, 9000 follow-up visits).

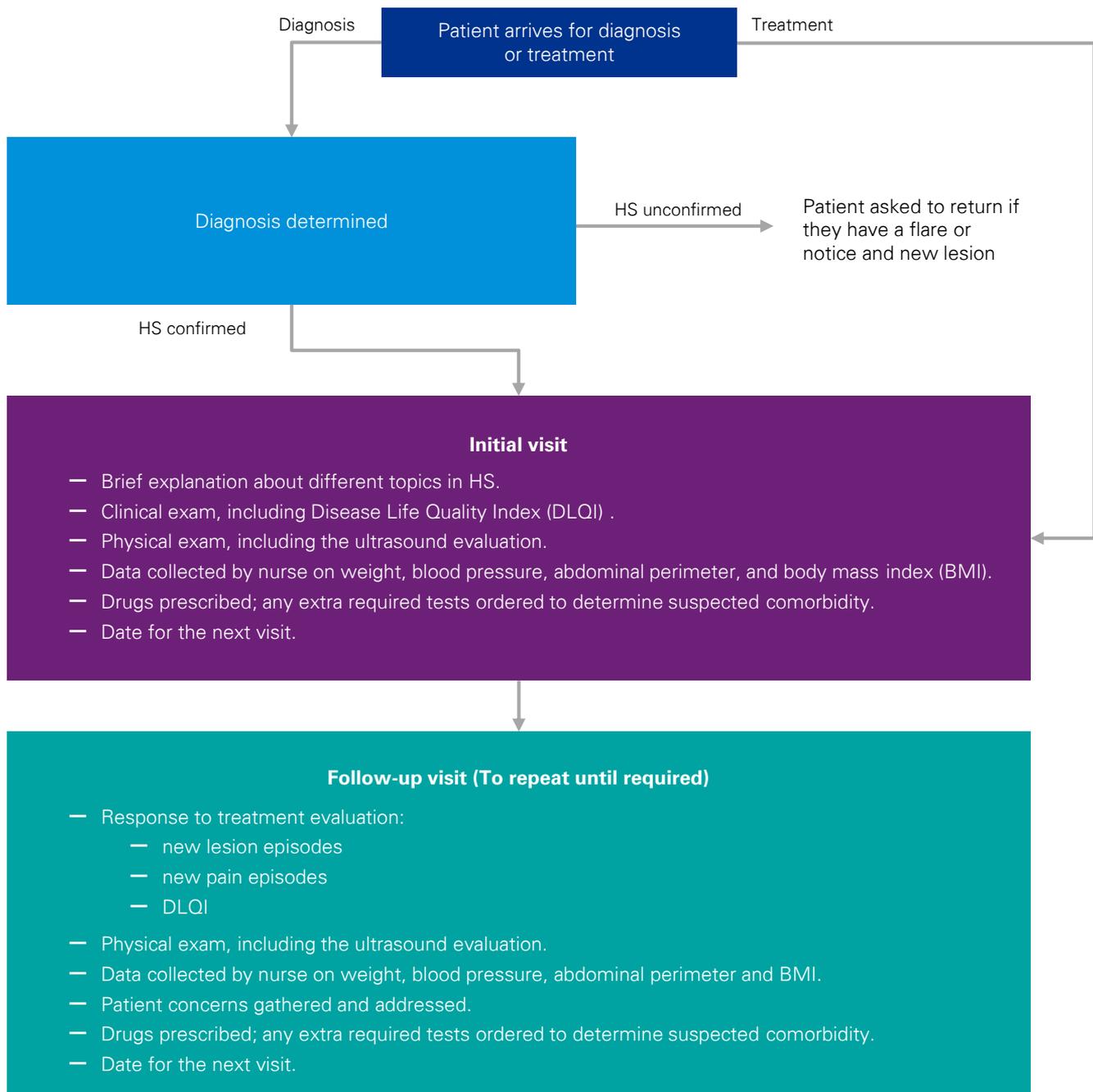
#### Catchment area

- Valencia, Comunidad Valenciana – Spain.
- Population: 200,000:
  - however, ~5% of new visits, and ~40% of follow-ups involve patients outside the catchment area.



**Estimated referral routes**

- Family doctors, 60%.
- Surgery, 20%.
- Rheumatology, 10%.
- Gastroenterology, 10%.





## 6.8.2 Challenges, interventions and benefits

We interviewed several practitioners to understand challenges across the patient pathway, and the interventions that have been put in place to address these.

	First symptoms	Diagnosis	Referrals	Treatment	Follow up
Challenges	<p><b>(1) Patient embarrassment</b> when facing unprepared clinicians</p> <p><b>(2) Limited patient awareness</b> of first symptoms</p>	<p><b>(1) GP apprehension in diagnosing</b> due to patient stigma</p>	<p><b>(1) Limited liaison between GP and dermatologist</b> resulting in patient frustration</p> <p><b>(2) Patients unwilling to leave GP care</b> to see unfamiliar clinicians, in unfamiliar settings</p>	<p><b>(1) Complex disease</b> with multiple comorbidities</p> <p><b>(2) Identification of disease staging difficult</b>, often requiring extensive skin removal and excision</p> <p><b>(3) Patients often used to self-medicating</b></p>	<p><b>(1) Patients' QoL impacted</b> both physically and mentally</p> <p><b>(2) Poorly informed self-medication</b> worsening symptoms</p> <p><b>(3) Access to care limited</b>, particularly for rural dwellers</p> <p><b>(4) Undetected symptom deterioration</b> resulting in surgery</p>
Interventions		<p><b>(1) HS awareness training</b> for GPs</p>	<p><b>(1) Tele-health</b> images sent from primary care to dermatologists</p>	<p><b>(1) Multi-disciplinary team (MDT)</b> for comorbid HS patients</p> <p><b>(2) Ultrasound</b> to understand disease staging accurately</p>	<p><b>(1,2) Patient group</b> providing network of patients</p> <p><b>(3,4) Topographic skin records</b> permitting doctors to compare lesion changes over time</p> <p><b>(N/A) HS patient registry</b> to track patient data</p>
Stated benefits		<p><b>(1) Earlier access to care</b> especially for rural communities</p> <p><b>(1) Improved speed of referrals</b> when GPs are aware of HS diagnostic</p> <p><b>(1) Patient reassured</b> on potential impact of treatment</p>	<p><b>(1) Improved access</b> with patients not requiring travel for diagnosis</p> <p><b>(1) Improved treatment plans</b> with dermatologists providing GPs with accurate staging</p>	<p><b>(1) Holistic patient treatment</b> improving HS patients' quality of life</p> <p><b>(2) Improved treatment selection</b> based on accurate staging</p> <p><b>(2) Reduced invasiveness of treatment plan</b> reducing need for surgery and medication</p>	<p><b>(1,2) Patient support</b> peer support and advice</p> <p><b>(3,4) Empirical long-term tracking</b> allowing for more accurate long-term prognosis of disease</p>



## 6.8.4 Key replication lessons for other centres

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**We asked the interviewees to identify the key factors for the successful replication of the interventions.**

### HS awareness training

Ensure adequate funding and expertise is available to develop the programme, and consider which modes of dissemination will be most suitable for your setting.

### Tele-health

Develop intervention protocols that allow it to work in conjunction with centre's operational procedures and time demands on staff.

### Multi-disciplinary team (MDT)

Design working practices that work with involved parties' budgets and the region's reimbursement procedures. Consider formalising interactions where large centres are involved.

### Ultrasound diagnosis

Ensure staff with adequate expertise are employed to run and interpret ultrasounds.

### HS patient group

Use online platforms to reach patients, developing offerings in response to the needs put forward.

### Topographical skin records

Ensure adequate funding and expertise is available to run the intervention sustainably.

### HS patient registry

Ensure patient volumes are sufficient to yield meaningful data for pattern finding.



Thank you

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