

Towards More Shared Decision Making in Dermatology: Development of Evidence-based Decision Cards for Psoriasis and Atopic Eczema Treatments

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In shared decision making (SDM) patients and physicians make treatment decisions together based on the best available evidence and the values and preferences of patients. SDM is very suitable for use in dermatological practice, but is infrequently applied by dermatologists. To support the application of SDM in dermatology we developed Decision Cards: 1-page overviews of possible treatment options, for use during a patient-physician consultation. Decision Cards provide answers to patients' most frequently asked questions, based on (inter)national guidelines, Summary of Product Characteristics, relevant literature, and clinical expertise. Three evidence-based Decision Cards were developed: 1 for biologicals or apremilast in psoriasis, and 2 for atopic eczema (1 for topical, photo- or systemic therapy, and 1 for systemic therapy only). More cards for psoriasis are currently in development. Patients, dermatologists and researchers collaborated in the development of the Decision Cards. This paper shares the framework used for the development of the Decision Cards, in order to support others in the development process.

Key words: shared decision making; encounter decision aids; psoriasis; atopic eczema; decision card.

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Shared decision making (SDM) can be defined as an approach in which physicians and patients share the best available evidence when faced with the task of making decisions, in order to choose the therapy that best suits a patient's values, preferences and needs (1).

Tan et al. (2) and Anstey & Edwards (3) wrote articles advocating more integration of SDM in dermatology. Many skin diseases have multiple treatment options, usually without a single best treatment. The best treatment depends on disease aspects (e.g. extent and location of the lesions), patient aspects (e.g. comorbidity, co-medication

SIGNIFICANCE

In shared decision making, patients and doctors share the best available evidence to find a treatment that best suits the patients' values and preferences. This process improves patients' knowledge and the likelihood of patients making decisions that are more congruent with their values, doctor-patient communication, and satisfaction with the treatment decision/decision making process. This paper describes the development of 3 Decision Cards to support this process: one for biologicals or apremilast in psoriasis, one for topical, photo- or systemic therapy in atopic eczema, and one for systemic therapy in atopic eczema. A framework that others can use to develop Decision Cards is presented.

and physical and emotional burden of the disease), and patient preferences (e.g. the frequency and route of administration, number of needed hospital visits or the need for controls). These aspects can vary between patients and in the same patient over time. Such preference-sensitive treatment decisions are most suitable for SDM (4).

Three steps have been proposed to apply SDM during a consultation: (i) acknowledge that a treatment decision has to be made and explore what role the patient wants in this decision making process, (ii) compare treatment options and discuss the benefits and harms of these options, (iii) make a treatment decision that best suits the patient's expectations, needs and lifestyle, guided by the experience of the healthcare team (5).

Patient decision aids (PDAs) are tools to support patients in the decision-making process, by providing information about treatment options and helping patients to identify their values. Encounter decision aids (EDAs) are PDAs developed for use during a consultation (6, 7).

The use of a decision aid improves patients' knowledge and the likelihood of patients making decisions more congruent with their values (8). It improves doctor-patient communication and satisfaction with the treatment decision and decision-making process, compared with usual care (8). Use of a decision aid may enhance treatment compliance, although studies report different outcomes on this subject (8).

The challenge in the development of decision aids is to provide scientifically correct information, which is helpful and understandable for patients. They are therefore preferably developed according to an established format. We developed Decision Cards; 1-page EDAs with an overview of different treatment options based on the questions most frequently asked by patients. They are similar to Option Grids, which have been designed and studied extensively by Glynn Elwyn's group (9–12), and make the treatment options easy to discuss because they are standardized and visually displayed (13). Decision Cards are preferably read by patients and physicians together (although patients can also take them home, as long as they engage in the decision making process), and support the discussion of individual patient's values and preferences, which are therefore only partly incorporated on the cards (9, 14).

To date, no Option Grids or Decision Cards are available in Dutch for any dermatological diseases, nor are such tools available in English for atopic eczema (AE). Since Decision Cards are designed for patients, it is important that they are available in the native language of a patient, and suitable for daily practice in a specific country.

It was decided to develop Decision Cards for psoriasis and AE, since treatment decisions for these diseases are preference-sensitive, many treatment options are available for these diseases, and because psoriasis and AE are common, hence many patients could benefit. This paper describes the framework used to develop the Decision Cards. This framework can be used as an example for the development of EDAs for other dermatological diseases.

MATERIALS AND METHODS

For the development of the Decision Cards a previously established framework was used, in which a clear order of consecutive steps was provided (Fig. 1) (15). This framework complies with the Dutch Protocol for the development of decision aids with guidelines (16), and was developed by the Knowledge Institute of the Dutch Association of Medical Specialists and the Netherlands

Patients Federation. Both have been initiators for the development of Decision Cards for multiple diseases. The format was inspired by that of the Dartmouth Institute for Option Grids (not published). The development and usage of Option Grids have been investigated for many years, but its trademark restrains the development of Option Grids by other researchers (9–12).

During the first phase, 2 project groups were formed; 1 for the development of a psoriasis Decision Card and 1 for the AE Decision Cards. Both project groups consisted of dermatologists affiliated with the Dutch National Society for Dermatology and Venereology (NVDV), patients, patient representatives of the national dermatology patient association (Skin Patients the Netherlands and Association for People with Atopic Dermatitis), researchers and project advisors experienced in the development of Decision Cards.

A Decision Card contains a maximum of 6 treatments due to the limited amount of space available (1 side of standard size A4 paper) (13). The project groups therefore defined a specific treatment category (e.g. systemic or topical therapies) and patient group (e.g. adults or children) per Decision Card. The project group selected treatment categories for which the need for more information on the treatment decision was most needed. Only treatments currently captured by the Dutch national guidelines were eligible.

In the 2nd phase, an invitation was sent via email to a cohort of patients with psoriasis and patients with AE. Of those who were willing to participate in the project, a selection was made for participation in a focus group, with the aim of recruiting a group of equal distribution in terms of age, sex, residence, education level and expertise with multiple treatments. Three focus groups, comprising 5 patients with psoriasis, 8 with AE for the first AE Decision Card, and 4 with AE for the 2nd AE Decision Card composed a list of important questions regarding the treatments.

Next, the project group added more questions based on their clinical expertise. An online survey with the complete list of questions was then sent to all psoriasis and AE patients in the cohort, members of the national patient societies, and a link to the survey was placed on the patient societies' websites. In this survey, patients were asked to judge the questions in 2 different ways:

- by rating the questions with a number from 1–10 (with 10 being the most important);
- by ranking the questions from most important to least important. If a question was ranked most important by a patient it received 1 point, the 2nd question received 0.5 points, the 3rd 0.33, the 4th 0.25, and the 5th 0.2 points. After the 5th question no points were awarded. The total number of points was then calculated for each question. Questions with the highest score were overall ranked as most important.

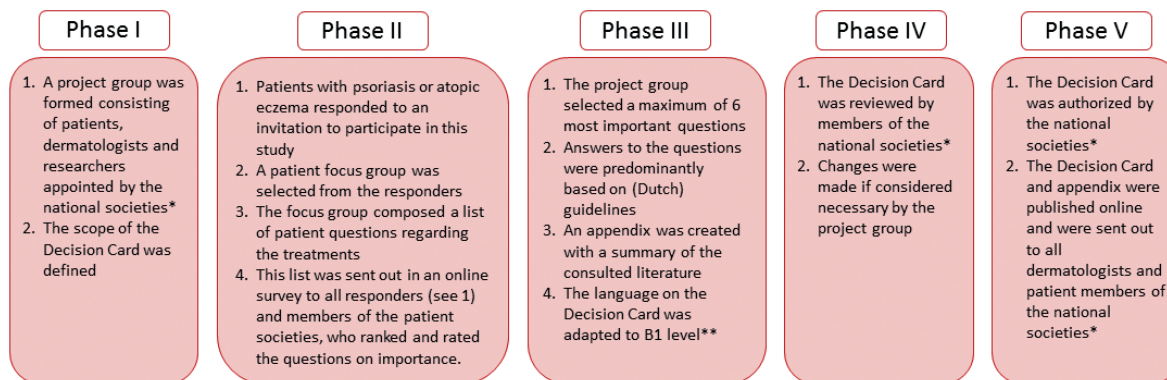


Fig. 1. Summary of the framework used for the development of a Decision Card. *Dutch National Society for Dermatology and Venereology and patient societies Skin patients the Netherlands and Dutch Association for People with Atopic Dermatitis. **According to the Common European Framework of Reference for Languages.

In the 3rd phase, a maximum of 6 most important questions were selected based on the patient surveys. If questions did not make this cut-off, but were often encountered in clinical practice according to the dermatologists, attempts were then made to merge them with other, already included, questions. In order to formulate answers to these questions, evidence from (inter)national guidelines (from the Netherlands (17, 18), the UK (19), the USA (20, 21) and the European Dermatology Forum (22, 23)) and summary of product characteristics (SmPC) texts were used. In case of discrepancies between guidelines, the national guideline was followed. If the consulted guidelines did not provide the answers, recent systematic reviews, meta-analyses and other (preferably randomized controlled) studies were consulted. Only if necessary, answers were based on expert opinions. Appendices were created containing a summary of the available and consulted literature and the rationale as to why certain information was or was not selected to be used for the answers on the Decision Cards (24–26).

In order to make the Decision Cards as accessible as possible to all patient groups the language used on the Decision Cards was adapted to B1 level according to the Common European Framework of Reference for Languages (27). After finalizing the first draft of the Decision Cards, members of the NVDV and the Dutch patient societies for psoriasis and AE were invited to give feedback (4th phase). In addition to the original framework, the Association Innovative Medicines (the industry association for the Dutch branches of innovative pharmaceutical companies) was invited to provide feedback. The suggestions received for modifications were then re-evaluated by the project group and, only if considered necessary, the answers on the Decision Cards were adjusted. The reasons for or against implementing the suggestions were collected and summarized in the appendix of the corresponding Decision Card. After this last step the Decision Cards were finalized and sent out to the NVDV and patient societies for approval and authorization (5th phase). Finally, the Decision Cards were published online at <https://consultkaart.nl>.

The Decision Cards were linked to the national guidelines so that any updates to the guidelines will be followed by an update of the Decision Cards.

RESULTS

The project group for the psoriasis Decision Card comprised 1 dermatologist, 1 dermatology researcher, 2 patient representatives and 1 project advisor. The project group for the

Table I. Decision Card: "Moderate to severe psoriasis: a biologic or apremilast?"

	Apremilast, 2015 (Otezla)	Adalimumab, 2007 (Humira, Amgevita, Hulio, Hyrimoz, Imraldi)	Etanercept, 2004 (Enbrel, Benepali, Erelzi)	Secukinumab, 2015 (Cosentyx)	Ustekinumab, 2008 (Stelara)	Infliximab, 2005 (Remicade, Remsima, Inflectra)
What does this treatment entail?	<ul style="list-style-type: none"> • Two pills are taken a day. • The intake is increased from 10 mg to 30 mg. • A blood test will be performed before start of treatment and during treatment only if necessary. 	<ul style="list-style-type: none"> • Self-applied injection. • One or 2 times a week. • A blood test will be performed before start of treatment and every 3–6 months during treatment. 	<ul style="list-style-type: none"> • Self-applied injection. • One or 2 times a week. • A blood test will be performed before start of treatment and every 3–6 months during treatment. 	<ul style="list-style-type: none"> • Self-applied injections: 2 at a time. • The first month once a week, thereafter once a month. • A blood test will be performed before start of treatment and every 3–6 months during treatment. 	<ul style="list-style-type: none"> • Self-applied injection or injection at the hospital. • Week 0 and 4. Thereafter once every 12 weeks. • A blood test will be performed before start of treatment and every 3–6 months during treatment. 	<ul style="list-style-type: none"> • An infusion is given at the hospital. • Week 0, 2 and 6, thereafter once every 8 weeks. • A blood test will be performed before start of treatment and every 3–6 months during treatment.
What is the effect of the treatment?	<ul style="list-style-type: none"> • The first effect can be noticed after 9–11 weeks.* • 34 of 100 patients (34%) notice a good effect.** • Unknown how many patients still benefit from this drug after 3 years. 	<ul style="list-style-type: none"> • The first effect can be noticed after 4–5 weeks.* • 70 of 100 patients (70%) notice a good effect.* • After 3 years 56 of 100 patients (56%) still benefit from this drug. 	<ul style="list-style-type: none"> • The first effect can be noticed after 6–7 weeks.* • 41 of 100 patients (41%) notice a good effect.** • After 3 years 51 of 100 patients (51%) still benefit from this drug. 	<ul style="list-style-type: none"> • The first effect can be noticed after 3–4 weeks.* • 78 of 100 patients (78%) notice a good effect.** • Unknown how many patients still benefit from this drug after 3 years. 	<ul style="list-style-type: none"> • The first effect can be noticed after 4–5 weeks.* • 72 of 100 patients (72%) notice a good effect.** • After 3 years 79 of 100 patients (79%) still benefit from this drug. 	<ul style="list-style-type: none"> • The first effect can be noticed after 3–4 weeks.* • 57 of 100 patients (57%) notice a good effect.** • After 3 years 51 of 100 patients (51%) still benefit from this drug.
What are the most common side-effects that occur in 10 or more of 100 patients (≥10%)?	<ul style="list-style-type: none"> • Gastro-intestinal complaints • Weight loss • Although not very common, there is a slightly higher risk of mental disorders such as sleep loss and depression. 	<ul style="list-style-type: none"> • Infections • Headache • Rash • Muscle aches • Gastro-intestinal complaints • Redness or itch at the injection site • Abnormalities in your blood test results 	<ul style="list-style-type: none"> • Infections • Hives • Redness or itch at the injection site 	<ul style="list-style-type: none"> • There are no known very common side-effects for this drug; however, every drug can have side-effects. • Allergic reactions during or after infusion 	<ul style="list-style-type: none"> • There are no known very common side-effects for this drug; however, every drug can have side-effects. • Allergic reactions during or after infusion 	<ul style="list-style-type: none"> • Infections • Gastro-intestinal complaints • Headache • Allergic reactions during or after infusion
Does this treatment affect my other disorders or medication?	<ul style="list-style-type: none"> • If you use i.a. rifampicin, anti-epileptics or St John's Wort, apremilast is less effective. • If you have a congenital metabolic disorder this drug might not be suitable. • In psoriatic arthritis this drug is usually not recommended. 	<ul style="list-style-type: none"> • Do not use this drug in severe heart failure. • If you have multiple sclerosis (MS) or systemic lupus erythematosus (SLE) this drug is less suitable. • In psoriatic arthritis this drug is preferred. 	<ul style="list-style-type: none"> • Do not use this drug in severe heart failure. • If you use medication for diabetes your blood sugar levels can lower after starting this treatment. • If you have multiple sclerosis (MS) this drug is less suitable. • In psoriatic arthritis this drug is preferred. 	<ul style="list-style-type: none"> • Caution is advised in patients with Crohn's disease or ulcerative colitis. • In psoriatic arthritis this drug is less preferred. 	<ul style="list-style-type: none"> • In psoriatic arthritis this drug is less preferred. 	<ul style="list-style-type: none"> • Do not use this drug in severe heart failure. • If you have multiple sclerosis (MS) or systemic lupus erythematosus (SLE) this drug is less suitable. • In psoriatic arthritis this drug is preferred.

Are you 18 years or older and diagnosed with psoriasis? Are you considering starting treatment with a biological or apremilast? This Decision Card can support you and your doctor when discussing treatment options. The Decision Card is based on the Dutch Psoriasis guideline 2017; newer drugs are not (yet) listed. These treatments are generally not suitable for patients with severe active infections or cancer, or for pregnant or breastfeeding women. If you also use other immune suppressing drugs there may be more risks of side-effects. During treatment live vaccines should be avoided. It is recommended to get the annual flu vaccine.
*Time until Onset of Action (TOA): time until 25% of patients achieve Psoriasis Area and Severity Index (PASI) 75. **PASI 75 after 12–16 weeks. i.a.: inter alia.

2 AE Decision Cards comprised 2 dermatologists, 1 dermatology researcher, 3 patient representatives and 1 project advisor.

Three Decision Cards were developed (see **Tables I–III**). For psoriasis, 1 card was developed for biologics or apremilast in psoriasis vulgaris, as this is the most frequently encountered treatment decision in our (third-line) hospital. For AE 2 cards were developed: one for systemic medication in AE (AE I) and one for different types of treatment in AE (topical, phototherapy or systemic therapy, AE II). All 3 Decision Cards were designed for adult patients.

In February and March 2017, online surveys with the proposed questions for the psoriasis and AE I Decision Cards were carried out. The survey for Decision Card AE II followed in August and September 2017. Thirty-four patients with psoriasis, 76 (AE I) and 60 (AE II) patients with AE completed the surveys. The characteristics of the patients are described in **Table IV**. The most important questions, including the mean rating score (0–10) and

weighted ranking, are described per survey in Tables SI–SIII¹.

For psoriasis the selected questions were:

- *What does this treatment entail?* Route and frequency of administration, hospital visits and blood tests were incorporated.
- *What is the effect of the treatment?* We showed: (i) the percentage of patients achieving a good effect, defined as Psoriasis Area and Severity Index (PASI) 75 (75% improvement of the PASI) after 3–4 months; (ii) the time until onset of action (TOA) (28), defined as the time until 25% of patients achieve PASI 75; and (iii) drug survival after 3 years.
- *What are the most common side-effects that occur in 10 or more of 100 patients ($\geq 10\%$)?* The very frequent side-effects, according to the SmPC texts, were added. After extensive discussions in the project group, risk of depression and sleep loss in apremilast were also added, since these are mentioned explicitly in the SmPC text.
- *Will this treatment affect my other disorders or medication?* Since psoriatic arthritis (PsA) is relatively common in patients with severe psoriasis, the effect of the drugs on PsA was added (17). Furthermore, diseases which are related and more common in patients with psoriasis (inflammatory bowel disease, multiple sclerosis and systemic lupus erythematosus), and diseases that make a clear distinction in the preference for certain drugs, such as heart failure, were discussed.

¹<https://doi.org/10.2340/00015555-3614>

Table II. Decision Card: "Atopic eczema: treatment options for systemic drugs in adults. (AE I)"

	Ciclosporin	Azathioprine	Methotrexate	Mycophenolate, mycophenolic acid	Prednisone
What does this treatment entail?	<ul style="list-style-type: none"> • Two pills are taken a day; before, during or after a meal. • This drug can be used for 1–2 years, and sometimes longer. 	<ul style="list-style-type: none"> • Two pills are taken a day; 1 hour before or 3 hours after a meal. • This drug can be used for 1 year, some people use it for several years. 	<ul style="list-style-type: none"> • One pill or self-applied injection is taken a week; 1 hour before or 1.5 to 2 hours after a meal. • This drug can be used for more than 5 years. 	<ul style="list-style-type: none"> • Two pills are taken a day; before, during or after a meal. • Some people use this drug for several years. 	<ul style="list-style-type: none"> • One pill is taken a day; before or during a meal. • It is not recommended to use this drug for a long time. In severe and acute flares you can take this drug for 2–3 weeks.
What is the effect on my signs and symptoms? And how quickly do they improve?	<ul style="list-style-type: none"> • Good effect on the signs and symptoms. • Good effect on itch. • The signs and symptoms reduce within 2–6 weeks. 	<ul style="list-style-type: none"> • Moderate effect on the signs and symptoms. • Moderate effect on itch. • The signs and symptoms reduce within a few weeks to a few months. 	<ul style="list-style-type: none"> • Moderate effect on the signs and symptoms. • Moderate effect on itch. • The signs and symptoms reduce within a few to 10 weeks. 	<ul style="list-style-type: none"> • Moderate effect on the signs and symptoms. • Probably a moderate effect on itch. • The signs and symptoms reduce within a few weeks to a few months. 	<ul style="list-style-type: none"> • Very good effect on the signs and symptoms. • Very good effect on itch. • The signs and symptoms reduce within 1 day to a few days.
What are the very frequent side-effects that occur in 10 or more of 100 patients ($\geq 10\%$)?	<ul style="list-style-type: none"> • Increased blood fats (such as cholesterol) • Tremors • Headache • High blood pressure • Excessive hair growth on the face/body • Impaired kidney function 	<ul style="list-style-type: none"> • Shortage of white blood cells due to impaired bone marrow function 	<ul style="list-style-type: none"> • Decreased appetite • Nausea, vomiting, stomach ache • Inflammation and ulceration of the mucous membranes of the mouth and throat • Stomach and oesophagus complaints • Impaired liver function 	<ul style="list-style-type: none"> • Blood poisoning • Shortage of white blood cells • Shortage of platelets • Anaemia • Nausea, vomiting, stomach ache, diarrhoea 	<ul style="list-style-type: none"> • There are many "frequent" side-effects (in 1–10 of 100 patients (1–10%)) such as disturbed blood sugar levels, mood swings and fluid retention.
Which disorders may worsen when you use this drug?	<ul style="list-style-type: none"> • Impaired kidney function • Disorders of the liver • High blood pressure • Gout 	<ul style="list-style-type: none"> • Impaired liver function • Impaired bone marrow function • Pancreatitis • Gout 	<ul style="list-style-type: none"> • Disorders of the liver or kidney • Impaired bone marrow function • Poor lung function or lung fibrosis (scarring of lung tissue) • Immune disorders • Gastric ulcer • Gout 	<ul style="list-style-type: none"> • Gout 	<ul style="list-style-type: none"> • Gastric or duodenal ulcer • Diabetes • High blood pressure • Osteoporosis • Mental disorders
When should you not use this drug?	<ul style="list-style-type: none"> • Are you pregnant or do you want to become pregnant? Then only use this drug under strict supervision of your doctor. • Are you breastfeeding? Then do not use this drug. 	<ul style="list-style-type: none"> • Are you pregnant, do you want to become pregnant, or are you breastfeeding? Or do you want to become a father? Then do not use this drug. 	<ul style="list-style-type: none"> • Are you pregnant, do you want to become pregnant, or are you breastfeeding? Or do you want to become a father? Then do not use this drug. 	<ul style="list-style-type: none"> • Limit your alcohol consumption to a minimum. • Are you pregnant, do you want to become pregnant, or are you breastfeeding? Or do you want to become a father? Then do not use this drug. 	<ul style="list-style-type: none"> • Are you pregnant or do you want to become pregnant? Then only use this drug under strict supervision of your doctor. • Are you breastfeeding? Then do not use this drug.

Have you been diagnosed with atopic eczema? This Decision Card can support you and your doctor when discussing treatment options for systemic drugs. It is based on the Dutch guideline Atopic eczema 2014. Systemic drugs are drugs that work throughout the whole body. All drugs suppress the inflammatory response and/or suppress the immune system, which improves your eczema. These drugs may increase the risk of infections and cancer. During treatment, live vaccines should be avoided. Are you deciding between a treatment with an ointment or cream, phototherapy or a systemic treatment? Then please use the Decision Card "Atopic Eczema: treatment options in adults".

Table III. Decision Card: 'Atopic eczema: treatment options in adults. (AE II)'

	Ointment, cream or lotion	Calcineurin inhibitors	Coal tar	Phototherapy (UVA, UVB)	Systemic drugs
What does this treatment entail?	<ul style="list-style-type: none"> Corticosteroids are applied on the skin 1 or 2 times a day, for 2 to 7 days a week How long corticosteroids need to be applied depends on: The severity of your eczema. The strength of the corticosteroids. Strength: 1, 2, 3, or 4, of which 4 is the strongest. How often the ointment is applied Where on the body it is applied. 	<ul style="list-style-type: none"> Calcineurin inhibitors are applied on the skin 1 or 2 times a day, for 2 to 7 days a week. It is safe to use this for a long time 	<ul style="list-style-type: none"> Coal tar is applied on your skin 1 or 2 times a day. You can do this every day It is safe to use this for a long time 	<ul style="list-style-type: none"> Visits to the outpatient clinic are needed for this treatment; 2–3 times a week over a period of 6–12 weeks In consultation with your doctor, treatment at home may be possible 	<ul style="list-style-type: none"> The specific type of drug influences the frequency and length of treatment These drugs (pills or injections) are taken 1 time a week to 2 times a day The drugs can be used for a couple of weeks to several years
What is the chance that signs (such as redness and scaling) and itch decrease?	<ul style="list-style-type: none"> This depends on the strength, how often it is applied and whether it is an ointment, cream or lotion: Good effect on signs. Good effect on itch. 	<ul style="list-style-type: none"> Moderate to good effect on signs. Moderate to good effect on itch. 	<ul style="list-style-type: none"> Moderate effect on signs Possibly good effect on itch 	<ul style="list-style-type: none"> Moderate to good effect on signs Moderate to very good effect on itch 	<ul style="list-style-type: none"> This depends on the drug: Moderate to very good effect on signs. Moderate to very good effect on itch.
What are the most important side-effects that can occur?	<ul style="list-style-type: none"> This depends on the strength, how often and where on the body it is applied: Pimples The skin can become lighter Red, itching bumps around the mouth A thinner skin resulting in small blood vessels becoming more visible and small bruises or stretchmarks There are no limitations 	<ul style="list-style-type: none"> These side-effects can occur on the skin where you apply the drug: Burning sensation Itch Redness and irritation in the face when drinking alcohol 	<ul style="list-style-type: none"> Skin irritation Allergic reaction Inflamed hair follicles Pimples Unpleasant smell Discolouring of your skin, hair, clothing and bedsheets 	<ul style="list-style-type: none"> These drugs can have many side-effects. We refer to the Decision Card 'Atopic eczema: treatment options for systemic drugs in adults.' 	<ul style="list-style-type: none"> Avoid alcohol completely or limit your use in combination with specific medications Most treatments cannot be used. In some cases treatment is possible under strict supervision of your doctor
What can I no longer do with this treatment?	<ul style="list-style-type: none"> Limit the amount or prevent sun exposure to your skin Do not use this treatment 	<ul style="list-style-type: none"> Limit the amount or prevent sun exposure to your skin Do not use this treatment 	<ul style="list-style-type: none"> Limit the amount or prevent sun exposure to your skin Do not use this treatment 	<ul style="list-style-type: none"> Limit the amount of sun exposure to your skin There are no limitations 	<ul style="list-style-type: none"> Limit the amount of sun exposure to your skin There are no limitations
Are you pregnant, do you want to become pregnant or are you breastfeeding?	<ul style="list-style-type: none"> This treatment is possible under supervision of your doctor 	<ul style="list-style-type: none"> Do not use this treatment 	<ul style="list-style-type: none"> Do not use this treatment 	<ul style="list-style-type: none"> There are no limitations 	<ul style="list-style-type: none"> Most treatments cannot be used. In some cases treatment is possible under strict supervision of your doctor

Have you been diagnosed with atopic eczema? This Decision Card can support you and your doctor when discussing the options for treatment. It is based on the Dutch guideline Atopic eczema 2014. All treatments inhibit the inflammatory response and/or suppress the immune system, which improves your eczema. Are you and your doctor considering systemic medication? Then please also use the Decision Card 'Atopic Eczema: possibilities for systemic treatment in adults'. Systemic drugs are drugs that work throughout the whole body.

For AE I the questions were:

- *What does this treatment entail?* The route and frequency of administration, need to take the drugs with or without a meal, and the possible duration of treatment were incorporated.
- *What will be the effect on my signs and symptoms? And how quickly will they improve?* Due to severe heterogeneity in the study, reported outcomes on clinical signs and itch, the project group had to take multiple different treatment effects into consideration. After careful comparison the project group categorized the treatment effects in a 4-point ordinal scale, ranging from no effect to very good effect.
- *What are the very frequent side-effects that occur in 10 or more of 100 patients (≥10%)?* The very frequent side-effects according to the SmPC text were reported.
- *Which disorders may worsen when you use this drug?* The absolute contra-indications derived from the Dutch guideline were added (18).
- *When should you not use this drug?* Advice for patients wishing to have children, breastfeeding, and alcohol use were discussed.

For AE II the questions were:

- *What does this treatment entail?* The route and frequency of the drug and the possible duration of treatment were added. For topical corticosteroids it was mentioned that the strength of the drug, the severity of AE, frequency and location of application all influence treatment duration.
- *What is the chance that signs (such as redness and scaling) and itch decrease?* The same 4-point ordinal scale as used in the AE I Decision Card was applied. Strength, frequency and type of ointment were added as influential factors for corticosteroids, and strength only for calcineurin inhibitors.
- *What are the most important side-effects that can occur?* For topical corticosteroids, coal tar and phototherapy, no very frequent side-effects are known. Therefore, the Dutch guideline was followed for the most important side-effects for these therapies.
- *What can I no longer do with this treatment? Are you pregnant, do you want to become pregnant or are you breastfeeding?* SmPC texts were used for these questions, as well as information about the treatments acquired from the pharmaceutical companies. If no information was available, expert opinions were incorporated.

DISCUSSION

In chronic illnesses, such as psoriasis and AE, it is especially important for patients to adopt a more active role in decision making, as, throughout the course of the disease, multiple treatment decisions need to be made (3, 29). The need for decision aids in dermatology, and especially short and feasible decision aids for busy clinicians, was previously indicated by Tan et al. (2), and is also highlighted by research that has

Table IV. Characteristics of the patients participating in the surveys

	Psoriasis n (%)	Atopic Eczema I – systemic treatment n (%)	Atopic Eczema II – any treatment n (%)
Participants	34	76	60
Men	13 (38)	14 (18)	14 (24)
Age			
< 18 years	0	2 (3)	1 (2)
18–30 years	1 (3)	4 (5)	3 (5)
31–50 years	9 (27)	19 (25)	16 (27)
51–70 years	24 (70)	47 (62)	34 (56)
> 70 years	0	4 (5)	6 (10)
Disease duration >5 years	32 (95)	67 (88)	52 (86)
Diagnosed with nail psoriasis	20 (59)	NA	NA
Diagnosed with psoriatic arthritis	21 (62)	NA	NA
Highest level of education			
Higher education ISCED 6–8	11 (32)	11 (14)	Unknown
Secondary education ISCED 3–5	9 (27)	30 (38)	Unknown
Lower education ISCED 0–2	14 (18)	14 (19)	Unknown

NA: not applicable; ISCED: International Standard Classification of Education.

shown time-constraints are one of the most important perceived barriers for physicians for the application of SDM (30). Decision Cards are compact tools and provide the most important information to make comparisons at a glance, which is sometimes all that is needed to make a decision (1–3, 13). We therefore believe that Decision Cards are useful support tools to improve SDM in the dermatological setting, and are optimistic that they will find their way into daily practice. We hope that, by sharing our experience, others will be able to develop Decision Cards to further enhance SDM.

Two other EDAs for dermatological diseases could be found. One EDA for psoriasis was presented in the British Association of Dermatologists (BAD) guidelines for biologic therapy for psoriasis 2017 (19). The treatments discussed in this EDA are slightly different, since ixekizumab was discussed and apremilast was not. Also, more and slightly different questions are answered: start dosages are not discussed; effectiveness is registered as PASI 90 instead of PASI 75; drug survival after one year instead of 3 years is mentioned; and side-effects causing cessation of the treatment or admission to hospital due to infection are provided. Another EDA was found for actinic keratosis, but no development methods were reported (31).

Strengths and limitations

The Decision Cards provided in this study were based on the previously described framework (15), which was based on the format of the Dartmouth Institute, and has been used previously for many Decision Cards. Since the Knowledge Institute successfully developed multiple Decision Cards, expertise from their advisors was beneficial for the development of our cards. Because the questions on the Decision Cards were defined by patients as most important, they provide relevant information for patients when facing a treatment decision. Data used to

answer these questions were derived from (inter)national guidelines, systematic reviews, international SmPC texts and, if necessary, primary research and clinical expertise. Relevant stakeholders, affiliated to dermatological, pharmaceutical and patient organizations, were involved (either in the development phase or in the review phase), which creates a good support base for the implementation and use of the Decision Cards. To provide transparency, for each Decision Card an appendix was made in which the quality of evidence of the consulted literature can be found. Because the cards are linked to the national guidelines, updates of the guidelines will guarantee updates of the Decision Cards. Since the Decision Cards are in Dutch and the language was adapted to the B1 level according to the Common European Framework of Reference for Languages, the Decision Cards will be useful for many psoriasis and AE patients in the Netherlands. For the purpose of this article, English versions of the Decision Cards are provided, which are loosely translated from the Dutch Decision Cards.

A few limitations need to be mentioned. Due to the limited space on a Decision Card only a selection of questions, treatments and information could be included. Also, sufficient evidence was not available to answer the questions properly for all treatment options. Since this might influence the treatment decision, it was mentioned on the Decision Cards whenever applicable. As the surveys for the most important questions were dispersed via a link on the websites of patient societies, response rates cannot be calculated. In both psoriasis and AE research many different outcome measures are used (32–34). Due to this heterogeneity it is difficult to compare evidence. Future studies should preferably report core outcomes (35). To promote high-quality control criteria for PDAs, the International Patient Decision Aids Standards (IPDAS) criteria were developed (36). Unfortunately, these criteria are not yet suitable for EDAs due to their compact size, but it is hoped that they will be applicable in the near future (14). Lastly, since the Dutch treatment guidelines were leading in the development of these Decision Cards, not all available treatments were discussed, and the answers provided on the Decision Cards can differ from other guidelines. Physicians from other countries are advised to check whether these decision cards are suitable for their country. There is a need to update the Decision Cards regularly in the future with the best available evidence. In order to do so, it might be favourable to base Decision Cards on living, international guidelines in the future, and adapt them to the availability of therapies in each specific country. If living, international guidelines do not become available in the near future, the Decision Cards should be updated with every guideline update, as currently agreed.

Future perspective

It is hoped that more Decision Cards will be developed, especially for topical, photo and systemic therapies in psoriasis, and eventually also for the (newer) biologics in both psoriasis and AE. In addition, the impact of Decision Cards on SDM in clinical practice should be evaluated. It might be helpful to develop EDAs that present information more graphically rather than textually.

To fully benefit from decision aids it is important that they are properly implemented. This will require a change in clinical routine and more attention for SDM during a consultation (5). Although some physicians feel SDM takes up too much time, SDM might also save time in the long run, through better compliance, better outcomes and selecting the correct treatment the first time a treatment-decision needs to be made (8). Decision Cards should not replace the conversation between the patient and physician, and physicians should provide patients with extra information if the decision card is not entirely suitable to their personal situation. Furthermore, in order to properly inform patients and enhance SDM correctly, the quality of decision aids is of importance. There is therefore a need to harmonize the development of decision aids, including EDAs. For this reason, we have started a collaboration with multiple other dermatology departments in the Netherlands, in order to reduce duplication of effort and resource expenditure, and we encourage others to do the same.

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Conflicts of interest: GK was involved as sub-investigator in clinical trials for Abbvie, Novartis, LeoPharma, Lilly, Janssen and Regeneron. PS has served as a consultant to AbbVie, Anacor, Leo Pharma, Novartis and Sanofi, has received independent research grants from Leo Pharma and Schering-Plough (> 5 years ago), has been involved in performing clinical trials with many pharmaceutical industries that manufacture drugs used for the treatment of psoriasis and atopic eczema, and is Chief Investigator of the Dutch AE registry – TREAT NL. RT was a consultant to Novartis, Sanofi and Janssen, and has received an independent research grant from Novartis. MV was involved as sub-investigator in clinical trials for Abbvie, LeoPharma, Lilly, Janssen and Regeneron.

REFERENCES

1. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ* 2010; 341.
2. Tan J, Linos E, Sendelweck MA, van Zuuren EJ, Ersser S, Della-valle RP, et al. Shared decision making and patient decision

- aids in dermatology. *Br J Dermatol* 2016; 175: 1045–1048.
3. Anstey A, Edwards A. Shared decision making in dermatology: asking patients, "What is important to you?" *Br J Dermatol* 2014; 170: 759–760.
4. Stiggelbout AM, Pieterse AH, De Haes JCJM. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns* 2015; 98: 1172–1179.
5. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision making: multistage consultation process. *BMJ* 2017; 359: j4891.
6. Zisman-Ilani Y, Shern D, Deegan P, Kreyenbuhl J, Dixon L, Drake R, et al. Continue, adjust, or stop antipsychotic medication: developing and user testing an encounter decision aid for people with first-episode and long-term psychosis. *BMC Psychiatry* 2018; 18: 142.
7. Durand MA, Yen RW, O'Malley AJ, Politi MC, Dhage S, Rosenkranz K, et al. What matters most: protocol for a randomized controlled trial of breast cancer surgery encounter decision aids across socioeconomic strata. *BMC Public Health* 2018; 18: 241.
8. Stacey D, Legare F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017; 4: Cd001431.
9. Elwyn G, Pickles T, Edwards A, Kinsey K, Brain K, Newcombe RG, et al. Supporting shared decision making using an Option Grid for osteoarthritis of the knee in an interface musculoskeletal clinic: a stepped wedge trial. *Patient Educ Couns* 2016; 99: 571–577.
10. Scalia P, Durand MA, Kremer J, Faber M, Elwyn G. Online, interactive option grid patient decision aids and their effect on user preferences. *Med Decis Making* 2018; 38: 56–68.
11. Barnett ER, Boucher EA, Daviss WB, Elwyn G. Supporting shared decision-making for children's complex behavioral problems: development and user testing of an option grid decision aid. *Community Ment Health* 2018; 54: 7–16.
12. Stiggelbout AM, Van der Weijden T, De Wit MP, Frosch D, Legare F, Montori VM, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012; 344: e256.
13. Elwyn G, Lloyd A, Joseph-Williams N, Cording E, Thomson R, Durand MA, et al. Option Grids: shared decision making made easier. *Patient Educ Couns* 2013; 90: 207–212.
14. Durand MA, Witt J, Joseph-Williams N, Newcombe RG, Politi MC, Sivell S, et al. Minimum standards for the certification of patient decision support interventions: feasibility and application. *Patient Educ Couns* 2015; 98: 462–468.
15. Framework for the development of Decision Cards (Dutch only) (last accessed Dec 4, 2019). Available from: https://consultkaart.nl/wp-content/uploads/2017/07/20170601_Web-tekst-pdf-Procedure-ontwikkeling-Consultkaarten.pdf.
16. Dutch Protocol for the development of Decision Aids with Guidelines (Dutch only) (last accessed Dec 4, 2019). Available from: https://www.patientfederatie.nl/images/voor_patiëntenorg/2018_leidraad_keuzehulp_bij_richtlijnen.pdf.
17. van der Kraaij GE, Balak DMW, Busard CI, van Cranenburgh OD, Chung Y, Driessen RJB, et al. Highlights of the updated Dutch evidence- and consensus-based guideline on psoriasis 2017. *Br J Dermatol* 2019; 180: 31–42.
18. Bruijnzeel-Koomen CAFM, Spuls PI, Bruin-Weller MSd, Pasmans GMA, Oranje A, Tupker R, et al. NVDV Richtlijn-Constitutioneel-Eczeem-2014 (last accessed Dec 4, 2019). Available from: <http://www.nvdv.nl/wp-content/uploads/2014/08/Richtlijn-Constitutioneel-Eczeem-2014.pdf>.
19. Smith CH, Jabbar-Lopez ZK, Yiu ZZ, Bale T, Burden AD, Coates LC, et al. British Association of Dermatologists guidelines for biologic therapy for psoriasis 2017. *Br J Dermatol* 2017; 177: 628–636.
20. Eichenfield LF, Tom WL, Berger TG, Krol A, Paller AS, Schwarzenberger K, et al. Guidelines of care for the management of atopic dermatitis: section 2. Management and treatment of atopic dermatitis with topical therapies. *J Am Acad Dermatol* 2014; 71: 116–132.
21. Sidbury R, Davis DM, Cohen DE, Cordero KM, Berger TG, Bergman JN, et al. Guidelines of care for the management

- of atopic dermatitis: section 3. Management and treatment with phototherapy and systemic agents. *J Am Acad Dermatol* 2014; 71: 327–349.
22. Nast A, Gismondi P, Ormerod AD, Saiag P, Smith C, Spuls PI, et al. European S3-Guidelines on the systemic treatment of psoriasis vulgaris. *J Eur Acad Dermatol Venereol* 2015; 29: 2277–2794.
 23. Wollenberg A, Oranje A, Deleuran M, Simon D, Szalai Z, Kunz B, et al. ETFAD/EADV Eczema task force 2015 position paper on diagnosis and treatment of atopic dermatitis in adult and paediatric patients. *J Eur Acad Dermatol Venereol* 2016; 30: 729–747.
 24. Appendix for Decision Card: Moderate to severe psoriasis: a biologic or apremilast? (last accessed Dec 4, 2019). Available from: https://consultkaart.nl/wp-content/uploads/2019/02/Evidence-document-Consultkaart-Psoriasis_biological-of-apremilast.pdf.
 25. Appendix for Decision Card: Atopic eczema: treatment options for systemic drugs in adults. (AE I) (last accessed Dec 4, 2019). Available from: https://consultkaart.nl/wp-content/uploads/2019/02/Evidence-document-Consultkaart-Constitutioneel-atopisch-eczeem_mogelijkheden-voor-systemische-medicijnen-bij-volwassenen.pdf.
 26. Appendix for Decision Card: Atopic eczema: treatment options in adults. (AE II) (last accessed Dec 4, 2019). Available from: https://consultkaart.nl/wp-content/uploads/2019/02/Evidence-document-Consultkaart-Constitutioneel-atopisch-eczeem_mogelijkheden-voor-behandeling-bij-volwassenen.pdf.
 27. The Common European Framework of Reference for Language (last accessed Dec 4, 2019). Available from: <https://www.coe.int/en/web/common-european-framework-reference-languages>.
 28. Nast A, Sporbeck B, Rosumeck S, Pathirana D, Jacobs A, Werner RN, et al. Which antipsoriatic drug has the fastest onset of action? – Systematic review on the rapidity of the onset of action. *J Invest Dermatol* 2013; 133: 1963–1970.
 29. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expect* 2006; 9: 25–36.
 30. Legare F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns* 2008; 73: 526–535.
 31. Decision aid Actinic keratosis (last accessed Dec 4, 2019). Available from: <https://dermatologycentral.typepad.com/resource/2017/04/actinic-keratosis-decision-aid.html>.
 32. Spuls PI, Lecluse LL, Poulsen ML, Bos JD, Stern RS, Nijsten T. How good are clinical severity and outcome measures for psoriasis?: quantitative evaluation in a systematic review. *J Invest Dermatol* 2010; 130: 933–943.
 33. Gerbens LA, Chalmers JR, Rogers NK, Nankervis H, Spuls PI. Reporting of symptoms in randomized controlled trials of atopic eczema treatments: a systematic review. *Br J Dermatol* 2016; 175: 678–686.
 34. Schmitt J, Langan S, Williams HC. What are the best outcome measurements for atopic eczema? A systematic review. *J Allergy Clin Immunol* 2007; 120: 1389–1398.
 35. Core Outcomes Set Initiative (CS-COUSIN) (last accessed Dec 4, 2019). Available from: <https://skin.cochrane.org/core-outcomes-set-initiative-csg-cousin>.
 36. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006; 333: 417.