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Defining patient-centered research priorities in pediatric dermatology

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Abstract

Background/Objectives: Patient and caregiver perspectives are critical in understanding dermatologic disease impact, presentation, and management in children. The Pediatric Dermatology Research Alliance (PeDRA) Patient Advisory Committee (PtAC), a group of patient representatives and parents of children with cutaneous disease, pursued a multistep, iterative, consensus-building process to identify comprehensive, high-priority research needs.

Methods: Building on discussions at the 2020 PeDRA Annual Conference, a research prioritization survey was developed and completed by PtAC members. Survey themes were aggregated and workshopped by the PtAC through a series of facilitated calls.

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Emerging priorities were refined in collaboration with additional PeDRA patient community members at the 2021 PeDRA Annual Conference. Subsequently, a final actionable list was agreed upon.

Results: Fourteen PtAC members (86.7% female) representing patients with alopecia areata, atopic dermatitis, vascular birthmarks, congenital melanocytic nevi, ectodermal dysplasias, epidermolysis bullosa, Gorlin syndrome, hidradenitis suppurativa, ichthyosis, pemphigus, psoriasis, Sturge–Weber syndrome, and pachyonychia congenita completed the survey. Following serial PtAC meetings, 60 research needs were identified from five domains: psychosocial challenges, health care navigation/disease management, causes/triggers, treatments to preserve or save life, and treatments to preserve or save quality of life.

Conclusions: Many pediatric dermatology research priorities align across affected communities and may drive meaningful, patient-centric initiatives and investigations.

KEYWORDS
dermatology, health care navigation, patient-centered, pediatric, priorities, psychosocial, quality of life

1 | INTRODUCTION

Patient and caregiver perspectives are important drivers for research and management of childhood skin disease. Eliciting insights from affected populations helps providers understand and honor patient preferences when co-creating treatment plans for children with cutaneous diseases such as atopic dermatitis, acne, psoriasis, and skin cancer.[1–3] Unique patient perceptions have led to the development of validated quality of life measurement tools, core outcome sets, and patient-centered approaches to counseling discussions in clinics.[4–6] Patient and caregiver voices also help fill knowledge gaps regarding the cutaneous clinical presentations and natural histories of rare syndromes.[2,7] Efforts to highlight patient viewpoints in the academic pediatric dermatology community are ongoing and may drive further investigational focuses.

As patients are key players in achieving meaningful research efforts, it is important to involve representatives from impacted disease communities when prioritizing research questions. Identification of universal research needs is challenging because each disease brings distinct burdens, diversity of treatments, variable presentations, and differing impacts on quality of life. Consensus priorities for translational dermatologic research in the United Kingdom were proposed in 2015 through clinicians and patient support group representatives, identifying 97 priority research questions.[8] Disease-specific research priorities, such as those for atopic dermatitis, psoriasis, and alopecia areata, have since been separately proposed by involving key disease stakeholders.[9–11] Importantly, children are a unique subset of dermatology patients, and there currently is no harmonized set of domains defining which pediatric dermatology research may be the most impactful for those affected.

In 2019, the Pediatric Dermatology Research Alliance (PeDRA) developed a Patient Advisory Committee (PtAC) as a forum for engagement between parents and patient representatives with cutaneous disease.[12] As of 2022, the committee consists of 15 representatives across 14 diverse dermatologic diseases including epidermolysis bullosa, facial vascular birthmarks, psoriasis, hidradenitis suppurativa, pemphigus, Gorlin syndrome, pachyonychia congenita, atopic dermatitis, Sturge–Weber syndrome, ichthyosis, alopecia areata, PHACE syndrome, congenital melanocytic nevi, and ectodermal dysplasias. Importantly, all representatives bring lived experience, with some participants also having population-level experience by virtue of leading (or involvement in) disease-focused patient groups. By closely involving patient representatives and caregivers in a pediatric dermatology research organization, affected communities have exposure to the latest relevant findings and close influence on emerging studies.

Here, input from patient representatives on the PeDRA-PtAC was gathered to organize a consensus-driven set of topics relevant to improving the lives of children with dermatologic diseases. Potential research questions and actionable items were proposed within each topic for future research and advocacy endeavors. Understanding such priorities from the patient and caregiver perspective is a pivotal step to advance the field of pediatric dermatology.

2 | METHODS

This project received an exemption determination from the Genetic Alliance institutional review board. A consensus-style approach used combined survey and serial meetings under the direction of an experienced facilitator (Figure 1). Following an introduction of the concept at the 2019 PeDRA Annual Conference, PeDRA formed the PtAC by working with leaders from patient advocacy organizations and individual patient stakeholders with connections to PeDRA to individually recruit patient representatives with a strong personal connection and reliable channels of communication to a disease

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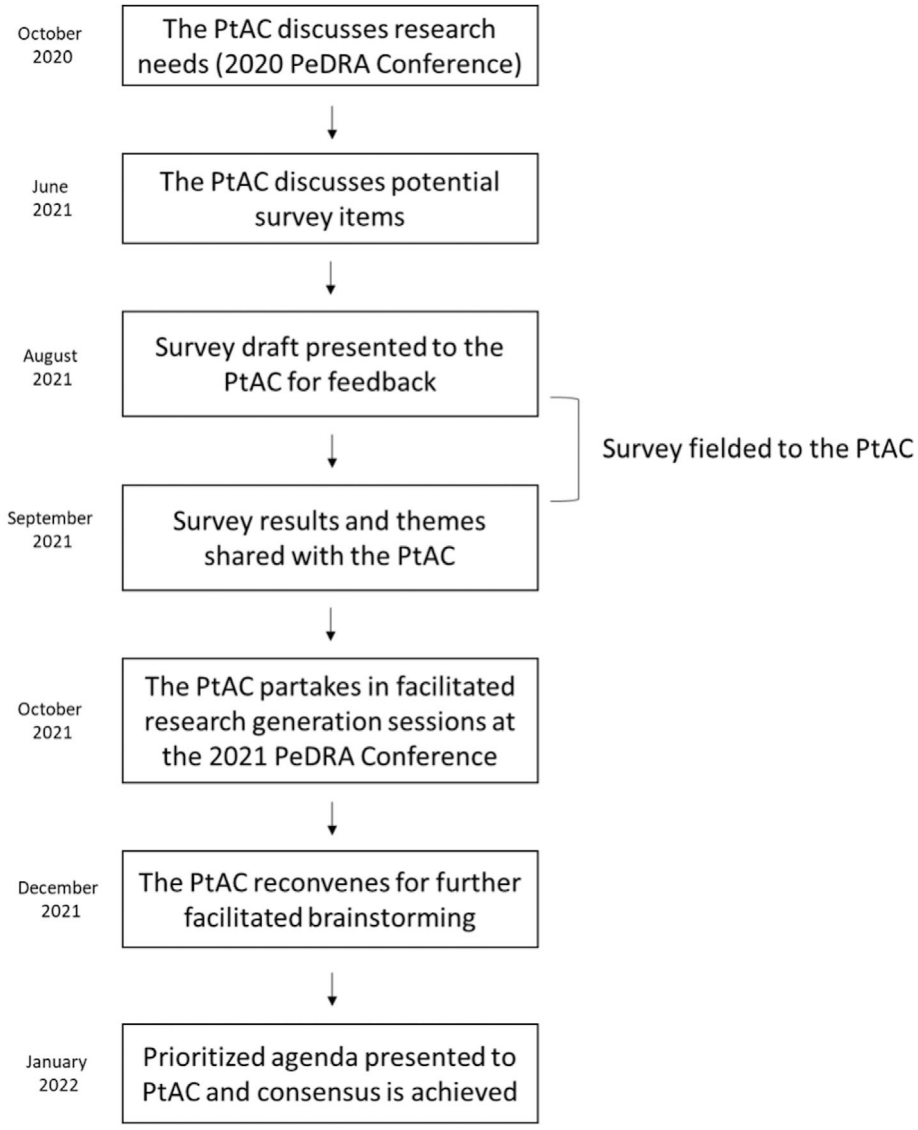

FIGURE 1 Key meetings from October 2020 to January 2022 for the Pediatric Dermatology Research Alliance (PeDRA) Patient Advisory Committee (PtAC) to develop a prioritized agenda for pediatric dermatology research needs.

community. PtAC recruitment prioritized individual perspectives, inter- and intra-community communication capacity, and familiarity with PeDRA and pediatric dermatology research. The group included 15 members at the time of this project. In October 2020, PtAC members broadly discussed research needs during a breakout session at the PeDRA Annual Conference. In June of 2021, the PtAC reconvened to identify the most relevant topics to investigate further in a survey. Based on this meeting, a survey was drafted and revised by members of PtAC. Ultimately, 22 items were included in 5 domains: (1) demographic and disease or condition characteristic factors, (2) understanding physical impact of disease or condition, (3) understanding psychosocial impact of disease or condition, (4) disease or condition management and quality of life, and (5) research and project types. The survey was fielded to all 15 representatives in the PeDRA-PtAC from August to September 2021.

Survey results (93.3% response rate) were aggregated and assembled before sharing data with the PtAC in a preliminary review discussion; results from that discussion and subsequent email dialogue resulted in a second iteration of prioritized research foci. This second iteration was further workshopped at the virtual 2021 PeDRA Annual Conference using World Café style idea generation breakout sessions,[13] in which another subset of PeDRA patient community members (patients and parents registered for the 2021 conference who voluntarily chose to attend the patient-specific breakout session, two of whom were also members of the PtAC) were present. This included a mixture of organizational leaders and patients from the vascular birthmarks, eczema, ichthyosis, nevus, PHACE syndrome, Sturge–Weber syndrome, and vitiligo communities. No clinician or professional scientist was present. Here, addressing emerging themes and challenges identified, members were divided into small groups and participated in an exercise to organize broad research and intervention ideas by complexity and estimated time to accomplish. Actionable items were narrowed down through this exercise and presented back to the PtAC. In a final round of facilitated brainstorming, the PtAC refined needs relevant across diverse disease states, versus needs within a more limited disease-

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TABLE 1 Major domains and themes identified for patient-centered research priorities in pediatric dermatology

Domain	Themes	Research needs, *n*[a]
Psychosocial challenges	Empowering patients to take charge of their own well-being and emotional health	17
	Creating an environment supportive of children with visible skin disease	
	Identifying links between disease manifestation and learning/cognition	
Navigating the health care system/managing disease	Reducing variability across providers and quality of care	18
	Supporting patients/families to identify high quality care and providers	
	Supporting patients/families to more efficiently/effectively navigate insurance	
Causes and triggers of diseases/conditions	Unlocking connections between the microbiome and disease onset	4
	Identifying genetic underpinnings of single and groups of diseases	
Treatments to prolong life	Creation of new therapies where none exist	11
	Identification of common treatment targets across rare diseases to incentivize therapeutic development	
	Identification of better skin cancer prevention or delay of onset when prevention not possible	
Treatments to address symptoms	Creation or identification of lowest risk but greatest benefit treatment of itch, pain, and visibility	10
	More robust guidance for treatment decision-making	
	More cost-effective treatment options or financing support	

[a]See Table 2 for research needs identified.

specific limited stratum, adjusting for relative weight. No research needs were completely excluded. A finalized agenda was agreed upon by the PtAC in early 2022.

3 | RESULTS

Fourteen survey respondents (86.7% female) represented patients with the following conditions: alopecia areata, atopic dermatitis (2), vascular birthmarks, congenital melanocytic nevi, ectodermal dysplasias, epidermolysis bullosa, Gorlin syndrome, hidradenitis suppurativa, ichthyosis, pachyonychia congenita, pemphigus, psoriasis, and Sturge–Weber syndrome. These respondents identified as the parent (without dermatologic disease) of a child with a pediatric dermatologic condition (33.3%), affected patient with history of pediatric dermatologic disease without affected children (33.3%), or a patient with history of pediatric dermatologic disease with affected offspring (26.7%). The composition of patient and family advocates who participated in the results synthesis sessions shared a similar diversity of disease experiences.

The two domains under which the greatest number of research needs were classified were "psychosocial challenges" ($n = 16$) and "health care navigation/disease management" ($n = 19$). The next three domains were "causes/triggers" ($n = 4$), "treatments to preserve or save life" ($n = 11$), and "treatments to preserve or save quality of life" ($n = 10$). For each of the five primary domains, common themes were identified (Table 1). A total of 60 research questions and needs were identified and grouped by research type (Table 2).

4 | DISCUSSION

Presented are the first comprehensive sets of pediatric dermatology research priorities derived from a patient and caregiver perspective, established by a unique group of stakeholders from different disease areas who share a connection to collaborative pediatric dermatology research and each other through the PeDRA-PtAC. The domains (based on cross-disease importance and commonality) this group arrived at were psychosocial challenges, navigation of the health care system/disease management, causes and triggers of disease, treatments to prolong life, and treatments to address symptoms. The 60 proposed items highlight patient-perceived gaps in patient-perceived existing research, clinical, and support efforts, and reveal common concerns of cancer, pain, itch, and visibility among other things. This list should serve as a useful reference for stakeholders while identifying meaningful pediatric dermatology research initiatives, and also be considered by funders, patient advocates, clinicians, and policy leaders to have high impact on affected pediatric communities.

Over half of the identified research needs (35 of 60) fell into domains of "psychosocial challenges" and "health care navigation and disease management," making these domains highly prioritized. Psychosocial challenges are a critical cross-disease focus. Negative effects on quality of life, self-esteem, and interpersonal relationships for both patients and caregivers are a consequence of many childhood skin conditions across all ages.[14] Atopic dermatitis, psoriasis, acne, and hidradenitis suppurativa are examples of the many pediatric dermatologic conditions associated with stigma, bullying, impaired relationships with family members, psychiatric impact, and suicidal

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TABLE 2 Patient-centered research priorities

	Research question or idea	Domain	Type
1	Do children with visible skin conditions in inclusion programs in school have improved academic success or ability to perform as compared to children with visible skin conditions without such inclusion programs in school?	PC	C
2	Do children with visible skin conditions report improved mental health/well-being in markets with significant public awareness/education and positive exposure campaigns as compared to children with visible skin conditions in markets without such campaigns?	PC	C
3	Which public awareness campaigns for stigmatized conditions have been most effective?	PC	C
4	Which peer support programs result in the greatest margin of improvement in children's self-reported assessment of mental health/well-being?	PC	C
5	Do children with visible skin conditions report improved mental health/well-being when in a care setting with integrated psychological support (a mental health professional on the multidisciplinary care team) as compared to children with visible skin conditions not in a care setting with integrated psychological support?	PC	C
6	Which biomarkers or other clinical markers of disease are most useful for predicting anxiety or depression?	PC	C
7	What is the best method for integration of mental health providers into the care team?	PC	C
8	Landscape analysis on how different consumer products celebrate/support visible skin differences in marketing.	PC	D
9	Surveys or landscape reviews of how various disease impacts affect ability to concentrate and learn.	PC	D
10	Identify or create registries that track biomarkers and their relationship to anxiety/ depression.	PC	D
11	Surveys or landscape reviews to see what may be missing from current peer support programs.	PC	D
12	Explore biomarkers for disease and identify any connection to likelihood or severity of anxiety or depression.	PC	B
13	Develop programs that use storytelling to empower patients and families.	PC	I
14	Incorporate visible skin disease into equity, diversity, and inclusion programs in schools.	PC	I
15	Programs or strategies to support learning despite disease manifestations or complications.	PC	I
16	Programs or strategies to support children to communicate their needs effectively to their parents.	PC	I
17	Revise practice guidelines to make referral to a mental health provider/therapist automatic upon diagnosis.	PC	I
18	Compare health plans that most effectively reduce barriers and provide seamless care.	H	C
19	Compare different interdisciplinary medical team approaches that best address the full spectrum of patient/family needs.	H	C
20	Compare co-production or shared decision-making models that best work for patients and families.	H	C
21	Compare different EMR platforms or approaches to identify the best option for care coordination.	H	C
22	Landscape analysis on different health plans' care coordination approaches.	H	D
23	Surveys of patient/family experiences with care coordination approaches and their lived lessons.	H	D
24	Surveys of patient/family experiences and lessons learned from finding their ideal providers.	H	D
25	Develop health care provider education for relevant expertise, communication, and partnership style.	H	I
26	Develop searchable database of providers/centers with specific expertise and knowledge.	H	I
27	Create methods for better care coordination between providers.	H	I
28	Develop an insurance "toolkit."	H	I
29	Develop a searchable database of anonymized experience/outcomes (effectiveness, side effects, specific improvements seen), especially in rare disease and for medications used off-label.	H	I
30	Develop a dictionary/ introduction for patients and families about what you are looking for in a provider, and what kinds of providers you need.	H	I
31	Create multidisciplinary clinics to address the full spectrum of needs.	H	I
32	Create an easily downloadable version of EMR that patients or parents can carry with them.	H	I
33	Create an insurance navigation "fast pass" for people who are "frequent users."	H	I
34	Create a campaign for greater uptake of clinical practice guidelines.	H	I
35	Develop a certification/ ranking system for providers.	H	I
36	Investigational study of the role of the microbiome as a cause or trigger for disease.	CT	B
37	Investigational study of genetic causes or triggers for disease.	CT	B
38	Survey of patients and families to identify trends or themes in potential environmental disease triggers.	CT	I
39	Survey of patients and families to identify familial patterns of disease expression.	CT	I

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TABLE 2 (Continued)

	Research question or idea	Domain	Type
40	Compare existing skin cancer treatments to see which is most effective in treating specific types of pediatric dermatologic skin cancers.	TL	C
41	Compare the most effective skin cancer prevention campaigns to see which one is most effective.	TL	C
42	Compare existing treatments that may be effective in one disease but have not been tested in others.	TL	C
43	Compare existing treatments for the management of recurrent pediatric skin cancers to see which is most effective in delaying recurrence.	TL	C
44	Compare existing skin cancer diagnostic tools to see which is most effective.	TL	C
45	Landscape analysis on potential common therapeutic targets between different forms of pediatric skin cancer.	TL	D
46	Landscape analysis on education children/parents receive on skin cancer from a young age.	TL	D
47	Find common unifying points across multiple therapeutic targets with high likelihood of non-academic interest/support.	TL	B
48	Develop new treatments for pediatric skin cancers.	TL	I
49	Develop new diagnostic tools for rapid detection of skin cancer.	TL	I
50	Create effective skin cancer prevention campaigns.	TL	I
51	Compare existing itch therapies to see which is most effective for which conditions and populations.	TS	C
52	Compare existing treatments to see which are most effective.	TS	C
53	Compare existing procedures to see which are most effective.	TS	C
54	Compare existing pain therapies to see which is most effective for which conditions and populations.	TS	C
55	Capture and analyze real-world data on benefits and risks of therapy for patients/families to use.	TS	D
56	Develop new treatments to prevent or reduce scarring.	TS	I
57	Partner with clinical professional society to develop patient-centered clinical practice guidelines.	TS	I
58	Develop new, low-risk therapies for itch.	TS	I
59	Develop new, low-risk therapies for pain.	TS	I
60	Develop new treatments to reduce visibility.	TS	D

Abbreviations: B, bench; C, comparative effectiveness research; CT, causes and triggers; D, descriptive; H, health care systems; I, innovation; PC, psychosocial challenges; TL, treatments to prolong life; TS, treatment of symptoms.

behavior.[14,15] The patient priorities here highlight an emerging theme within the psychosocial challenges domain: a need to empower patients in a supportive environment. Support groups and programs have positive effects on children with skin disease and family members,[16,17] an area identified by the PeDRA-PtAC for needed continual focuses in order to identify best support strategies to improve existing programs and develop new strategies.

The second predominant domain, "health care navigation and disease management," represents a common challenge for patients and caregivers. Existing barriers in pediatric dermatologic care include financial obstacles (treatment cost, selective insurance acceptance), geographic location, and prolonged wait times.[18,19] Socioeconomic disparity additionally limits access to pediatric dermatologic appointments for minority patients.[20] Thus, the PeDRA-PtAC agenda includes items to compare health plans, create patient insurance education, improve access to providers, and coordinate care. In addition, conditions seen by pediatric dermatologists may affect multiple organ systems (i.e., epidermolysis bullosa, Gorlin syndrome, neurocutaneous syndromes) requiring multidisciplinary care.[21–23] The presented priorities encompass identification of effective interdisciplinary and multidisciplinary models, as well as innovations to help patients navigate this complex process.

The remaining three domains surrounding causes/triggers and treatments provide a patient-centered direction for further disease-specific research efforts. The priorities for "causes and triggers of cutaneous disease" highlight bench and innovation style research to increase understanding of the role of genetics, the microbiome, and the environment. For treatment domains, life-saving/prolonging treatments are largely applicable to higher mortality conditions (i.e., skin cancer), whereas the quality of life-preserving/improving treatment domain priorities apply across many conditions. Patient-centered methods in developing dermatologic management approaches have been previously successful, such as those for biologic decision making in psoriasis.[24] Future treatment investigations with a similar patient-centric approach may be broadly useful in pediatric dermatology.

While the community-level knowledge of disease experience among individual participants contributed to a broad corpus of findings, limitations for the implemented approach exist. Representatives were selected based on a collaborative approach between PeDRA leadership and stakeholders with existing connections to PeDRA (based on factors such as organizational history and disease-specific opportunity to participate in collaborative pediatric dermatology research). Openly acknowledging the impracticality of efficiently and

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effectively representing multiple patient populations, each composed of thousands to millions of individuals, the unique approach led to a small consensus group size, lack of comprehensive representation of all childhood skin diseases, and subjective assessments. As a result, not all items are applicable to every pediatric dermatologic disease, and the priorities are intended to serve as a flexible guiding tool that may inform future large-scale consensus initiatives, patient surveys, and focused research. In addition, as part of a semi-informal qualitative consensus process, the survey technique relied on the expertise of an experienced facilitator and no validated thematic analyses were performed. Individuals who contributed to the testing and development of the survey were the same participants completing the survey. While this approach provides the advantage of iterative steps that led to the inclusion of relevant items in a diverse group of stakeholders, bias in the form of an "echo chamber" may occur in which pre-existing beliefs are reinforced.[25] The anonymity of the survey, allowance to free-type additional issues, and incorporation of outside community members who did not develop or complete the survey at a concluding discussion session balance this limitation.

Generalizability challenges arose during the consensus process for unique needs between and across specific diseases, such as the variability of treatment approaches for diseases that require special care and wide diversity of symptomology severity for affected children. The group acknowledged that while some research needs are paramount within a given disease population, they are necessarily unique and narrowly applicable. Conversely, other research needs span disease populations and would equally benefit all patient communities. Both cross-disease and disease-specific priorities were included here to allow for patients, clinicians, and researchers to proceed with helpful initiatives.

Research priorities developed here should be interpreted with both methodologic strengths and flaws considered. The PeDRA-PtAC items identified provide a unique and actionable foundation for impactful patient-centric research in the context of a collaborative pediatric dermatology research network. Expanded efforts with attention to a systemic method of selecting stakeholders, engaging a larger group in a longer list of patient populations, in addition to using more formal methodologic thematic selection, may improve validity of research needs and provide valuable supplements to this work.

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CONFLICT OF INTEREST

Michael Siegel, PhD, and Katherine Devenport are employed by the Pediatric Dermatology Research Alliance. Holly Neale, MD served for 1 year as the Pediatric Dermatology Research Alliance Fellow. Jennifer Austin is employed by the International Alliance of Dermatology Patient Organizations.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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