

Supplementary material E

Study information sheet for patients

Information about the project

Development of a core domain set for managing Hidradenitis Suppurativa

What is the purpose of the study?

The aim of the study is to establish agreement on which features of the disease should be measured and reported in all clinical trials for the treatment of Hidradenitis Suppurativa (HS). Researchers refer to this list of features as a core domain set (COS).

The reasons for developing a core domain set are to:

- Ensure that researchers measure all features of the disease that are deemed important to parties interested in the disease, including patients.
- Allow for comparison of treatments by ensuring that all clinical trials measure the same features of the disease.

The results of this study will improve the quality of future HS drug trials, and it is an important step towards the development of better treatment for HS.

What is a clinical trial?

A clinical trial is an experiment with the purpose to help answer one or more of the following questions:

- Does a treatment work?
- Does it work better than other treatments?
- Is a treatment safe to use?

Who is asked to participate in the surveys?

Participants in the surveys include patients, doctors, nurses, as well as representatives from pharmaceutical industries that make medications for HS, and from regulatory agencies, which approve medications for use in HS. We will invite approximately 50-70 patients to complete the survey. Patients and professionals will have an equal say in the study, so your input is extremely important.

What is the Delphi method?

The Delphi method is a way for people with different opinions and experiences to obtain agreement on a complicated matter. The technique requires that participants complete online surveys approximately 3-4 times between July and September. Between surveys, information will be provided on the results of the previous survey to encourage agreement. The process ends when sufficient agreement is obtained.

Do I have to complete all of the surveys?

Yes. During the survey process, you may have the feeling that you are answering the same questions several times, but it is important that you consider the information provided and answer all questions carefully. Skipping questions or dropping out of the survey process may cause the results of this study to become useless.

What is the timeline for the project?

Questionnaires will be administered to participants 3-4 between July and September. The deadline for completing each questionnaire will be set to 7-10 days. We expect the results to be published in 2017.

Thank you for your contribution to advancing the care of patients with Hidradenitis Suppurativa.

Best regards,

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The HISTORIC (Hidradenitis Suppurativa cORe outcomes set International Collaboration) Steering group: a multinational collaboration among IDEOM, Cochrane, and Zealand University Hospital Roskilde



Commitment To Completing the Entire Delphi Process

It is very important that you complete the questionnaires in each round, even if the Delphi group does not share the same opinions as you. The reliability of the results is reduced if participants drop out of the study before it is complete. If participants drop out because they feel their opinions are in the minority, the final results will overestimate the degree of agreement.