





Requirements for Brazilian Outpatient Centers of Excellence in Hidradenitis Suppurativa: Consensus Co-Creative Study

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Background: Hidradenitis suppurativa (HS) is a chronic skin condition. Its complexity and impact on patients highlight the need for multidisciplinary care that can address the physical, psychological, and social aspects. Centers of excellence can ideally provide the necessary infrastructure, resources, and expertise to effectively treat HS. However, there are still no consolidated models of centers of excellence in HS, and establishing their foundations is an intricate research challenge. Purposely, design and co-creation as innovation techniques are helpful approaches to this type of research.

Methods: In this study, we conducted a co-creation with consensus among HS specialists to propose the criteria and requirements to establish outpatient centers of excellence of HS in Brazil. We followed a linear process with mixed methods in 6 stages.

Results: The process resulted in 10 categories for establishing outpatient centers, including their respective requirements, rationale, and classification. The categories include onboarding and welcoming; infrastructure and procedures; infusion therapy; flows and referrals; staffing; disease management; metrics during diagnosis; metrics during treatment; awareness and advocacy; research and education.

Discussion: The idealized outpatient centers can play a role in the complete multidisciplinary treatment for HS and advancing the science of healthcare services by providing a focus for research, training, and translation of findings into practice.

Keywords: hidradenitis suppurativa, centers of excellence, co-design, consensus, health services research, patient-centered care, community-based participatory research, healthcare innovation

Introduction

Hidradenitis suppurativa (HS) is a chronic, inflammatory, recurrent, debilitating skin disease of the hair follicles that presents as painful, deep-seated, inflamed lesions in the apocrine gland-bearing areas of the body, most commonly in the axillae, inguinal, and anogenital regions.¹ The estimated global prevalence of HS varies from 0.05% to 4.1%. The disease is twice as common in women and affects the age group between 18 and 44 years but affects children and adolescents as well.² In Brazil, the prevalence is estimated at 0.41%, and the mean age is approximately 40 years, with a higher prevalence in adolescents (0.57%) and adults (0.47%).³

HS has a substantial impact on quality of life considering that symptoms appear early in adolescence or young adults, interfering with physical and mental health and with the choices and opportunities that the patient may have throughout

their life.^{4,5} High rates of depression and anxiety have been reported in HS patients, also including indirect self-destructiveness, chronic pain, damaging effects on sexual health, and a nearly 2.5-fold higher suicide risk compared to the general population.^{6–10} There is also the financial impact due to the difficulty of working, high rates of absenteeism and presenteeism, low income, cost of treatment, medical visits, and exams, among others.¹¹

Based on the HS consensus of the Brazilian Society of Dermatology,¹² continuous and multidisciplinary actions are required in managing HS at its all stages. Given the undertreatment and lack of knowledge of HS within the health system in Brazil, actions are needed to strengthen the vision of a single place that orchestrates integrated care in HS management, either providing or directing patients to an established referral network. However, this is not a reality in Brazil, as it is estimated that most patients remain undiagnosed and without access to adequate treatment. Accreditation in the healthcare sector, as occurs in centers of excellence, is used globally as a strategy to ensure a high baseline level of healthcare quality,¹³ and one of its advances is the emphasis on evaluating the outcome results for specific diseases, associated with the effectiveness in the use of clinical guidelines.¹⁴

Centers of excellence allow the synergy of results by using expertise and specialized resources in a specific health problem, reducing barriers, and investing in continuous actions to improve the quality and value of health.¹⁵ From the perspective of patients with HS, there is an important gap in delivering their priorities, such as personalized treatment and therapeutic plans, available treatment options, greater use of multimedia resources, assistance in accessing medications, scheduling appointments for flares, and coordinating referrals.¹⁶ However, to the best of our knowledge, there is still no consolidated model of center of excellence or reference in HS in Brazil, and there are very recent (published in 2023) related initiatives for specific cases in the US.^{17,18}

Establishing centers of excellence is a complex milestone that involves the study of the delivery, organization, financing, and outcomes of healthcare services.^{19–21} Conducting research in this field requires a deep understanding of the complex interplay between social, economic, and clinical factors that shape healthcare systems and the delivery of services.¹⁹ Purposely, there is growing evidence to support the use of innovation, design, and co-creation techniques in healthcare services research.^{22–26} This approach is useful considering that healthcare services are a complex and dynamic system that involves multiple stakeholders and that their input and involvement are crucial for creating services that are effective, efficient, and responsive to the needs of patients and communities.^{22,27}

In this study, we assumed the premise of the complexity of the HS disease alongside the relevance of establishing centers of excellence for its treatment, besides the complexity of healthcare services research to propose these centers. Therefore, we aimed at an innovation project using a co-creation approach with medical experts and other stakeholders to propose the characteristics that qualify a center of excellence for HS treatment in Brazil.

Materials and Methods

This is a co-creation study^{28,29} with HS specialists and a Mixed-Method Modified Delphi approach³⁰ to develop the criteria and requirements for creating centers of excellence in HS in Brazil. We followed a linear process with mixed methods in 6 stages summarized in Figure 1 and detailed in the next subsections.



Figure 1 Overview of the creation process.

Patient Journey Mapping

A patient journey mapping was developed in 2021 as an internal initiative at Novartis Brazil to reveal pain, needs and opportunities throughout the HS patient's journey. In this creation, mixed materials from different sources were used, including: an advisory board with 7 dermatology medical experts (MEs, chosen because they have publicly recognized experience) in HS discussing general aspects of the disease; a survey with 37 dermatologists from the 5 regions of Brazil on the challenges, needs, opportunities and trajectory of patients with HS; an advisory board with 5 patients discussing their journey; among other internet and social media content analyzed in a UX desk research process. After analyzing and triangulating all materials, the journey report was built with approximately 100 pages and dozens of strategic recommendations to improve the local health ecosystem.

As the patient journey was developed for internal purposes and served as the kickoff for this study, further details are beyond the scope of this article. The main conclusions of the journey outline the high complexity of the disease, the delay of about 10 years until diagnosis, the substantial need for comprehensive and multidisciplinary care in HS, the limitations of the Brazilian healthcare system, the considerable HS prevalence, whereas there are still few epidemiological data and a high number of underdiagnosed and undertreated patients.

After mapping the journey and its conclusions about the significant challenges of HS, a long-term co-creation project with medical experts in HS from Brazil was conducted. The scope of work was to develop plans and projects to support the improvement of the HS scenario in Brazil and generate a positive impact on the entire health ecosystem. As the first result of the initiative, this study was developed.

Workshop I, the Kickoff

Based on information from market intelligence and from the Brazilian Society of Dermatology, we mapped the main dermatologists, medical experts (MEs) in HS in Brazil who could participate in a long-term co-creation project. Among the criteria considered were participation in national working groups on HS, relevant publications on HS, proven experience treating patients, absence of conflict of interest, among others. Medical experts were formally invited and 7 of them agreed to participate throughout the project, also becoming authors of this study. These MEs are from 3 different regions of Brazil and work in the public (government-run system) and private health sectors in Brazil, which represents a diversified and comprehensive group and is substantial for co-creation projects.³¹

As a first step, MEs were invited to a 4-hour kickoff workshop in May 2022. The workshop was organized and conducted by 2 Novartis UX and Service Designers. Other multidisciplinary Novartis professionals participated in the workshop contributing to the discussions. Among the profiles were professionals from the areas of medical, research, product, marketing, and innovation. The workshop was divided into 4 parts. In the 1st part, the HS patient's journey with HS was presented to the participants and, from this, the designers conducted a guided discussion to map the main difficulties of the patients in each stage of the journey and what actions or ideas could be implemented to improve the journey, which thereafter was called by opportunities. In the 2nd part, the listed opportunities were clustered based on common or interdependent characteristics and the MEs freely distributed, each one, 5 votes on the opportunities they considered most relevant. In the third part, the 3 most voted opportunities were discussed in an ideation exercise called "how might we"³² in which the MEs indicated possible practical actions to implement the opportunities. Finally, in the fourth part, MEs distributed votes prioritizing which opportunity should be implemented first.

As an output from the kickoff workshop, the prioritized opportunities were, in descending order, the creation of centers of excellence, disease awareness activities, and the development of scientific studies of real-world evidence. MEs and Novartis participants agreed that the project sequence would be designed to address the co-creation of centers of excellence.

Discovery Research

Seeking to understand the rationale and methodology used in the conception of centers of reference and excellence, we sought equivalent studies to conduct benchmarking. The aspects we analyzed were the main categories of requirements and type of specifications used. The 3 references we compared were the studies of centers for Urticaria,³³ Thalassemia,³⁴ and Bowel Disease.³⁵ Based on benchmarking, we listed 6 main pillars of requirements to be established, as follows:

1. Infrastructure: building size, rooms and settings, specific equipment, leadership, documentation format, communication, etc.
2. Team: number of professionals, specialties available, knowledge required for each profile, team ceremonies, etc.
3. Disease management: knowledge about consolidated guidelines, guided anamnesis, metrics, therapeutic algorithm, patient data recording, etc.
4. Research and education: development of clinical trials, participation in research networks, sending data to registries, careers of those involved, courses, training, educational activities, etc.
5. Awareness and advocacy: advertising, patient tracking, social networks, advocacy and guidance services, relationship with societies and patient associations, etc.
6. Others: open to other criteria and suggestions that do not fit into the previous categories.

Using the 6 pillars as an interview script, the UX and Service Design team conducted semi-structured interviews with each ME to gather individual opinions on the equivalent requirements for HS centers. Each interview lasted up to 40 min and was conducted remotely during July 2022. All findings from the discovery research were synthesized using a reduction technique of thematic analysis³⁶ to gather an initial, unified list of categories and their respective requirements.

Workshop 2, Refining and Clustering

We brought the MEs together for the second time in a workshop in August 2022 to refine and cluster the requirements generated in the previous stage. As in the first workshop, UX and Service Designers from Novartis facilitated the activities, and multidisciplinary professionals from Novartis were participants contributing to the discussions.

The categories and requirements for centers of excellence were written on sticky notes and arranged on a wall in front of the MEs, who formed a semi-circle to discuss. Using focus group techniques,³⁷ facilitators led a guided discussion looking at each requirement individually. Throughout the session, requirements were refined, deleted, or added, and new categories were clustered. Additionally, participants discussed the differences in the functioning of the public (government-run system) and private health sectors in Brazil and how these factors would influence the establishment of centers in each sector. In consensus, the MEs decided that the same requirements would apply to both sectors, given the need for quality standardization. However, since the public health sector has more structural limitations,³⁸ the MEs defined that the requirements should not be exclusionary, ie, unfeasible to be implemented.

In the same rationale about the requirements not being exclusionary, the participants observed that some requirements were relevant, but were expendable because they were uncritical to the proper functioning of a center of excellence, which was called “nice to have” requirement. Conversely, the essential requirements were called the “must have”. Hence, this classification can be used in counting as a number that distinguishes the rating and level of conformity among several centers. At the end of the workshop, the MEs reached a consensus on categories and requirements, along with a preliminary classification between “must have” or “nice to have”. Therefore, the MEs decided that each requirement would need to be defined in either classification and this would need to be performed by voting to reach a majority consensus.

Poll to Classification

The previous stage resulted in a total of 10 categories and 66 requirements. To reach a consensus on their ranking, we created an electronic poll using the Microsoft Forms tool. The approach follows the iterative voting process inspired by the Mixed-Method Modified Delphi method.³⁰ Each requirement was written alongside an indication of its preliminary ranking between “must have” or “nice to have”. To respond, there was a field in which each ME selected whether they agreed or disagreed and another optional field for justifications and free comments. The first round of the poll was answered by MEs in mid-September 2022.

Analyzing the results of the first round of the poll, at least 2/3 of MEs agreed on 58 of the 66 requirements. In a second round during mid-October 2022, we placed the 8 requirements with divergence into a new poll alongside some of the collected justifications. For each requirement, there was a field for the ME to vote and an optional field for justifications and free comments. In the second round, at least 2/3 of MEs agreed on all 8 remaining requirements, resulting in the final list and classification.

Workshop 3, the Deep Diving

The list of requirements was completed, but still needed a more detailed specification containing the justification arguments as well as how to measure or implement each requirement. Similarly, the model of Urticaria centers of excellence³³ contains, along with each requirement, its explanation, and its deliverable item. To conceive an equivalent specification, we conducted a third workshop with MEs in November 2022.

As in the previous ones, the workshop was facilitated by the team of UX and Service Designers from Novartis, and multidisciplinary professionals from Novartis contributed to the discussions with MEs. The workshop activities were organized in 2 parts. In the first part, we provide MEs with sheets of paper containing tables with the requirements and columns with space to fill in the rationale and the deliverable or method of measuring the requirement. MEs were divided into 2 discussion groups, each with part of the list of requirements. When the groups finished filling in, we exchanged the sheets for each group so that all participants could read and contribute to the content of all the sheets. In the second part of the workshop, the participants organized the main topics to write the text of this article and agreed on the next steps of the project. [Figure 2](#) contains some photographs of the workshops conducted with MEs. People in the figure have provided informed consent for their images to be published.

Results

Using the ME consensus at the end of the co-creation study, we consolidated 10 requirements categories for centers of excellence in HS, each with their respective requirements and classifications. The next subsections detail each category and the rationale considered. The [Supplementary File 1](#) contains the 10 tables in Brazilian Portuguese that are equivalent to the presented in English throughout the text.

Onboarding and Welcoming

In the structure of a center of excellence in HS, it is essential to have a clean and comfortable waiting room capable of providing welcome and relevant information about the disease. The center should guarantee exclusive available appointments (regulated by the government-run service or private consultation appointment) and provide necessary support in emergency situations, either through emergency care structures or even guidance on how to proceed in specific situations. In cases where a center does not have its own structure for emergency care, a detailed referral flow must be established. The possibility of short-term scheduling (fittings) should also be offered, given the possibility of flare episodes. [Table 1](#) details all onboarding and welcoming requirements.



Figure 2 Photos from workshops 1, 2, and 3 showing participants during discussion, refinement, and specification exercises. On the wall, there are the patient's journey, problems, opportunities, votes, and responses from the cocreative exercises.

Table 1 Requirements About Patient Onboarding and Welcoming for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Waiting room.	An airy, clean and comfortable place for welcoming, adequate waiting, entertainment and information.	Evidence of suitable waiting room.
	Explanatory appointment managing the patient's expectations.	The importance of discussing a medium and long-term therapeutic plan with the patient.	The existence of a standard operational procedure.
	Provide care or guidance in emergency situations.	Care for emergencies such as generalized infection, flaring, or hospitalization due to complications.	The existence of service flow/guidelines for emergencies.
	Schedules available for short term.	Patients may need immediate appointments and extra visits because of the nature of the disease.	Existence of flow for immediate scheduling or fitting
	Facilitation of internal and external referral flow for patient arrival and guarantee of vacancies for care.	The ease of access from other internal (ie, primary care, if any) and external locations. Each center should know its referencing network reality to create adequate flows.	Proof of routine HS care. It is important to have specific codes and criteria for referral to centers of excellence in the public service.
Nice to Have	Triage, conversation and preparation room.	A room for information where it is possible to have pre- and post-consultation with a nurse and/or doctor	Evidence of the existence of a suitable room.
	Space or setting for emergency care.	(Related to the item above) - relationship with emergency personnel, information about the disease. It should have names and contact details of the responsible dermatologist.	Connection with the responsible for excellence in an emergency.
	Spacious and well-ventilated premises.	Patients are embarrassed by the odor or secretion and this requires more privacy	Evidence of the existence of a suitable room.
	Productive waiting room with videos, lectures, pamphlets and/ or interviews.	(Related to the item above). A waiting room where the patients can acquire knowledge. Patients who are aware of the disease are more likely to achieve good outcomes. Optimization of doctor and patient time.	Evidence of patient education material.

Infrastructure and Procedures

The physical structure must contain basic items to assist patients, which include a doctor's office, procedure room for draining abscesses, infiltrations and changing bandages. If these rooms are not available, a detailed referral flow with service protocol must be defined. The presence of a gynecological stretcher and appropriate gowns for the physical examination should also be offered for the comfort of both the professional and the patient, as well as to allow for a detailed examination of the body areas affected.

The availability of high-frequency ultrasound (portable or fixed) for staging, mapping, and tracking progress is an item considered nice to have. However, if it is not available, a detailed referral flow to a trained professional who will carry out the examination is essential, and a flow to the report of the exam findings as well. The offer of advanced bandages (eg, vacuum-assisted closure) and procedures such as Laser and LED light therapy for wound healing are also considered as nice to have. [Table 2](#) lists all infrastructure and procedures requirements.

Table 2 Requirements About Infrastructure and Procedures for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Room for small or medium-sized procedures	There is a need to perform a relief procedure, drainage, botulinum toxin, infiltration and dressings, etc.	Evidence of adequate room with proper equipment.
	Stretcher with legging for gynecological examination	There is a need for proper examination of the perineal area.	Evidence of available and usable equipment.
	Infiltration materials	This is an essential item in the procedure room for relief, diagnosis and proper examination.	Corticosteroid infiltration (triamcinolone, betamethasone). Evidence of material available.
	Drainage materials	This is an essential item in the procedure room for relief, diagnosis and proper examination.	Evidence of the material is available in a reasonable quantity.
	Disposable gown for full exam	This is an essential item in the procedure room for relief, diagnosis and proper examination.	Evidence of the material is available in a reasonable quantity.
	Certified ultrasound OR defined alternative referral flow	Used to perform imaging of lesions. The equipment must be certified and operated by a trained physician. Alternatively, the center may have a defined referral flow with the name of the procedure, equipment used and the responsible professional.	Equipment in operation with an indication of its certification OR protocol evidence of the referral flow.
Nice to Have	Materials for bandages and vacuum	Advanced bandages for active lesions and for post-operative wounds by secondary intention. Also relevant for post-operative wound care service or home dressing.	Evidence of the material is available in a reasonable quantity.
	Dressing/bandage ambulatory	Post-operative wound follow-up service for home dressing.	Evidence of adapted premises.
	Laser and LED light therapy	Post-operative wound follow-up service for home dressing. Relevant for more serious and deep wounds.	Evidence of corresponding equipment.

Infusion Therapy

Given the importance of immunobiological treatment to control the inflammatory condition of HS,³⁹ the presence of a dedicated outpatient infusion center or referral flow following local health standards and legislation is necessary (must have). Protocols for administration, package, and transport, as well as other characteristics of infusion or injectable procedures, must be continuously monitored by a properly trained and qualified team. These requirements are specified in [Table 3](#).

Flows and Referrals

HS is a condition associated with several comorbidities. Accordingly, evaluation and follow-up by a multidisciplinary team is fundamental. Comprehensive care requires a well-defined referral and counter-referral flow that includes the

Table 3 Requirements About Infusion Therapy for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Infusion follow-up activities.	Immunobiologicals are efficient and appropriate treatment for HS – requires proper management to ensure efficiency.	Standard operating procedure with guidelines, application, packaging, transport, emergency contact.
	An infusion center suitable for the national norms.	Offer an infusion service that has a flow for referral and emergency contacts.	Evidence of infusion center or referral.

different actionable specialties involved. Among them are nutritionists, psychologists, social workers, stoma therapy nurses and/or experts in dressings, as well as the different medical classes involved (general practitioner, endocrinologist, gastroenterologist, proctologist, dermatological surgeon, urologist, plastic surgeon, cardiologist, rheumatologist, gynecologist, sports medicine physician). At the same time, we defined it as “nice to have” having this multidisciplinary team present in the same physical location as the center of excellence. Table 4 presents all the requirements about flows and referrals.

Staffing

To meet the needs of a center of excellence in HS, its team should include specialists who are directly involved and have knowledge in HS care. In this sense, the dermatologist is a key player in leading the team and referring patients to the appropriate specialists when necessary. Likewise, the presence of a nurse qualified to treat HS patients is indispensable. Training, validation of protocols, updates, and clinical discussions should be evaluated in periodic meetings (quarterly), being monitored and recorded in the minutes (must have). The presence of personnel who act as a concierge, providing agility to the bureaucratic processes of requesting tests and medications, as well as the action of a pharmacist for medication reconciliation, are considered nice to have. The list of staffing requirements is presented in Table 5.

Disease Management

The management actions must include minimum information in the medical record (physical and/or digital) to facilitate the exchange of information and data between the different centers in the country. This data will be important for generating evidence and analyzing strategies that can shorten the journey of patients. It is crucial that everyone on the team has full knowledge and easy access to the Brazilian¹² and other international consensus, including but not limited to

Table 4 Requirements About Flows and Referrals for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Referral and counter-referral system	HS is associated with several comorbidities, requires multidisciplinary care and other specialties.	Standardized procedure with responsible persons and flow for referral to other specialties - routing list.
Nice to Have	Nutritionists	Higher prevalence of obesity, metabolic syndrome, which aggravates HS with higher cardiovascular risk. Guidance for weight loss, to control comorbidity and to reduce inflammatory load.	Evidence of routine care and/or of those responsible.
	Additional medical specialties	Relevant specialties to address the possible comorbidities of the patient. This includes general practitioner, proctologist, dermatological surgeon, urologist, plastic surgeon, cardiologist, rheumatologist, gynecologist, sports medicine physician.	Evidence of routine care and/or of those responsible.
	Stoma therapy nurse and/or expert in dressings	It can be incorporated into the Dressing/bandage ambulatory. It is relevant for dealing with more complex patients who have ostomy, fistulas, tubes, catheters, drains, incontinence, etc.	Evidence of routine care and/or of those responsible.
	Social worker	Social worker to support access to transportation, social benefits, patient rights, among others.	Evidence of routine care and/or of those responsible.
	Psychologists	Address patients who have depression, anxiety, difficulty dealing with the disease.	Routine care of those responsible.
	Interconnection between the specialties	The multiple specialists need to be involved in discussing multidisciplinary cases among themselves.	An effective forum among those responsible.

Table 5 Requirements About Staffing for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Recurring staff meeting – quarterly (at least every 3 months)	Every 3 months, establish a meeting to update, validation of protocols, the alignment of work modes, action planning, and other relevant matters.	Document containing the main points/ checklist. Multidisciplinary group (doctors, nurses, pharmacists, etc.).
	Led by dermatologist	A dermatologist must orchestrate the actions of others specialties.	Professional register (Medical society CRM)
	Nursing team	Nursing care and support.	Professional register (Nurse society COREN).
	Scientifique forum	Clinical and scientific meetings to discuss some cases and clinical practice. The frequency can be defined according to the needs of the center.	Document containing the main points/ checklist.
	At least, one medical expert with exclusive dedication (preferably dermatologist).	HS is a chronic and complex disease that demands high dedication.	The medical expert should be an HS expert (eg. participation in HS congresses and scientific production).
	Frequent trainings	All team members should be trained frequently.	Certificates or tests proving the training or expertise.
Nice to Have	Pharmacist	A pharmacist is necessary to warn and understand drug interactions. It should be fundamental in infusion clinics/patients using multiple medications.	Professional register (society COFEM).
	Concierge / primary nurse / novice resident (RI)	Professional who helps contact / supports the patients.	Organization chart.
	Annual Teams Meeting: Review of the working year	A significant annual meeting, it can also be the final meeting of quarterly meetings	Document containing the main points/ checklist.

the European⁴⁰ and North American⁴¹ ones. Also, photographic documentation of the cases is essential, preferably stored in the medical record, accompanied by the appropriate consent forms. The complete requirements are detailed in [Table 6](#).

Metrics During Diagnosis

For the evaluation of the patients seen, first at the time of diagnosis, items such as quality of life measured by the DLQI (Dermatology Life Quality Index), pain assessment¹⁰ measured by the visual analogue scale (VAS), extent of the disease measured by the Hurley scale and severity of the disease measured by the IHS4 should always be recorded at the time of diagnosis. [Table 7](#) details the complete specification.

Metrics During Treatment

In the clinical follow-up of patients with HS, centers of excellence should periodically evaluate the most updated core domain set, including apply the objective and validated scales, both physician reported and patient reported outcomes. IHS4, Hurley, and DLQI.^{42,43} Subjective scales of satisfaction surveys to monitoring and improving the center's actions are also indispensable. We recommend that the application be made at least every 6 months by physical or digital means. [Table 8](#) details the complete specification.

Awareness and Advocacy

HS patients journey faces several challenges during their journey, such as late diagnosis, lack of information about appropriate treatments, and lack of knowledge of the medical community about the disease. Thus, the active role of the

Table 6 Requirements About Disease Management for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Standard protocols and guides	Standard operating procedure that describes the functions and responsibilities of each one.	Guide or procedure checklist.
	Brazilians consensus and European guide	It is essential to have the deep understand of the consensus for all members of the team.	Available for access by members. Documented after discussion.
	Electronic medical record	Medical record with main information which facilitates the interface between the centers and enables epidemiological analyses.	Documentation of: 1. General data; 2. Comorbidities or other diseases; 3. Previous and current treatments with event dates; 4. HS family history; 5. Smoking and anthropometric data. 6. Clinical outcomes.
	Image record	Photograph of the lesions to assess the clinical response and evolution of the case, especially for cases with surgical intervention.	1. Term of consent 2. Images saved digitally, preferably in the patient's medical record.

Table 7 Requirements About Metrics During Diagnosis for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	At least one objective and one subjective metric	The need of comprehensive and comprehensive evaluation.	Evidence of application of scales at the time of patient admission.
	Initial DLQI	Assessment of the impact on quality of life.	
	Initial Hurley	To plan surgical approach.	
	Initial count of the number of: nodules, abscesses, and fistulas. Calculate IHS4. Take into account and annotate anatomic compromised areas and respective extension. Number and/or frequency of exacerbations	To dynamically assess HS severity in an international scoring system.	
	Pain scale	To understand certain aspects of a patient's pain, including pain duration, severity, and type.	

center of excellence in HS in promoting informative and educational actions for the entire community is fundamental. Some of the necessary actions that must be led by these centers include having an institutional website, active presence on social networks, events dedicated to HS, direct guidance channels on access and rights, training of new specialists in the area, among others. [Table 9](#) presents all the requirements about awareness and advocacy.

Research and Education

Promoting teaching and research in HS is a commendable responsibility of centers of excellence. This action generates a social impact by building capacities and fostering innovation in the field, thus contributing to the development of evidence-based policies and practices. It is recommended (nice to have) that centers of excellence in HS have a culture

Table 8 Requirements About Metrics During Treatment for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Count the number of: nodules, abscesses, and fistulas. Calculate IHS4. Consider and annotate anatomic compromised areas and respective extension. Number and/or frequency of exacerbations. Perform at each routine visit or at least each 3–6 months.	The need of comprehensive and reproducible evaluation.	Evidence of the application of objective and subjective scales by physical or digital means.
	Hurley at least every six months.	To plan surgical approach and evaluate Hurley progression in each area.	
	DLQI at least every six months.	Assessment of the impact on the quality of life and its evolution.	
	Patient satisfaction survey, at least every six months.	To measure the perception of the patient who attends the center recurrently to identify aspects of improvements.	
Nice to have	Other physician related outcomes as number and types of scars (atrophic, hypertrophic, dyschromic)	To measure and monitor the disease progression.	Evidence of the application of objective and subjective scales by physical or digital means.
	Other patient related outcomes, as WPAI, HADS, NRS for pain and pruritus,	To measure and monitor the disease impact.	

Table 9 Requirements About Awareness and Advocacy for a Center of Excellence in HS

Requirement		Rationale	Measurable
Must Have	Active presence on social networks.	Disseminate and seek early diagnosis.	Evidence of the existence of profiles on social networks with some recurrence of posts.
	Own website of the center of excellence.	Facilitate patient finding at regional centers.	Website address and evidence that it is working.
	Training events for professionals from other services.	There is a need to update and empower new HS specialists, as well as generate outreach.	Evidence of at least one annual HS training event.
	Offer content to patients (eg, e-books, video booklets, case studies).	Complement the guidance of patients and encourage the maintenance of the bond with the center.	Evidence of the materials created.
	Promote events dedicated to HS.	There is a need to provoke awareness and dissemination.	Evidence of at least one annual event on HS open to non-specialist public.
	Patient education and guidance services (eg, rights, access).	Serve as an information channel for patients, including social networks, booklets, mailing lists, groups on WhatsApp. Preferably a hotline.	Evidence of actions performed and that the service remains in force and available to patients.
Nice to Have	The dissemination of the centers to the entire medical class.	Participation with other specialties – present HS in other symposia, congresses, and specialties events other than just dermatology.	Evidence of dissemination performed at least annually.
	Dissemination in local or regional media.	There is a need to provoke awareness and disclosure. Preferably presence at live events and interaction with active local communicators, such as radio, TV and local media.	Evidence of communications performed at least annually.

Table 10 Requirements About Research and Education for a Center of Excellence in HS

Requirement		Rationale	Measurable
Nice to Have	Participation in data registry.	Relevance of contributing data for centralization in registries.	Documentation proving participation.
	Internal academic programs.	Training and education for professionals.	The corresponding documentation or internal policy and record of achievement.
	Scientific production.	Contributing to the dissemination of knowledge resulting from the center.	Studies that were published in proceedings or in journals.
	Relationship with research centers.	To facilitate scientific dialog and the production of studies.	Any documentation proving a relationship.
	Structure or availability for conducting research.	To facilitate scientific dialog and the production of studies.	Corresponding internal documentation or policy and/or dedicated premises.
	Offering fellows and scholarships to interns and other researchers.	To facilitate scientific dialog, production of studies and training of new professionals.	Evidence of documentation or corresponding internal policy.
	Offering the possibility for professionals to perform immersion and visits.	To facilitate the training of new professionals and give visibility to the center.	Corresponding documentation or internal policy.

focused on teaching and research through actions such as internal academic programs, scientific production, links with research centers, openings for scholarships and fellowship programs. The list of requirements is defined in Table 10.

Discussion

Successful development of a center of excellence first requires a profound understanding of the delivery model and its benefits.¹⁵ However, proposing healthcare services such as centers of excellence is a complex process that involves the study of the organization, delivery, and financing of healthcare services, as well as the outcomes and impacts of these services on patients, populations, and societies.^{15,44} This complexity arises from the fact that healthcare services are a dynamic and interconnected system that involves multiple stakeholders, including patients, caregivers, healthcare providers, payers, policymakers, and researchers.^{24,44} As a result, healthcare services research requires a multidisciplinary and systems-level approach that considers the various components and interactions within the healthcare system.^{20,26}

Our co-creation approach was an innovation initiative that managed to stimulate the active participation of stakeholders in health research practice, leading to enable this study featuring the requirements for a center of excellence in HS with a detailed understanding. To foster a co-creative process between stakeholders and researchers, it is important to create meaningful partnerships by providing an open environment for collaboration, respect for different perspectives, and the development of joint and interdisciplinary objectives.^{22,24,27} In our experience, by involving relevant expert stakeholders in the design process, we gained a deeper understanding of the problems and challenges faced by HS patients that might use healthcare services. A key benefit of co-creation in healthcare services research is that it can lead to more effective and efficient solutions that are more likely to be successful and sustainable in the long-term.^{45,46}

The treatment of HS requires a multidisciplinary approach, as it involves addressing not only the physical symptoms of the condition but also the psychological and social impact of the disease on the patient.¹² This may involve coordinating care among dermatologists, surgeons, primary care providers, mental health professionals, and other healthcare providers. We believe that, by working together, these healthcare providers can develop a personalized treatment plan that addresses the physical, emotional, and social needs of the HS patient. This is a key advantage that centers of excellence provide to the populations they serve.^{15,47}

Given the evidenced complexity of treatments, the existence of specialized centers may improve the HS patient journey and lead to the optimization of clinical, surgical, and multidisciplinary care. Likewise, a center of excellence is necessary to offer society and the local health system visibility to the disease, access to trained professionals, and encourage publications and generation of evidence.¹⁵ In addition to the assistance purpose, these centers can serve as hubs for research, training, and dissemination. Moreover, centers of excellence in HS can help build capacity and foster innovation in the field and can contribute to the development of evidence-based policies and practices that improve the quality, accessibility, and value of healthcare services regarding HS treatment.

While this study provides comprehensive criteria for establishing outpatient centers of excellence for HS in Brazil, it does have some limitations. Firstly, our process was linear, which may not account for the multifaceted nature of healthcare systems. The study was also based on consensus among HS specialists, which may not cover perspectives from other healthcare professionals or patients. Furthermore, the applicability of these criteria may vary in different regions within Brazil due to socio-economic and infrastructure differences. Finally, the translation of findings into practice may encounter challenges due to policy or financial constraints.

Conclusion

In this paper, we featured characteristics that can qualify a center of excellence for HS treatment in Brazil using a co-creation approach. To improve the quality of reception for patients, centers specializing in treating patients with HS must follow standardized norms to provide medical support in its various aspects. Multidisciplinary clinical care, diagnostic imaging methods, and, when necessary, a surgical environment are some of the essential requirements to reduce the patient's journey in search of control of the disease. The idealization of a center of excellence for the care of HS patients is imperative for the reality of the disease in Brazil. Based on the current scenario, in which most patients and primary care or emergency professionals are not aware of the disease, the formation of a center of excellence creates opportunities for education and dissemination about HS intending to mitigate unmet needs and prepare the local health system to fully meet the needs of HS.

This co-creation study may be considered a starting point for a deeper discussion adapted to the different realities of each service, city, region, or country. Co-creation has the potential to create innovative and creative solutions that would not otherwise be possible. The process encourages the exchange of ideas and solutions, while also engaging participants in the development and implementation of solutions. This creates a more efficient, effective, and innovative approach to healthcare challenges. Co-creation can help develop a better understanding of the healthcare context and create meaningful solutions that are tailored to the needs of stakeholders. It also increases the likelihood of successful implementation and sustainability of healthcare solutions.

The standardized infrastructure of the centers specialized in HS may bring opportunities for research among the different centers. The care and certification of the different areas of specialized care must be discussed taking into account the local and national regulatory entities, as well as the conditions of the public (government-run, in Brazil's case) and private health systems. We hope that this study encourages discussion on the topic and helps shorten the journey of patients with HS to comprehensive and quality care.

Institutional Review Board Statement

This study was approved by the internal scientific committee. Datavision Ref AIN-MS -115825.

Data Sharing Statement

Any supporting data are available from the corresponding author upon reasonable request.

Informed Consent Statement

The people appearing in the figures are authors of the study and/or provided informed consent for their images to be published.

Acknowledgments

Acknowledgments to project contributors: A Galvão, B Cormanich, C Barão, E Souza, J Koellreutter, J Spohr, L Maran, L Martins, L Neves, M Lemos, M Ramos, P Pinheiro, and S Pereira.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

The study was funded by Novartis.

Disclosure

AVEC received grants, consultancy, and speaking honoraria from AbbVie, Janssen, Leo Pharma, Boehringer Ingelheim, Novartis, Eli-Lilly, Sanofi, GSK, and UCB. DHB received grants, consultancy and speaking honoraria from AbbVie, Janssen, Eli-Lilly, and Novartis. RSS received grants, consultancy and speaking honoraria from AbbVie, Boehringer Ingelheim, Janssen, Eli-Lilly, Leo Pharma, Novartis, and Sanofi. GVD received grants, consultancy and speaking honoraria from AbbVie, Bayer, Biolab, Boehringer Ingelheim, Galderma, Janssen, Eli-Lilly, Leo Pharma, UCB, Novartis, Sanofi and Pfizer. MCMR reports a speaker for AbbVie, Novartis, Janssen, Sanofi, Pfizer and advisory board for AbbVie, and Novartis. RFM reports a speaker and/or advisory board from Janssen, Pfizer, Leo Pharma, Novartis, Boehringer-Ingelheim, and AbbVie. RSS received grants, consultancy and speaking honoraria from AbbVie, Boehringer Ingelheim, Janssen, Eli-Lilly, Leo Pharma, Novartis, Sanofi. WGGC received grants, consultancy and speaking honoraria from AbbVie, Amgen, Boehringer Ingelheim, Galderma, Janssen, Eli-Lilly, Leo Pharma, UCB, Novartis, Sandoz, and Pfizer. EAB, MEMS, FGT, RFN, GC, EYT, ALPP, CCV, RGT, and BR were employees or provide services for Novartis during the study. The authors report no other conflicts of interest in this work.

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