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# Development of Patient Decision Aids for Plaque Psoriasis and Acne

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## Abstract

**Introduction:** Despite proven benefits in other medical specialties, there is a paucity of patient decision aids (PDAs) in dermatology. The present study developed online PDAs for acne and psoriasis, incorporating iterative patient and physician feedback, in accordance with International Patient Decision Aid Standards (IPDAS).

**Design and Method:** Content was adapted from clinical practice guidelines and primary research and formatted for an 8th grade reading level. Feedback on content and format was obtained through focus groups with 15 psoriasis patients and survey with 34 acne patients. Feedback on presentation and clinical utility of the PDAs was gathered by survey from 51 physicians in Canada and the United States. Each data collection stage informed further development.

**Results:** Demand for decision support, and satisfaction with the PDAs was high among patients. Physicians were approving of content and expressed a strong interest in PDA use.

**Conclusion:** Patients and physicians approve of the PDAs' content, format, and intended use. Online PDAs allow accessibility for patients and may reduce barriers to use for physicians.

*Keywords: patient decision aids, psoriasis, acne, decision-making, shared decision-making, patient preference, patient engagement*

## Introduction

### Burden of Acne and Psoriasis

Acne and psoriasis adversely affect millions of people. Acne is the 8<sup>th</sup> most prevalent disease

globally [1]. It affects 80-100% of people at some point in their lives and up to 50 million Americans annually [2]. Psychosocial and emotional distress is common among acne patients [3]. Psoriasis is also prevalent, affecting around 2-3% of people [4] and approximately 7.5 million Americans [5]. Psoriasis patients may have low self-esteem, fear of rejection, and anxiety [6]; up to 60% of patients experience depression [5]. The impact of dermatological diseases on psychosocial well-being requires that treatment decisions incorporate patient preferences and values in addition to clinical evidence [7].

### Patient Decision Aids

Patient Decision Aids (PDAs) inform patients of the risks and benefits of their health care options and engage them in decision-making with their physician. Despite over two decades of research on the benefits of such interventions [8] and growing emphasis of informed shared-decision making in policy and practice [9-13], few decision aids are available in dermatology [7]. A previous PDA for psoriasis [14] demonstrated reduced decisional conflict and increased preparation for decision-making among psoriasis patients [15]. However, advances in psoriatic treatment render this PDA, along with the sole other existing PDA for plaque psoriasis [16], lacking in the full range of treatment options. Two PDAs for acne [17, 18] are limited in scope of treatment options and provide little evidence of development or effectiveness. Thus, the need for comprehensive and widely accessible evidence-based PDAs for acne and psoriasis is currently unmet.

The objectives of this study were to update the existing PDA for psoriasis with recent treatment content and a more accessible format. In addition, we aimed to create a new PDA for acne. Both PDAs were developed to be comprehensive and comprehensible, and they were informed by iterative rounds of patient and physician input.

## Methods

### PDA Development

We searched the literature for clinical practice guidelines published in English for psoriasis and acne since 2011 and 2008, respectively. Guidelines that were solely consensus-based, addressed pediatric populations, or provided non-specific treatment recommendations were excluded. Information regarding efficacy, safety, convenience, cost, and method of delivery was extracted from the remaining nine psoriasis [5, 19-26] and four acne [27-30] guidelines. Content from the previous psoriasis PDA [14] was used when no updated information was found. Where guidelines provided non-specific data, or in the case of recently approved drugs, primary research was used [31-41]. For acne treatments, [Drugs.com](http://Drugs.com) was consulted along with guidelines for serious adverse effects.

Extracted content was adapted for an 8<sup>th</sup> grade reading level. Where data was available, safety and efficacy metrics were displayed in pictographs, as suggested by International Patient Decision Aids Standards (IPDAS), [42, 43]. For acne, treatment information on risk of side effects was largely insufficient to present in this low-numeracy format.

Two dermatologists (JT and RD) oversaw extraction and drafting. Two dermatologists external to development further revised the content for accuracy and comprehensiveness. Following expert review, content was transferred to a website.

The online format widens accessibility and interactivity, allowing patients to personally tailor and revisit their decisional process [44]. The website is formatted in a stepwise fashion, modelled after similar PDAs. A status bar shows progress through each of six steps (Figure 1). Once the PDA is **complete, patients may print a "Patient Summary Page"** (PSP; Figure 2), summarizing their decisional



Figure 1. *Online Format of the Patient Decision Aids.*



Figure 2. *Patient Summary Page (PSP).*

process, to bring to their physician in consultation or keep for their own records.

## Iterative Study Design

Following each of three stages, data were analyzed and used to inform further development of content and format. The Chesapeake Independent Review Board approved this study.

In Stage 1, patients were recruited from a dermatology clinic in Windsor, Canada to provide information on decision making needs and feedback on disease- and treatment-specific content. Participants viewed an abbreviated version of PDA content before attending a focus group.

**Stage 2 evaluated patients' opinions** of the full PDAs and their applicability to decision-making. Psoriasis participants from Stage 1 and additional patients were recruited using the same method as in Stage 1. Participants were sent a link to the psoriasis PDA for review prior to their focus group. Acne participants were recruited using flyers posted at two local post-secondary institutions, a poster in the clinic waiting room, advertisements on social media, and by phoning former patients. Participants viewed the acne PDA online before completing a 42-item online survey.

In stage 3, a 21-item online survey was forwarded to members of the Acne and Rosacea Society of Canada, the Diversified Business Communications Medical Group online forum, and the RxDERM-L online forum. This survey included questions related to a sample PSP and general questions regarding PDA use.

## Results

### Stage 1 – Patient focus groups

#### Psoriasis

Thirteen psoriasis patients participated in one of three two-hour audio-recorded focus group sessions. Participant demographics are shown in Table 1. Recordings were transcribed and reviewed for accuracy. Transcripts were analysed using inductive thematic analysis [45, 46]; the results **appear in the appendix entitled “[Thematic Analysis of Psoriasis Focus Group 1.](#)”**

Safety, cost, effectiveness, and convenience were of greatest importance to patients when making

decisions. Participants requested more detail about the effects of long-term treatment use, changes in side effects over time, rare but severe adverse events, and mild or inconvenient side effects. Convenience was described as embarrassment, duration, frequency, and time spent preparing and taking treatment.

**Participants were satisfied with the PDAs' appearance, language, and credibility.** They generally understood the content and identified it as patient-friendly, but suggested photos, graphs, and testimonials to supplement content. Participants stated that the PDA was successful in communicating information about treatment options and many learned of options that had never been shared by their physician (often biologics). Participants also requested more information on complementary or non-medicinal options and information to help better understand their disease. The latter included understanding what caused their psoriasis, lifestyle changes to reduce triggers, and the impact of their environment and surroundings.

Regarding decision making, participants described the expertise patients hold of their body and symptoms and a need to advocate for themselves with physicians. Participants also recognized the **expertise of physicians' medical authority.** All participants felt the opportunity to converse with a physician about their condition was important; however, participants were divided in terms of when this discussion should occur (i.e. PDA use pre- or post-diagnosis).

#### Acne

Despite telephoning approximately 480 former acne patients and receiving interest through public advertising, only 12 patients enrolled in a focus group. Of these, only one attended the session. Data from this participant, along with information from non-attendees, were not used to inform major changes to the PDA. However, they were used to improve recruitment and methodology for Stage 2.

### Stage 2 – Patient focus group and survey

#### Psoriasis

Seven patients participated in one of two 90-minute focus group sessions. Participant demographics are

in Table 1. Five participants (71%) had previously taken part in Stage 1. As in Stage 1, recordings were transcribed and analysed using thematic analysis (see appendix titled, "[Thematic Analysis of Psoriasis Focus Group 2](#)").

Participants approved of the PDA website layout and found it easy to use. Participants identified the pages of the PDA as helpful and agreed there was a logical progression towards a final decision. Suggestions for improvement included clarifying technical instructions, indicating treatments by severity, adding a note-taking feature, creating printable summaries of PDA content and results, and adding visuals of psoriasis severity and the treatments themselves.

Participants found the PDA informative and credible, stating that it equipped them with the knowledge required to engage in decision-making with their physician. Participants reported they would use the PDA primarily to discuss treatment decisions with their physician and would prefer to complete it before a consultation. Some wanted to share the PDA with their doctor via email or printed copy. Others wanted the PDA in multiple languages, or more PDAs for different medical conditions.

#### Acne

Forty participants completed the 20-minute online survey. Thirteen were excluded for failure to meet inclusion criteria (younger than 16 years, n=2), incomplete responses (n=5), and failure to provide consent (n=6). Characteristics of the resulting sample (n=27) are shown in [Table 1](#) and select responses in [Table 2](#).

All participants agreed the My Options page was helpful, with similar agreement on the sections about treatment effectiveness, side effects, and convenience, specifically (93-100%, n=25-27).

The majority (67%, n=18) indicated the PDA contained the right amount of information and that information was not biased (70%, n=19). Participants reported the My Values page helped them think about their values (93%, n=25) and defined values **were described as "clear" (82-100%, n=22-27)**. When asked what additional values should be included throughout the PDA, responses included frequency,

cost and duration of treatment, and duration of results. Most participants (82%, n=22) found the My Trade-offs page useful to compare their values against treatment options. At the My Decision page, the majority (93%; n=25) were completely or somewhat ready to make a treatment decision with their physician. When asked what would make patients feel prepared to make a decision, two wanted a **physician's opinion, two wanted case studies or testimonials from others who have used treatments**, and three wanted greater treatment details.

Almost all participants (96%, n=26) agreed they would use the PDA to make a treatment decision. The majority of participants (96%, n=25) were somewhat or very likely to recommend the PDA to someone else.

Impressions of the overall PDA were positive. Patients found it informative regarding the disease **and treatment options and described it as "personal" or useful to learn about themselves**. One participant **felt otherwise, stating that "in person interviews" and professional diagnosis would be preferable to PDA use**. Most approved of the layout and appearance of the PDA. Aside from two concerns about mobile accessibility and page-specific instructions, the majority found the PDA easy to access and straightforward to use.

#### Stage 3 – Physician survey

Seventy-one physicians participated. Twenty (28%) were excluded for incomplete responses. Characteristics of the resulting 51 participants are shown in [Table 3](#) and quantitative responses in [Table 4](#).

Most physicians (66%, n=33) responded positively towards reviewing the PSP if brought by a patient and none would decline the PSP. However, 11 (22%) indicated they would research the PSP before use and two (4%) expressed concern over a lack of familiarity with the PDA content and development, complexity for patients, and time constraints. All understood the purpose of the PSP. Physicians agreed they would use the information on patients' preferred treatments (77%, n=39) and values (78%, n=38). Most reported there was an appropriate



amount of information (66%, n=33) and no information was missing (63%, n=34). When asked what might increase their likelihood to use a PSP, responses included **“the patient expressing values and decisions verbally”, providing more information, and “if my office administered it after a correct diagnosis was made by myself.”**

**Physicians’ preferences on completion of a PDA** were: independent patient completion, bringing only the PSP to a consultation (n=34) followed by patient completion during consultation with a physician (n=22). Two indicated they would not use the PDAs and one stated a lack of time in consultation precludes the use of PDAs. The most common preferences for when patients should use PDAs were: before visiting a dermatologist (n=17), and before visiting a general practitioner (n=13).

Physicians agreed the PDAs had accurate content (84%, n= 43), patient friendly language (86%, n=43), had appropriate detail (73% agree, n=37), and followed a logical order (86%, n=43). Concerns expressed were: computer literacy and font size, specifically for older patients; insufficient cognitive ability of some patients; varying regional availability of treatments; a need to ensure the physician has the final say in treatment decisions; time and logistical constraints of administering PDAs in consultation; and the length and complexity of the PDAs.

## Discussion

Participants indicated high satisfaction with the **PDAs’ content** and appearance and valued the personalized features. Participants almost unanimously reported they would use the PDA when making a treatment decision. Results indicate the **PDAs satisfy patients’ needs for information and** tailored decision support and encourage discussion with a physician. Further, suggestions for delivery method and timing indicate patient interest in widespread dissemination of the PDAs to ensure physicians and other patients are aware of them.

Consistent with previous research [47-49], the most important factors in treatment decision-making for all participants were effectiveness, safety, cost, and convenience. These factors are included in the PDA

with the option to add additional customized personal values.

For psoriasis patients, information on diet, environment, lifestyle habits, and non-traditional treatments was of particular interest. This corresponds with findings that complementary and alternative medicine (CAM) use is prevalent among psoriasis patients [50]. Many psoriasis patients also stated understanding their disease was critical to choosing treatment. Patients expressed frustration over unclear triggers, symptoms, and potential prevention; they found comfort in sharing these experiences. This desire for social support and willingness to share experiences with other disease sufferers has been shown previously among psoriasis patients [51, 52] and confirms the significant impact of psoriasis on quality of life [53, 54].

Acne patients suggested including testimonials or patient case studies. However, evidence to support the use of patient narratives in PDAs is conflicting [55]. Patient narratives also risk biasing readers to make choices similar to the narrator or altering **patients’ understanding of treatment risks and** benefits [55]. The authors decided against including personal stories to ensure the information presented remained evidence-based and balanced.

Most physicians responded favorably to the PDAs with high approval of content accuracy, clarity, and detail. The majority would use one in some form and few physicians in the current study were hesitant to use the PDAs. One felt PDAs should only be used with select patients and some cited time and healthcare system constraints. Previous research indicates the greatest barriers to PDA use include physician attitudes towards decision-making, physician perceptions of time pressures, and physician-perceived applicability to the patient or clinical setting [56, 57]. The overall positive attitude of physicians towards PDAs in our study is indicative of their perceived value; however, specific comments highlight potential barriers to implementation.

One barrier may be time sequence for administration of PDAs. Physicians preferred that patients use the PDAs independently, before attending a consult

with a dermatologist or general practitioner. Patients similarly preferred using the PDA to inform themselves and prepare questions prior to discussion with their physician. Unlike hardcopy PDAs or brief PDAs intended for consultation, the current online format enhances accessibility. **Patients may find these PDAs through a physician's recommendation or through online search engines.** Patients may complete the PDA at their own pace and review their responses in preparation for their appointment. The addition of a PSP conveniently **facilitates informing physicians of patients' values and treatment preferences while maintaining time-efficient consultations.**

A recurring theme among patients and physicians was the authority of the physician. Some patients **identified the importance of their physician's opinion or a second opinion before committing to a decision.** Similarly, there was concern on the part of some physicians in allowing patients to make autonomous treatment decisions. However, PDAs are not intended to delegate decision-making to the patient. Simply making information patient-friendly or patient-tailored is insufficient in decision-making if there is no accompanying conversation with the physician [58]. We highlight that the goal of PDAs is to inform patients of their options and the relevant risks and to elicit their values in order to enhance their engagement in an informed discussion with their physician.

#### Limitations

Consistent presentation of treatment efficacy throughout the acne PDA was hindered by variation in outcome measures utilized in acne literature; there is no standard measure for assessing acne severity. As efficacy is among the most important factors to patients in treatment selection, it is critical that credible, consistent measures are established to disseminate research findings to physicians and patients.

Although there was high demand for information regarding CAM treatments for psoriasis, a lack of available evidence in clinical practice guidelines precluded greater inclusion in the PDA. Given the risks and widespread usage of CAM, often without sufficient clinical discussion and despite poor

evidence of efficacy and safety [50], greater evidence must also be established for non-traditional treatments.

Stages 1 and 2 are limited by small sample sizes. However, this is typical for qualitative research and thematic analyses. Stage 1 acne PDA findings were impacted by low focus group enrollment. Issues of scheduling, transportation, or permission inherent to this younger cohort may have hindered the ability to join a focus group. However, increased interest in the online survey may imply positive uptake of the final PDA in its online form.

The inclusion of psoriasis participants from Stage 1 into Stage 2 may have introduced response bias, by nature of previous experience with PDA content. However, the objective of focus groups in each stage was sufficiently distinct to elicit new feedback from these participants. In addition, that most participants in the second focus group round had knowledge of prior iterations of PDA content may have allowed for deeper and unique insights than with entirely unfamiliar participants. For example, repeat participants were able to view that their comments on the PDA content in the first focus group had been considered. Therefore, they could focus entirely on the PDA application and online format in the second group.

Stage 3 may be susceptible to sampling bias, as voluntarily participating physicians may have been biased by familiarity with or favorable attitudes towards PDAs. However, this method had the benefit of quickly reaching a wide range of practitioners, as is reflected in the diverse practice locations and specialties of participants.

Finally, the PDA and all stages of the study were limited to English speakers. Although both PDAs have a North American target audience, they could easily be adapted to other regions. To remain widely comprehensible, the PDAs should be translated to other languages.

#### Conclusion

These PDAs address an identified need for evidence-based decision support tools for dermatology. The

intent of these PDAs is to stimulate shared discussion of treatment decisions between patient and physician. The online delivery of these PDAs allows accessibility for patients and may reduce common barriers to use for physicians. The current PDAs provide open-access resources to facilitate patients and physicians facing treatment decisions in skin disease. Further evaluation will determine effectiveness in increasing knowledge of disease and treatments, improving preparedness for decision-

making, and reducing decisional conflict. These PDAs are maintained by Windsor Clinical Research Inc. and accessible at [www.informed-decisions.org](http://www.informed-decisions.org).

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Table 1. Characteristics of Focus Group and Survey Respondents from Stages 1 and 2.

Characteristic	Psoriasis Patients				Acne Patients	
	Stage 1 Focus Group		Stage 2 Focus Group		Survey	
N	13		7		27	
Age Mean (SD)	61(11.75)		61(11.75)		21.59(4.73)	
	N	%	N	%	N	%
Gender						
Male	6	40	3.0	43	17	63
Female	7	47	4.0	57	10	37
Education						
Current High School Student	-	-	-	-	1	4
High School Graduate	4	27	1.0	14	2	7
Some College	4	27	4.0	57	2	7
College Certificate/Diploma	2	13	1.0	14	1	4
Some University	1	7	1.0	14	12	44
Undergraduate University Degree	2	13	-	-	5	19
Graduate Degree	-	-	-	-	3	11
No response	-	-	-	-	1	4
Ethnicity						
White/European	11	73	5	71	21	78
First Nation/Metis/Inuit/Native Canadian	-	-	1	14	-	-
Black/African/Caribbean	-	-	-	-	1	4
Latino/Latina	1	7	-	-	-	-
Middle Eastern	-	-	-	-	1	4
East Asian/Chinese/Japanese	-	-	-	-	3	11
Mixed/Biracial	1	7	1	14	1	4
Presence of Disease						
Yes	12	80	7	100	25	93
No	-	-	-	-	2	7
Unsure	1	7	-	-	-	-
Diagnosis by a Physician						
Yes	-	-	5	71	10	37
No	-	-	-	-	15	56
Unsure			2	29	2	7
Previous PDA Use						
No	12	80	6	86	25	93
Unsure	-	-	-	-	2	7
Missing	1	7	1	14	-	-

Table 2. *Acne Patient Survey Responses.*

Select Responses	N	%
My Options Page		
This information was helpful	27	100
Was there enough information presented?		
1 – Not enough	0	-
2	0	-
3	2	7
4 – The right amount	18	67
5	6	22
6	1	4
7 – Too much	0	-
Information about how well treatments work was helpful	27	100
Information about possible side effects was helpful	26	96
Information about treatment convenience was helpful	25	93
My Values Page		
The definition "Cost" was clear	26	96
<b>The definition "Risk of serious side effects" was clear</b>	25	93
The definition "Convenience" was clear	22	82
The definition "How well treatment works" was clear	27	100
My Decision Page		
How ready did you feel to make this choice?		
1 – Not ready	0	-
2	1	4
3	1	4
4 – Somewhat ready	6	22
5	6	22
6	4	15
7 – Completely ready	9	33
Patient Decision Aid Use		
How might you use this with your doctor or health care professional? (select all that apply)		
Make a list, as you read it, of questions to ask during an appointment	12	-
Ask to show your doctor or health care professional during an appointment from your smartphone or tablet	11	-
Print it out to bring to an appointment	5	-
I would not use it with my doctor or health care professional	0	-
How likely would you be to recommend this patient decision aid to a family member or friend with acne?*		
1 – Not likely at all	0	-
2	0	-
3	1	4
4 – Somewhat likely	5	19
5	7	26
6	5	19
7 – Very likely	8	30

For binary response items, the most common response is displayed.

\*One participant did not respond to this item.



Table 3. Demographics of physician survey participants.

Characteristic		
Total	51	
Age M (SD)	53.1 (10.29)	
	N	%
Gender		
Female	32	64
Ethnicity		
White/European	26	52
East Asian/Chinese/Japanese	7	14
South Asian/Indian/Pakistani	6	12
Latin/South American	2	4
Middle Eastern	8	16
Polynesian	1	2
Specialty		
General Practice	27	54
Dermatology	17	34
Obstetrics and Gynecology	2	4
Anesthesiology	2	4
Pathology	1	2
Pain Medicine	1	2
Years Practicing		
Less than 5	3	6
5-9 years	7	14
10-14 years	5	10
15-19 years	5	10
20+ years	31	61
Practice Location*		
United States	10	20
Canada	28	56
India	4	8
Iran	4	8
Brazil	1	2
Tunisia	1	2
Columbia	1	2
No Previous PDA Use	37	73

\*One participant did not respond to this item

Table 4. *Physician Survey Responses.*

Select Responses	N	%
How might you respond if a patient brought you a Patient Summary Page like the one you just reviewed? I would...*		
Review this Patient Summary Page with my patient to help them make a decision	33	66
Want to research where the information came from before using the Patient Summary Page	11	22
Ask the patient to summarize their thoughts for me, rather than reading the Patient Summary Page	3	6
Have a nurse or other staff member discuss the Patient Summary Page with the patient	1	2
Other (see text for qualitative responses)	2	4
Did you understand that the information on the Patient Summary Page was based on a patient's responses?		
Yes	51	100
Was there enough information presented on the Patient Summary Page to help you make a shared treatment decision with your patient?*		
There was not enough information	13	26
There was the right amount of information	33	66
There was too much information	3	6
I would not use this Patient Summary Page with a patient	1	2
Please select all that apply. How might you use or recommend the use of these decision aids? I would....		
Not use either of these decision aids	2	-
Use one/both of these decision aids with my patients in a consultation	22	-
Recommend my patients complete one/both of these decision aids on their own and bring their Patient Summary Page to our next appointment	34	-
Recommend my patients use one/both of these decision aids on their own	10	-
Have a nurse or staff member use one/both of these decision aid with my patients	6	-
Promote one/both of these decision aids indirectly in my waiting room	6	-
Promote one/both of these decision aids directly to colleagues or other staff	2	-
When do you think patients should use these decision aids?		
Before they visit a general practitioner	13	-
Before they visit a dermatologist	17	-
In a waiting room before an appointment with a general practitioner or dermatologist	8	-
After their initial appointment with a general practitioner or dermatologist	10	-
If treatment is not effective or adhered to	3	-

\*One participant did not respond to this item.

Thematic Analysis of Psoriasis Focus Group 1.

Theme	2 <sup>nd</sup> Tier Theme	3 <sup>rd</sup> Tier Theme	Definition	Quote
PDA Presentation	Communication	Clear and Precise	The PDA is clear and precise.	“Very precise.” “When you read through it’s understandable.”
		Good Layout of Website	The layout of the website facilitates comparing treatment options.	“It’s laid out very easily and you could go to all the different categories...so going down one column or across to see you could compare.”
		Patient-Friendly Language	The PDA avoids medical jargon.	“It wasn’t medical jargon with the chemical makeup of what [the drug] is.” “When they did use something really medical... there was some kind of italics...to explain what the word meant...”
		Credibility of PDA	The PDA appears to be a credible resource.	“I could see this was well-researched.”
		Mis-understandings	General misunderstandings of website content or format.	“...I thought maybe [the Learn More button] would be links to drug companies.” “The only question I had about the website was whether I had to make a password and login.”
Treatment Related Suggestions		Treatment Cost Suggestions	Patient suggestions related to cost information.	“... A way to find out if your drug plans covers it.”
		Treatment Efficacy Suggestions	Patient suggestions related to displaying treatment efficacy.	“Show how many have excellent improvement. Show how many have average.” “...it’s the same icons for average control here and excellent control for the other ones, change the colour.”
Recommendations Based on Severity		Doctor-Diagnosed Severity	Patients want treatments suggested to them based on doctor-diagnosed severity.	“You’ve already been diagnosed... they can kind of give you what to look at further on this site.”
		Self-Diagnosed Severity	Patients want treatments suggested to them based on self-diagnosed severity.	“Have this site help you figure out how much psoriasis you have and then from there, give you suggestions.”

Thematic Analysis of Psoriasis Focus Group 1, *continued.*

Visual Suggestions	Final Summary	Suggestions to visually summarize PDA information.	"...there could be a summary at the end... all the drugs have effectiveness in green bars and the cost in red bars."
	Photos of Disease	Patients want more photos of psoriasis severity, treatment options, and before and after treatment.	"It could have some pictures on there of different types." "Or even a before and after treatment. What you can expect in results."
	Testimonials	Using real people to share their experiences with psoriasis via video.	"...somebody actually doing a video where they show you what kind they have and what actually worked for them."
Decision-Making Process	Administration of the PDA	Discuss with an Expert in Person	Patients want to discuss information with an expert in person. "I would like more information in person from a nurse who gives a list of other treatments."
	Method of delivery	Preferred methods of being informed of, and completing, the PDA.	"For those who don't use computer much, a hard copy of the information on the website would be good." "The nurse could give you the website."
	Timing	Suggestions related to when the PDA should be administered.	"After a diagnosis you get the website link and then you get information on "What did I just agree to?" "You get the information after the diagnosis and prescription. The information comes too late."
Expertise in Decision-Making	Doctor Should Make the Treatment Decision	A treatment decision requires medical expertise.	"The website gives me information, but I don't make the treatment decision. My doctor does. I'm not an expert. I didn't go to medical school, I need the doctor's expertise."
	Patient as Expert	Patients are experts on their bodies and can monitor their disease more thoroughly than a health professional.	"...when certain things happen and you go to a doctor and he'll tell you it's one thing and, well, doctor I know my own body. This is not like me. I know something's not right here and you're saying the opposite."
Informative	Enables Discussion	The PDA facilitates discussion with doctors.	"Well, you can have a good, intelligent conversation with your doctor with this information and they won't sweep you under the rug."



Thematic Analysis of Psoriasis Focus Group 1, *continued*.

		Informs Patients	The PDA provides patients with information.	“If you knew the website content before a doctor’s appointment it would save a lot of time. You wouldn’t have to ask basic questions like what is a corticosteroid or something like that. You would already know about it. So you would be more informed.”
Patient-Identified Information Gaps	Treatment-Related Factors Important to Patients When Making a Treatment Decision	Importance of Psoriasis Clearance	Patients want treatment that clears their psoriasis.	“I want it gone.”
		Importance of Convenience	Patients want to know how inconveniencing treatment.	“I find the way you take it as well. It’s minor, but still kind of important. Like if you have to take a pill once every week, it’s different than if you have to take it every day.”
		Importance of Cost	Treatment cost and insurance coverage are important.	“And cost is another big one. Some things aren’t covered. I have no coverage so I have to pay everything out of pocket.”
		Importance of Side Effects	Patients want to avoid side effects.	“Side effects. You have to balance the side effects with your severity.”
More detailed information on treatment		Complementary Treatment Options	Patients want information about non-medicinal treatment options.	“What other treatments can be helpful? She wants products that can balance out using drugs all the time. She doesn’t always want to be using corticosteroids, she wants a balance with natural treatment options.”
		Detailed Info on Each Treatment	Patients want greater detail on each type of treatment.	“The generic names are all long ones... give them an easy name they know.” “But I think that IV is a lot more distinctive than just a shot once every two weeks. I just don’t know how you would differentiate that.”
		List of Ingredients	Patients want to know the medicinal and non-medicinal ingredients of a drug.	“...Know what fillers are being used or what the chemical makeup is of the drug.”
		Contraindications	Patients want information about complications with other medications and lifestyle habits.	“Like methotrexate....That’s the one with severe liver damage if you drink alcohol....It’s good to know what you shouldn’t do while taking a medication.”

Thematic Analysis of Psoriasis Focus Group 1, *continued.*

More Detailed Information on Safety	Mild Side Effects	Patients want information about mild and inconveniencing side effects.	"...would it give you a side effect of an upset stomach or headache or something related..."
	Serious Side Effects	Patients want more detailed information about serious side effects from the PDA.	"It could probably be more in depth. I mean what's a serious infection? There are so many varieties. How do you know what caused that reaction?"
	Long Term Side Effects	Patients want information about potential side effects with prolonged treatment.	"Sometimes too, I think the onset of side effects don't happen right away. You might be on it one, two, three months and all of a sudden you're having problems."
Understanding Psoriasis	Disease demographic info	Patients requested more information on psoriasis demographics, such as region and age.	"Does [psoriasis] affect specific regions...how common is it with other ethnicities? How common it is in older people than younger people?"
	Environmental Factors	Patients want to know how the environment and surroundings can affect psoriasis.	"What's going to make it worse...maybe it does go back to fabric, the environment, maybe it's the quality of the air."
	Triggers	Patients want to understand how lifestyle choices can potentially trigger or worsen psoriasis.	"If you doctor said at 18, '...If you stop smoking it might get better. Lose weight, it might get better. Deal with your stress, it might get better.' An added way to approach it on top of whatever medical treatment there is."
	Understanding the Causes of Psoriasis	Understanding the causes of psoriasis can assist with understanding treatment.	"I think understanding what [psoriasis] is and the causes of it trumps the others. Is it life threatening? I don't know." "But knowing more about [psoriasis] for me would have helped with what to do to avoid it."
Convenience	Application Site	Patients want to know about biologic treatments are how they are administered.	"...if anybody has to give themselves those shots. How convenient is that? Where do they give you the injections?"
	Embarrassment	Patients want to avoid treatments that can cause embarrassment.	"She doesn't want to go to work with anything in her hair. She doesn't want to have any treatment that may be intrusive to her daily life and she doesn't want anything embarrassing."

Thematic Analysis of Psoriasis Focus Group 1, *continued*.

Frequency and Duration	Patients want information on how often and how long treatments need to be taken.	“How do you take it? How many times you take it...? You take one needle a month or one pill a day or creams are use as needed.” “How long you need to take it.”
Time Spent on Treatment	Patients want information on how long a specific treatment will take to prepare and administer.	“Maybe try to put a time value to it. So if you’re going tanning, try and put a number to that.. And throw that number out there, this will be two hours of your time.”



Thematic Analysis of Psoriasis Focus Group 2.

Theme	Sub-Theme	Definition	Quote
Content	Clarify Definitions	Revise treatment definitions to more commonly understood terms.	“So maybe change the word complementary.” “Is that pink salt?” [balneotherapy]
	Clarify Psoriasis Severities	Explain in greater detail what constitutes each psoriasis severity.	“...how severe it that? What percent is mild? What percent is severe?”
	My Decisions Page	Feedback specific to the My Decision Page.	“I think it’s good because you set your priorities of what you think you can deal with.”
	My Trade Offs Page	Feedback specific to the My Trade-offs Page	“It made it easier to realistically decide.”
	My Values Page	Feedback specific to the My Values page.	“I thought it was an extremely helpful context to put in perspective for me.”
	Order of Steps	Whether or not the order of the steps leading to a decision makes logical sense	“It was logical to me.” “After you talk about yourself then you have your opinion on what should be done.”
	Severity-based recommendations	Outline which treatments may be best for different severities of psoriasis.	“It could have a little paragraph or...something that might pop up too while you’re filling this out. Maybe it gives you a couple ideas ...maybe these types of treatments might be a little more difficult, these might be better....”
	Visuals	Add visual examples of psoriasis and treatments.	“...Maybe people don’t know what a tanning bed looks like, so show an actual tanning bed.” “Showing how [psoriasis] starts, when it’s going in remission....”
Decision Making Process	Credibility	Patients feel the information is credible.	“I think part of that is the actual source of the material because there’s a lot of BS out there as well as a lot of good stuff...It’s great because it gives me enough information.”
	PDA is Informative	The PDA informs patients.	“To have a website like this to go to, people would know what they want to ask. And what they want to try. They will have knowledge.”
	Preparedness	The PDA prepares patients to discuss making a treatment decision with an HCP.	“I think this helps you very much be prepared with what you want to ask. And if you didn’t know anything about it. I think it’s really good.”
Delivery	Dissemination of the PDA	Make the PDA easy to share and widely accessible by promoting it through dermatology societies, doctors’ offices, and online.	“Is there a dermatological society of Canada where you could bring it to and they could cascade it?” “When a new patient is booking, whoever is booking the appointment can



Thematic Analysis of Psoriasis Focus Group 2, *continued*.

			ask if they have internet...here's information that might be helpful..."
Expansion of PDA	Translate the PDA into other languages and create more PDAs.		"Is it available in different languages?" "I think it should be for more conditions."
Sharing the Decision	Patients do not want to make a treatment decision alone.		"I think it would be good but to have it correlate with a visit to your doctor...I might make the decision to do, say, biologics for example and it's totally inappropriate."
Sharing the PDA with HCP	Patients would prefer to share the PDA with their HCP via email or printed copy.		"You could print it and bring it in." "Why could that not be emailed to our family doctors?"
Timing of administration	Patients feel the PDA should be used before an appointment with an HCP.		"I'd think it would be better coming in earlier when you're talking to the doctor about what's available and what he suggests."
Website Functions	Access to Glossary	More user-friendly access to definitions on website.	"You have to go to the definition and then scroll up and down because I couldn't get enough information on my screen..."
Technical Instructions		Patients want clearer terms for technical instructions and website functions.	[My Values Page]"Put your mouse on the line and move it... Drag and drop is a real technical term."
Ease of Use		Patients found the website easy to use.	"Yeah, I found it very easy. The layout was good...It was very simple to use."
Note Section		Patients suggested a note-taking section in PDA.	"...a place where you could log and add your notes to it like a diary thing."
Results Page		Provide a personalized results page summarizing the PDA.	"It could give you a list of what you specified as far as your treatments and that."
Print Functions		Provide the ability to print out the PDA and results page.	"When will these results be able to be printed?" "I like to write on stuff, so I'd like a hard copy."