



## Epidemiological Study of Hidradenitis Suppurativa (HS) in Australian Population

*One of the most rigorous and largest general population-based HS epidemiological studies reported thus far, for the first time sheds light on the prevalence and impact of HS in Australia as well as the demographic characteristics of the sufferers.*

### SITUATION

A large global pharmaceutical company was seeking a partner for a cross-sectional, observational, population-based study to determine the prevalence of the rare disease Hidradenitis Suppurativa (HS) in the Australian adult population focusing on the demographics, management pathways and diagnosis rate of individuals living with HS. With any rare disease, establishing prevalence is extremely difficult. But with HS, a chronic inflammatory disease, which can cause great pain and disfigurement, many patients are reluctant to talk about their symptoms or seek help from physicians, thus adding an additional layer of difficulty in this particular study.

### UNIQUE EXPERTISE FOR THE PROJECT

George Clinical not only has strong capability in interventional studies but also in observational research. Our experience with complex, novel studies helped researchers adopt a flexible, effective study design that also included cost savings. Due to the challenging nature of this study, our scientific team handled the implementation. George Clinical knew it was mandatory to set up an implementation plan that provided a simple and pragmatic approach to collect the data. We brought a strong understanding of the ethics process and the healthcare system in Australia allowing us to effectively engage with the ethics team and clinicians.

Expert services provided by George Clinical to help sponsors with this large and difficult study included protocol writing, project conduct and management, statistical analysis, clinical study and report write up.



## Key Results



### TIME AND MONEY SAVED

Modified existing consumer survey to avoid costs of creating new medical study



### HIGH PERCENTAGE OF RESPONDENTS

Door-to-door population survey  
17,050 Surveyed  
11,433 Responded



### USE OF SCIENTIFIC TEAM

Implementation by George Clinical Scientific Team due to nature of rare disease associated with stigma

## SCOPE OF STUDY

This observational study was conducted in Australia over eleven months in the therapeutic area of dermatology, rare disease. No intervention was administered and exposure to any risk factors would be similar to exposures in the general population. Over 17,500 individuals were contacted and asked to fill out a previously validated questionnaire that ultimately identified HS patients within the population.



*"An opportunity to contribute to the body of knowledge and the science led George Clinical to implementation of this study by our scientific team in order to most effectively tackle all of the challenges we knew were ahead. We're proud to have been a part of this study and look forward to any other opportunities to help reduce the current average of 7.2 years between symptom onset and HS diagnosis and prevent further progression, pain and disability to those few who are suffering from such a debilitating condition," stated Maria Ali, Chief Medical Officer, George Clinical.*

## CHALLENGES

At the outset, we wanted to avoid the time and expense of creating an entirely new HS-specific health survey. In addition, rare diseases always pose a challenge in an epidemiological study, and with HS, the stigma associated with the disease and its symptoms increases the difficulty in obtaining compliant respondents. Because of this, we were aware from the outset that our recruitment might be quite low.

## SOLUTIONS

Due to the nature of the project and its association with a rare disease, George Clinical chose to combine the expertise of our lead statistician with the lead of our medical and scientific department to implement this study. In order to avoid the excessive time and expense it would have required to create an entirely new medical survey for this project, George Clinical was able to save both time and money by piggybacking our health survey on an expert consumer survey panel that was successfully modified to our specific needs and designed to elicit the desired responses from respondents.

## RESULTS

The survey was successfully completed and out of 11,433 Australian residents who answered the HS questionnaire, 88 screened positive for HS. Our best estimates of prevalence were calculated from the HS survey questions and suggest a prevalence of 0.67% (95% CI 0.53%–0.84%). We concluded that this condition has substantial morbidity and that diagnosis in the community is likely very low (<10%).



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