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Development of a shared decision-making tool in vitiligo: an international study*

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Summary

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Conflicts of interest

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Data availability statement

Data obtained for this study are available upon request to the corresponding author.

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Background Shared decision-making tools (SDMt) are visual tools developed to promote joint medical decisions between physicians and patients. There is a paucity of such tools in dermatology.

Objectives To develop and validate a SDMt for use in specialized consultation for vitiligo.

Methods A prospective cross-sectional study was carried out from March 2019 to March 2020. We first conducted a qualitative study of topics discussed by patients and clinicians during therapeutic decision-making in the setting of a specialized consultation for vitiligo using an anchored-theory method, which allowed conceptualization of the SDMt. The usefulness of the SDMt was evaluated by a working group of multidisciplinary health workers and patients with vitiligo. Consensus on the final tool was obtained through an e-Delphi method.

Results We recruited 30 patients with vitiligo for the qualitative study, which identified 91 topics related to therapeutic decision-making. Hierarchical clustering analysis confirmed the distribution of these topics in two subgroups (general treatment goals and priorities, and topics specific to each treatment). The consensus of a multidisciplinary group was used to develop the SDMt. The tool was comprised of eight A5 cards, which addressed face repigmentation; body repigmentation (limited area); body repigmentation (extended area); partial or complete depigmentation; coping with the disease; stabilization of disease; maintaining repigmentation; and disease information. Cognitive interviews confirmed the satisfaction, readability and usefulness of the SDMt. The SDMt was then translated and culturally validated in English.

Conclusions We developed a tool for shared decision-making in nonsegmental vitiligo, which we translated and cross-culturally validated in a US patient population with vitiligo to ensure its generalizability.

What is already known about this topic?

- Therapeutic management in vitiligo is often challenging and requires long-term adherence.

- Shared decision-making tools (SDMt) are visual aids that may help patients better define what they would like to achieve in terms of treatment.
- In dermatology, there have been various decision support tools developed but none for vitiligo.

What does this study add?

- We developed a SDMt that was tested in 30 French and 10 US adult patients with vitiligo who reported high satisfaction rates with the use of this tool during consultation.
- This SDMt for vitiligo may help patients better define how they would like to improve their adherence to treatment and what they consider successful in terms of treatment.

What are the clinical implications of this work?

- The SDMt for vitiligo can be used routinely in daily clinical practice, which may help to increase patient adherence to treatment.

Vitiligo, a chronic disease characterized by acquired depigmented macules, affects 0.5–1% of the world's population.¹ Despite the fact that vitiligo is an established autoimmune disorder, it is still often considered a cosmetic disease, even though it is perceived by patients to be severe and stigmatizing,² and therapeutic management is often difficult. Several treatment options exist for vitiligo, including topical treatments, phototherapy, surgery and oral immunosuppressants.³ Guidelines for the treatment of vitiligo recommend combination treatments that include at least one form of light treatment.^{4–6} In extensive forms of vitiligo, these treatments often allow partial repigmentation but are usually time consuming and costly, resulting in a significant disease burden. Moreover, vitiligo is a chronic skin disease requiring clinical management for months to years, making adherence to the treatment strategy a crucial point in its success. Therefore, achieving a balance between disease and treatment burden is key, and physicians and patients need to collaborate to adapt the treatment regimen to each patient.

A shared decision is a process of decision-making where patients and caregivers reach a consensus based on both the clinical evidence and the patients' values.⁷

Shared decision-making tools (SDMt) are usually visual aids (leaflets, maps, websites, apps, etc.) designed to present the advantages and disadvantages of the different treatment options available for a specific chronic disease.^{8,9} They provide patients and clinicians with the means of considering multiple options and thereby improve the chance that decisions reflect both scientific data and the patients' will.^{10–14} Generally, these tools are recommended for chronic diseases where a range of treatment options exists, including no treatment.¹⁵ Decision support tools have been reported to increase patients' knowledge about their illness, their satisfaction with the decision

made and its congruence with the values they express, as well as a reduction in decisional conflict and regret, resulting in improved adherence to treatment.^{8,10} In the field of dermatology, very few decision support tools have been developed and, to the best of our knowledge, there is no SDMt for vitiligo.^{16–19}

The main objective of this study was to develop a SDMt to be used in daily clinical practice to help adult patients with nonsegmental vitiligo prioritize treatment options and modalities.

Materials and methods

We developed a SDMt for vitiligo following the recommendations of the International Patient Decision Aid Standards (IPDAS) collaboration.^{20,21} A multistep approach was used in the development of the SDMt: (i) identification of priority domains for patients; (ii) selection of domains to be included in the SDMt for vitiligo; and (iii) creation and testing of the SDMt (Figure S1; see Supporting Information). All steps occurred during an international bicentre study that took place from March 2019 to March 2020.

Patients

Participants were consecutive adult patients (> 18 years old) attending consultation for nonsegmental vitiligo in medical centres in France (Créteil) and in the USA (Worcester, MA). All participants provided written consent to participate. The study was approved by the local ethics committees of the University Hospital Centres of Paris (reference number 2019-A00378-49) and University of Massachusetts (reference number H00019518), and was conducted according to the principles of the Declaration of Helsinki.

Step 1: identification of priority domains for patients

The aim of the first step was to identify topics mentioned by patients and clinicians during discussion regarding treatment with the aim of ensuring that all treatment priority domains deemed essential for patients or clinicians were covered.^{22–24} In the first step, patients with vitiligo who attended consultations had their consultation audio-recorded, transcribed verbatim and analysed using an anchored theory-based approach.^{25–27} Coding was performed after each consultation session independently by two researchers (J. Sh., K.E.). Coding was then discussed before the next round of interviews. Sample size was driven by data saturation (whereby additional data did not add new findings). We used a mixed-methods approach using a hierarchical clustering analysis of the extracted items.^{28,29} The aim of this analysis was to group items by similarity, for example patients who talked about constraints with applying topical tacrolimus also talked about natural sun exposure and difficulty in repigmenting their hands, thus forming a group. The hierarchical clustering method was complementary to the anchored-theory analysis. The latter focused primarily on the structure of discourse within the same interview. In contrast, analysis by hierarchical clustering gathered elements of speech not according to the structure of the speech, but by grouping themes evoked by the same patients, which allowed us to assess the robustness of the findings.

In addition to verbatim consultations, the clinical and demographic characteristics of the patients were documented, including age, sex, phototype,³⁰ vitiligo history (first consultation or follow-up, patient already treated or never treated), extent of vitiligo using the self-assessment vitiligo extension score (SA-VES)³¹ and the perceived severity of vitiligo using a visual analogue scale. Finally, we also asked patients to complete the following self-reported outcomes: (i) the Dermatology Life Quality Index;^{32,33} (ii) the six-item Stigma Scale (translated into French), to assess perceived stigma;³⁴ (iii) the Patient Health Questionnaire-9, for a quick assessment of depression;³⁵ and (iv) the General Anxiety Disorder-7.³⁶

Step 2: selection of domains to be included in the shared decision-making tool for vitiligo

We used an e-Delphi method to select which priority domains should be included in the SDMt for vitiligo. The purpose of this e-Delphi process was to obtain consensus from a working group on the exact content of the SDMt (i.e. wording and elements to present). It involved three rounds of online questionnaires, with three reminders over a period of 3 weeks. We aimed to involve approximately five participants from each stakeholder group (i.e. dermatologists, other health providers and patients) and one methodologist in the working group.

In the first round of the e-Delphi process, the results of the domains previously identified during the qualitative analysis were sent to all members of the working group with eight open-ended questions, in order to clarify the expectations of

every stakeholder. In the two other rounds, each domain selected in the first round was clarified using the following questions: (i) Do you think this element of the tool (element name) is appropriate? (answer: yes/no); and (ii) Do you have any comment or suggestion on this element of the tool (element name)? (open-ended question). Consensus was defined a priori by obtaining at least a 75% positive response.

Step 3: creation and testing of the SDMt

From the previous steps, we developed a preliminary SDMt for vitiligo. The tool was then tested in consultation with patients with vitiligo and debriefed with them during cognitive interviews.³⁷ Debriefs investigated the usefulness, appropriateness and readability of the SDMt. In addition, to confirm the readability of the tool, a corrected French Simple Measure of Gobbledygook (SMOG) index was performed on the final SDMt using the online software Textalyser. The SMOG index is a simple measure of readability that estimates the number of years of education needed to understand a text. The aim was to achieve a readability score < 8 (excellent).^{38–40} At this stage a dermatologist (J.-P. Castelnau) not previously involved in the study evaluated the IPDAS quality criteria checklist for our SDMt.⁷

American English translation and testing of the shared decision-making tool

The SDMt was translated into English by two native English speakers. It was then cross-culturally validated at a US referral centre for vitiligo (Department of Dermatology, University of Massachusetts Medical School, Worcester, MA) as follows. The SDMt was used in patient consultations. The patients answered the following scales and questions: SURE, the Decisional Conflict Scale (DCS) and CollaborATE;^{41–43} ‘Do you think the decision tool you were presented is easily understandable?’; ‘Did it help you to choose between the different treatment options?’; ‘Do you think some information is lacking in this tool?’; ‘Do you have any additional comments?’ The SURE and the DCS aim to measure uncertainty about a medical decision. The DCS score ranges from 0 to 100, with a lower score indicating lower decisional conflict. CollaborATE aims to evaluate the shared-decision making process. Owing to the low number of patients included, these scores were predominantly used to detect a major issue with the SDMt rather than to evaluate its effect.

As recommended by the IPDAS we also asked the clinician involved about the acceptability and useability of the tool.

Back-translation into French was performed by an independent translator, and compared to the original by K.E. The readability of the translated SDMt was assessed by a SMOG index.

Statistical analysis

Statistical analyses were performed using R (version 3.5.1). Descriptive analysis of the population was carried out. Basic

Table 1 Description of the study population (n = 30)

Median (IQR) age (years)	40 (20–71)
Women	21 (70)
Fitzpatrick phototype	
I	2 (7)
II	12 (40)
III	9 (30)
IV	5 (17)
V	1 (3)
VI	1 (3)
First consultation	11 (37)
Already had a treatment	21 (70)
Median (IQR) skin area with vitiligo (%)	3 (1–41)
Median (IQR) proportion of skin area with vitiligo (%)	
Face	5 (0–50)
Torso	1 (0–42)
Limbs	3 (0–58)
Feets	7 (0–50)
Hands	18 (0–75)
Median (IQR) VAS severity	5 (2–10)
Stigmatization	1 (0–6)
Depressive symptoms	
None	21 (70)
Light	5 (17)
Moderate	2 (7)
Intermediate	1 (3)
High	1 (3)
Anxiety	
None	14 (47)
Light	7 (23)
Moderate	4 (13)
Severe	5 (16)
Decrease in QoL	
None	4 (13)
Minor	11 (37)
Moderate	6 (20)
Very important	7 (23)
Extremely important	2 (7)

Data are n (%) unless otherwise indicated. IQR, interquartile range; QoL, quality of life; VAS, visual analogue scale.

summary statistics, such as proportions, means and SDs, were used to characterize population attributes.

Results

Step 1: identification of priority domains for patients

Thirty patients were recruited in step 1. The demographic and clinical details of the patients are provided in Table 1. A total of 149 topics were identified (Table 2). Of these, 91 (61.1%) were related to the treatment or treatment decision, 37 (24.8%) to the need for information about the disease and 15 (10.2%) to the psychosocial consequences of vitiligo. Nine other topics were related to care and disease progression. Of note, topics may be present in two or more categories.

The 91 topics related to therapeutic decision-making were divided into two subgroups: one gathered items by type of

Table 2 Results of the hierarchical clustering analysis

Cluster	Items clustered
Repigmentation of visible areas	Items about applying topical tacrolimus (unpleasant on the face), difficulty repigmenting the hands, natural light therapy for photo-exposed areas
Difficult to categorize	Modality and hindrance of maintenance treatment and localized home phototherapy, time needed for face repigmentation
Treatment priority	Priority: repigmentation, stabilization, therapeutic abstinence, maintenance of repigmented areas
Cost	Price of topical tacrolimus and localized home phototherapy
Advantages of localized home phototherapy vs. conventional phototherapy	Contraindication of phototherapy and advantages of advantages of localized home phototherapy
Face repigmentation	Face repigmentation as a treatment priority and tolerance to topical tacrolimus
Oral steroids	Modality and aims of oral steroids
Side-effects of phototherapy and steroids	–
Discouragement about therapeutic options	Therapeutic adherence, scepticism about treatment efficiency and question about new treatment availability
Difficult to categorize	Psychological support, difference between medical and public ultraviolet cabin, side-effects of topical tacrolimus
Advantages of phototherapy	–
Modality of phototherapy	–
Modality and aim of topical steroids	–
Total depigmentation	–
Lesions noticeability	Make-up, contrast increased initially by phototherapy
Children custody during phototherapy	–
Constraints and time before repigmentation with phototherapy	–
Constraints of tacrolimus	–
Constraints of localized home phototherapy	–
Difficult to categorize	Treatment of the genital area, treatment when the patient feels ready

treatment, and one related to items on therapeutic objectives and priorities. In the first subgroup, efficacy, benefit, constraints and side-effects were expressed for each type of

treatment. In the second subgroup (objectives and treatment priorities), priorities included repigmentation of all lesions, repigmentation of the hands, repigmentation of the face, information on the disease and its evolution, disease stabilization, maintenance of repigmentation, therapeutic abstention and psychological support. Information on the disease and its evolution was expressed as the sole objective of the consultation in three of 30 patients. However, it was found to be a secondary objective, sometimes in the form of more specific requests in our population, and was mentioned independently of other therapeutic objectives. We therefore grouped these specific requests into the 'disease information group'. The need for information on the disease included 37 specific

requests for information, which were used to create the information about the disease part of the SDMt.

Results of the hierarchical clustering (dendrogram) are shown in Figure 1 and detailed in Table 2. The cut of the dendrogram allowed the identification of 20 groups. The hierarchical clustering was consistent with the results of the qualitative analysis.

Step 2: selection of domains to be included in the shared decision-making tool for vitiligo

Sixteen members of the working group responded in the first round (five dermatologists, one methodologist, two

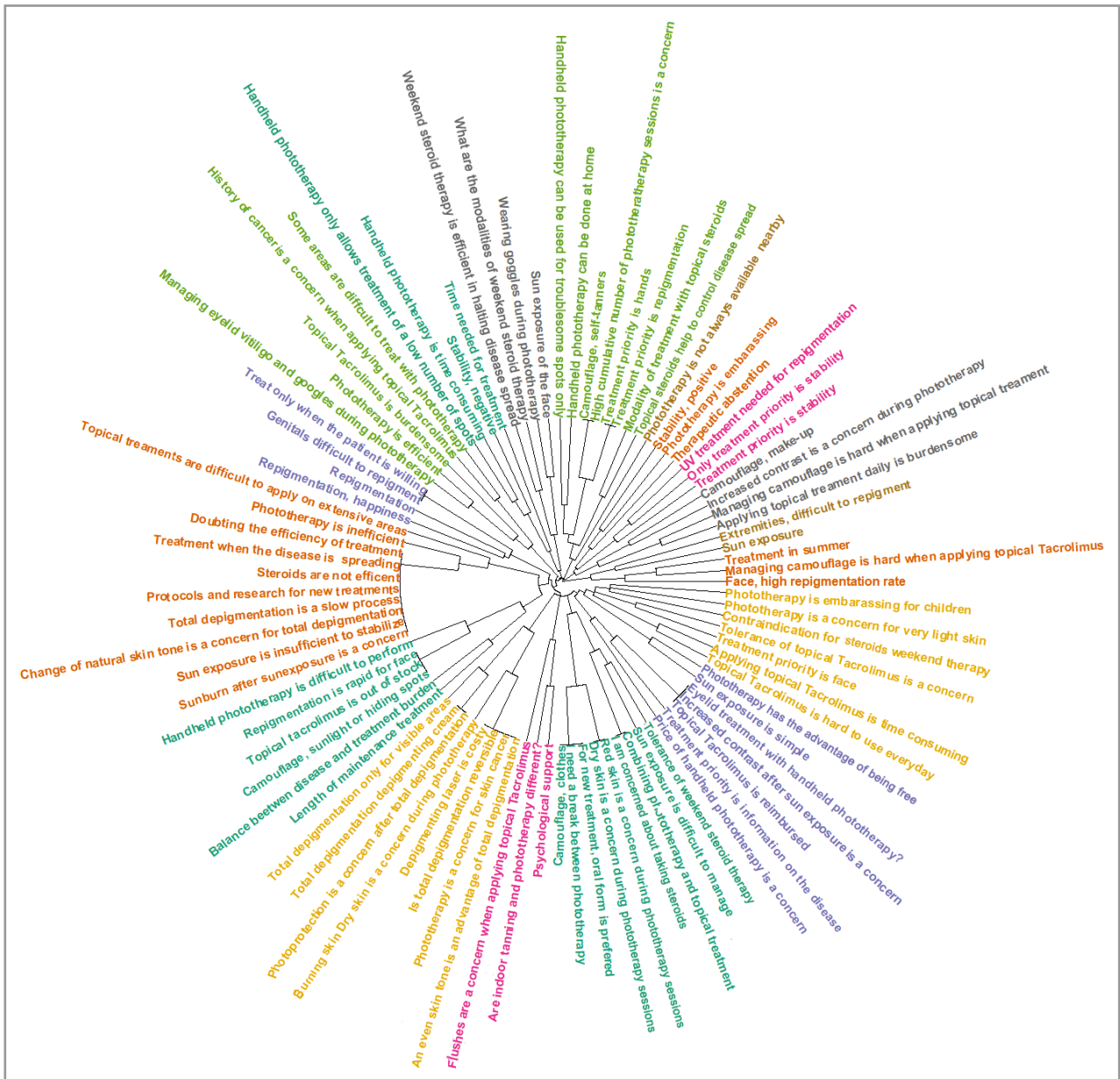


Figure 1 Clustering of themes revealed by patients during consultations for vitiligo. Each cluster is represented in a different colour. UV, ultraviolet.

psychologists, three phototherapy and therapeutic education nurses, and five patients). Consensus for each card was reached after the third round of the e-Delphi process, which ended the questionnaire.

In the first round, members of the working group insisted on the need for the patient to have a global overview of all possible therapeutic options, and also the option of focusing on one of the treatment modalities. In response to both requests, and keeping in mind the importance of the SDMt in clarifying patients' treatment priorities, a prototype for the SDMt for vitiligo was developed in the form of A5 format paper cards, each presenting a treatment, along with its advantages, constraints and side-effects. Content was derived from a literature review of available guidelines.⁴⁻⁶ The cards are intended to be used as follows: the complete set of cards is presented by the caregiver to the patient, who is asked to choose as many cards as desired and rank them by priority. The selected cards are then discussed successively according to the priority order given by the patient. If several cards are ranked at the same level of priority, they are discussed jointly.

Following the e-Delphi process and feedback from experts on the prototype, eight cards were created with the following objectives: (i) repigmentation of the face; (ii) coping; (iii) stabilization of pathology; (iv) maintenance of repigmented zones; (v) body repigmentation (total body); (vi) body repigmentation (limited surface area); (vii) information on the disease; (viii) partial or complete depigmentation.

Step 3: creation and testing of the shared decision-making tool

The corrected French SMOG score was 6.43, confirming excellent readability. The SDMt met the IPDAS quality criteria for the content and development parts, with an overall score for these two parts of 36/43.

Ten French patients were involved in testing the SDMt. The cards were well received by all patients, who acknowledged that the cards helped clarify their needs in terms of treatment and knowledge. One patient said, 'Now I know what I want', after using the tool and another said, 'I'm clearer about the disease'.

American English translation and testing of the shared decision-making tool

Nine patients were included to test the American English version of the SDMt. The mean (SD) CollaboRATE score was 24.9 (27) (range 21-27), all patients had a SURE score of 4/4, and the mean DCS score was 10.2 (range 0-21.9), indicating that patients were certain of their decision and perceived their collaboration with their caregivers as excellent. Finally, all patients found the questionnaire easy to understand and exhaustive, and only one patient claimed not to be helped by the tool in selecting the different options. The clinicians involved found the tool acceptable and easy to use. The back-translation was judged not to differ significantly from the

original SDMt in French. The SMOG index was 7.9. The final SDMt is presented in Figures 2 and 3.

Discussion

We have developed, according to a systematic method, a novel SDMt for vitiligo. We first initiated a qualitative study to clarify the organization of the SDMt. As a result of the qualitative analysis, we decided to present a detailed tool of vitiligo treatments organized by the objectives of consultation. We then sent these results to a working group of different stakeholders, including patients, dermatologists and other health providers specifically involved in the management of vitiligo. To ascertain readability and adequacy, we further tested our tool with patients in a real-life setting. Finally, to ensure its generalizability, we translated and cross-culturally validated our tool in a US patient population with vitiligo.

We decided not to include melanocyte transplant treatment because of its sparse availability and its primary indication for segmental vitiligo, which was not included in this study. Similarly, the disease information card could not answer all the questions arising from the qualitative analysis. However, as noted previously, the importance of an SDMt is not necessarily to provide exhaustive information, but to be appropriate in initiating a conversation about the available treatment options. The clinician is able to supplement the information as needed.¹³

One of the major issues of medical decision aids is the sometimes vague and ill-defined nature of their intended use, or the exact therapeutic issue that the decision aid wishes to address.¹⁰ Indeed, the concept of shared medical decision-making covers a range of situations. Therefore, it is of crucial importance to follow guidelines developed specifically for decision aid development. This is what we have done following the recommendations of the IPDAS by first clarifying the conceptual framework. One of the primary aims of a SDMt is to make patients aware of the availability of different therapeutic choices, to discuss their preferences and to clarify the therapeutic options, including both disadvantages and benefits. This is an important point for the relationship between the patient and the physician as it will help patients to define what is the best objective to achieve for them, making them an active component of the therapeutic decision. In vitiligo, false ideas are very widespread. Many patients think that the disease is only driven by psychology, without physical symptoms. Some also believe that sunlight must be completely avoided and that no treatment is available that could help them. The development of this SDMt is thus crucial for explaining the disease and the therapeutic opportunities that can be offered.

Our SDMt is, to our knowledge, one of the first to be used in patient consultations that has been developed in the field of dermatology.^{44,45} Such tools have been developed in other chronic diseases such as type 2 diabetes, and have been reported to increase patient adherence to treatment.⁴⁶ In vitiligo – unlike in diabetes – there is no approved treatment. In addition, treatments are given for months, whereas the first signs of repigmentation can take several weeks or even



Figure 2 Final shared decision-making tool, cards 1–4.

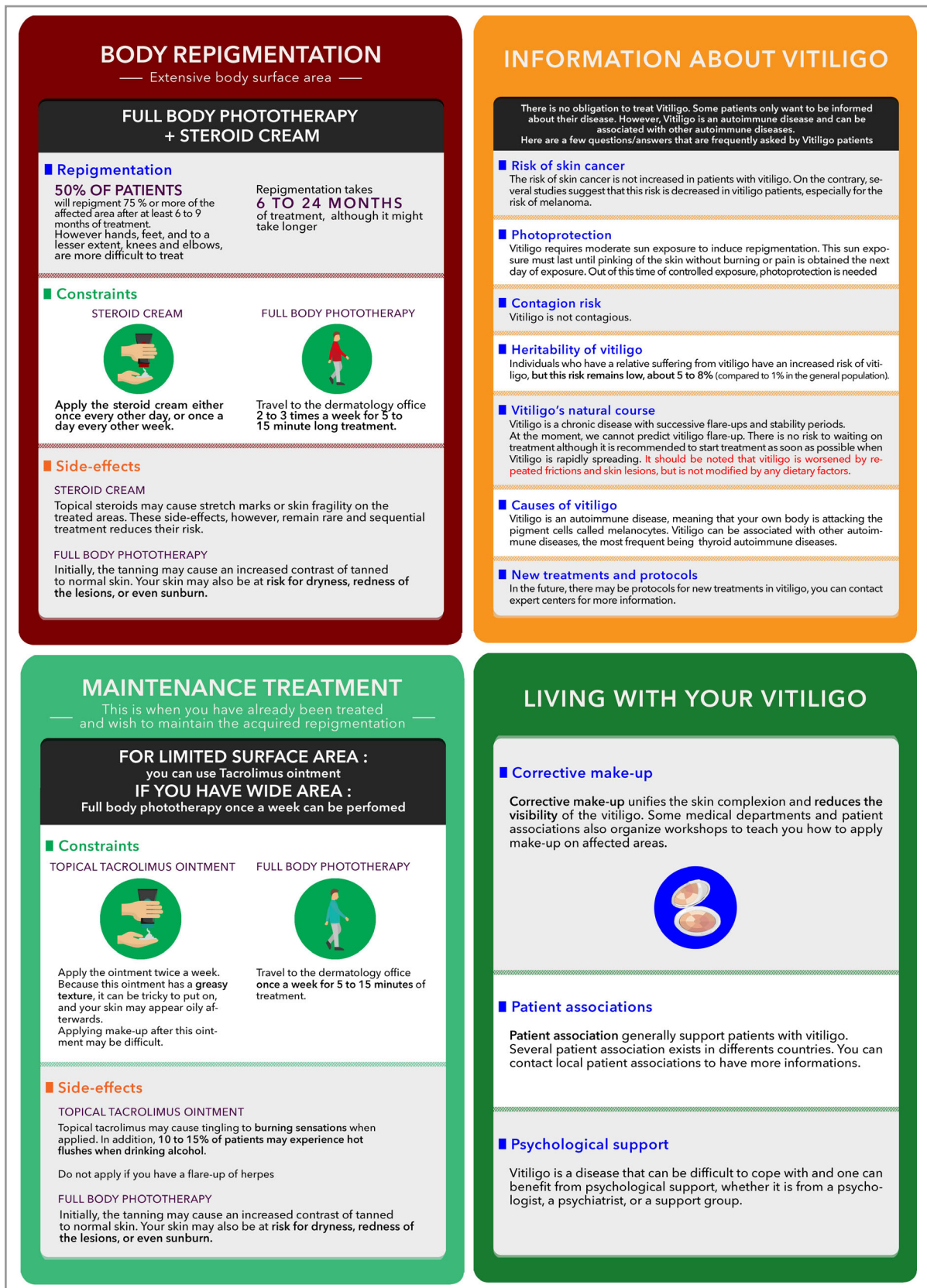


Figure 3 Final shared decision-making tool, cards 5–8.

months to be visible. This can be discouraging for patients. Maintaining adherence to treatment requires motivated patients. Many treatment failures that we have seen at our tertiary care centres are due to the early discontinuation of the treatment by demotivated patients. This new SDMt is an important step toward treatment success as improved adherence could lead to better efficacy as the patient is more engaged and has a better understanding of the treatment objectives.

The main limitation of the study is the lack of efficacy demonstrated in a randomized controlled trial. An additional limitation is that our SDMt lacks information on the level of evidence of the elements presented. Again, we favoured its readability, as well as response to patients' needs.

Finally, our SDMt was developed using the available treatment options for vitiligo. In fact, topical steroids and immunomodulators, systemic steroids and ultraviolet light are used off-label and have been proposed based on available data and physicians' expertise. However, vitiligo is a disease for which there are emerging treatments that are expected to reach the market in a few years,⁴⁷ and thus our tool will be regularly updated accordingly. For this purpose, and in accordance with the recommendations of IPDAS, we established a team of vitiligo experts who will participate in these updates by integrating any new treatment with a marketing authorization or a sufficient level of evidence. This might be the case for topical and systemic Janus kinase inhibitors, which are currently being tested in phase II and III studies in patients with vitiligo. Any significant changes will be submitted to the full working group for evaluation and testing in consultation before being added to the SDMt.

We developed a tool for shared decision-making in non-segmental vitiligo in French, which we translated and cross-culturally validated with a US patient population with vitiligo, to ensure its generalizability. This tool is an important step toward patient-centred care in vitiligo and in dermatology.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Figure S1 International Patient Decision Aid Standards 2005: criteria for judging the quality of patient decision aids.