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### Research Result Summaries

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# Focus Group Evaluation, Health Care Provider Assessment, and Randomized Controlled Trial of a Patient Decision Aid for Hidradenitis Suppurativa

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Consistent with the TCPS 2 (4.7) this is a research summary provided to participants and should not be considered a formal publication of results.

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### Recommended Citation

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Informed shared decision-making between patients and health care providers can be facilitated by the use of patient decision aids (PDAs). PDAs are tools that provide evidence-based treatment options and clarify patient values and preferences. Prior to this research, no PDA existed for hidradenitis suppurativa (HS), a complex dermatological condition. Thus, the objectives of this research were to (1) develop a PDA for HS with input from patients and physicians, and (2) conduct a randomized controlled trial (RCT) to test its effectiveness during treatment decision-making compared to the Mayo Clinic HS website.

The PDA was developed in accordance with International Patient Decision Aid Standards. Its content was based on the North American Clinical Management Guidelines for HS and reviewed by 3 dermatologists and 2 patient representatives prior to being transformed into an online PDA. Feedback on PDA content and presentation was obtained from 7 HS patients who are members of the online support group Hope for HS. All indicated that the treatment options included in the PDA contained the appropriate amount of information, and most (71%, n=5/7) found it helpful to see these options compared to their values. At the end of the PDA, all but one stated they were either ready or very ready to make a treatment decision. All indicated that they would recommend the PDA to their friends and family with HS. 5 physicians across North America provided feedback on PDA content, presentation, and applicability to practice. The majority (60%, n=3/5) agreed that the content was accurate and that the amount of detail was appropriate. Most (80%, n=4/5) also agreed that the language was patient-friendly. All but one indicated that they would recommend patients use the PDA and bring their Patient Summary Page to their next appointment.

The participant blinded, parallel group RCT was conducted online with HS patients from the online support groups HS Warriors for Research and Hope for HS. 21 and 20 participants were randomized to the PDA and Mayo Clinic group, respectively. 15 and 13 participants in the PDA and Mayo Clinic group, respectively, fully completed the RCT, and only their data was assessed. The PDA group showed significantly improved levels of knowledge, lower levels of decisional conflict, and increased levels of preparedness for decision-making compared to the Mayo Clinic group.

The HS PDA received positive feedback from both patients and physicians. It was also shown to improve patient knowledge, reduce decisional conflict, and increase preparedness for decision-making. It is available at [www.informed-decisions.org](http://www.informed-decisions.org) and is free to use. Detailed findings of this research will be submitted for inclusion in an academic journal.