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## Online decision aid for patients with psoriasis

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There are many treatment options for psoriasis and it can be challenging to choose the best option for an individual patient. Evidence-based medicine indicates treatment decisions should be based on the best available evidence, physicians' clinical expertise and the values and desires of the patient. While guidelines and meta-analyses aid physicians by providing overviews of the evidence, a recent systematic review showed that the patient perspective is often underexplored in consultations with patients with psoriasis.[1]

Shared decision making (SDM) is an approach in which treatment decisions are made by physicians and patients together, taking patients' values and preferences into account.[2] Our recent survey study among patients with psoriasis or atopic dermatitis and dermatologists in the Netherlands showed that dermatologists experience a significantly higher level of SDM compared with patients. Also, our study showed the need for SDM in the treatment of these diseases, as 26% of patients reported that no treatment options were discussed.[3]

Short consultation times and a lack of patient knowledge about their disease and treatment options were identified as barriers for SDM.[1,3] These barriers may be overcome through the use of patient decision aids (PDAs). PDAs provide an overview of treatment options to support patients and physicians in the decision-making process. PDAs improve patient knowledge, help patients to clarify their values and promote patient engagement and autonomy, leading to more value-congruent choices.[4]

We developed a PDA for psoriasis, based on the Dutch guideline Psoriasis 2017,[5] which meets the International Patient Decision Aid Standard criteria. These criteria require PDAs to provide information that is understandable for patients, based on up-to-date high-quality evidence, in order to help patients identify their personal values and provide support in deliberation.[6] The PDA is online in both Dutch and English and freely accessible to everyone.[7] The content and development process are summarized below.

A working group was established consisting of three dermatologists, one dermatology resident, two researchers (one with a dermatology background and one with an SDM background) and two patients with psoriasis representing the Dutch association for patients with psoriasis.

Patient opinion led in defining the scope of the PDA. The patient participants indicated that taking the step from topical or phototherapy towards systemic therapy raises most questions and concerns. Although we did not find any literature supporting this claim, it is in line with our clinical experience. The Dutch guideline recommends starting conventional systemic treatments before biologics.[5] Therefore, the conventional systemic therapies (methotrexate, fumarates, ciclosporin, acitretin) were included. Apremilast and biologics (presented as a group) are presented as options to patients who reported previous use of conventional systemic drugs. The options of no treatment, lifestyle changes, topical therapy and phototherapy are outside the scope of the PDA, but are mentioned in the introduction of the PDA in order to inform patients sufficiently.

The therapeutic outcomes covered in the PDA are efficacy (on skin, nails and joints), most frequent side-effects, frequency and route of administration, frequency of clinic visits and blood tests, and other considerations such as dietary restrictions, if applicable.

We partly personalized the decision aid by showing only relevant information after some initial questions regarding, for example, previous treatments or pregnancy wish. The treatment options are presented separately and afterwards all options and outcomes are summarized in a grid (Table 1). To help patients in identifying their values, they are asked to rank the outcomes according to importance (e.g. effect on skin, side-effects). The 'results' can be printed, including notes or questions for the physician.

PDAs help physicians and patients to choose the most suitable therapy, but should not replace the personal interaction between patient and physician. In addition, outcomes of a decision aid are by no means binding.

One possible limitation of this study is the lack of focus group sessions with patients before starting the development process. Also, for some patients the decision aid might be too extensive.

To our knowledge, one other psoriasis PDA is available in English, which helps patients to choose which type of treatment (no treatment, topical therapy, phototherapy or systemic therapy) is suitable for them.[8] We believe that the more detailed information on systemic therapy in the Dutch psoriasis PDA is a valuable addition, and a major step in improving SDM in psoriasis. A study to measure the effects of the decision aid regarding the level of SDM and patient satisfaction is currently ongoing.

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Preview of the summary grid of the decision aid for patients with psoriasis

## Compare the treatments

In the table you see the characteristics of the different treatments. You can tick and untick the treatments and characteristics you are interested in. This way, you can compare the different treatments.

| Eigenschap | Methotrexate | Fumarates | Ciclosporin | Acitretin | Apremilast | Biologics |
|---|---|---|---|---|---|---|
| In how many people does their skin improve? | 40 of 100 | 40 of 100 | 50 of 100 | 25 to 75 of 100 | 34 of 100 | 40 to 80 of 100 |
| Does it work for nails? | Yes. | Unknown. | Yes. | Unknown. | Yes. | Yes. |
| Does it work for joints? | Yes. | No evidence available. | Possibly. | No. | Yes. | Yes. This varies per biologic. |
| How quickly does it work? | 3 weeks. | 4 weeks. | 2 weeks. | 5 weeks. | 9 weeks. | 4 weeks. This varies per biologic. |
| How much experience is there with the drug? | A great deal. | A lot. | A lot. | A lot. | Quite a lot. | This varies per biologic. |
| How long can you use it? | Years. | Years. | Max 2 years. | Years. | Years. | Years. |
| Type | Pill or injection. | Pill. | Pill. | Pill. | Pill. | Injection or IV. |
| How often to take? | Once a week. | 1 to 3 times per day. | 2 times per day. | Once a day. | 2 times per day. | 2 times per week to once every 3 months. |
| Number of checkups? | Once every 3 to 6 months. | Once every 3 months. | Once every 3 months. | Once every 3 months. | Only at start of treatment. | Once every 3 to 6 months. |
| Side-effects that occur very often | None. | Hot flashes, stomachache, nausea, diarrhea and reduced immune system function. | Headache, shaking of the body, extra hair growth on the body, high cholesterol, high blood pressure, kidney function disorders. | Dry eyes (difficulty wearing contact lenses), dry nose (nose bleeds), dry lips or mouth, thirst, infection of mucous membranes, chipping of the skin, hair loss, muscle aches, high cholesterol, high blood pressure, reduced liver function. | Nausea and diarrhea. This mostly passes within 4 weeks. | This varies per biologic:<br>Infections, rash or itching at the area of the injection. |

IV, intravenous.

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Conflicts of interest: Ph.I.S. has served as a consultant to AbbVie, and Sanofi, has been involved in performing clinical trials with many pharmaceutical industries that manufacture drugs used for the treatment of atopic dermatitis, and is Chief Investigator of the Dutch atopic dermatitis/eczema registry TREAT NL. E.M.B. has served as a consultant to Janssen Immunology and Novartis, is involved in performing clinical trials with pharmaceutical industries that manufacture drugs used for the treatment of inflammatory skin diseases and is co-founder of TrackCura. M.H. is the founder of PATIENT+. D.D. and M.B. are employed at PATIENT+. W.d.K. has participated in the advisory board for Janssen, Eli Lilly, Leo, AbbVie, UCB, Allmirall, Celgene and Novartis. I.v.E. has served as a patient advocate as a representative for the Psoriasispatiënten Nederland in trails and projects for Boehringer Ingelheim, Janssen and Almiral.