



## Background

Every pediatric skin disease is associated with burdens unique to their own patient community and shared with the burdens of others. In 2019, PeDRA established a **Patient Advisory Committee (the “PeDRA-PAC”)** as a forum for engagement between parent and young adult patient representatives from these communities. With a direct connection to PeDRA, the PeDRA-PAC, interacts in the context of an active research network, with exposure to the latest research in the field and ability to influence emerging studies. As of October 2021, the PeDRA-PAC include 15 members representing 14 diseases and conditions (alopecia areata, atopic dermatitis, facial birthmarks, congenital melanocytic nevi, ectodermal dysplasia, epidermolysis bullosa, Gorlin syndrome, hidradenitis suppurativa, ichthyosis, pachyonychia congenita, PHACE Syndrome, pemphigus, psoriasis, and Sturge-Weber Syndrome).

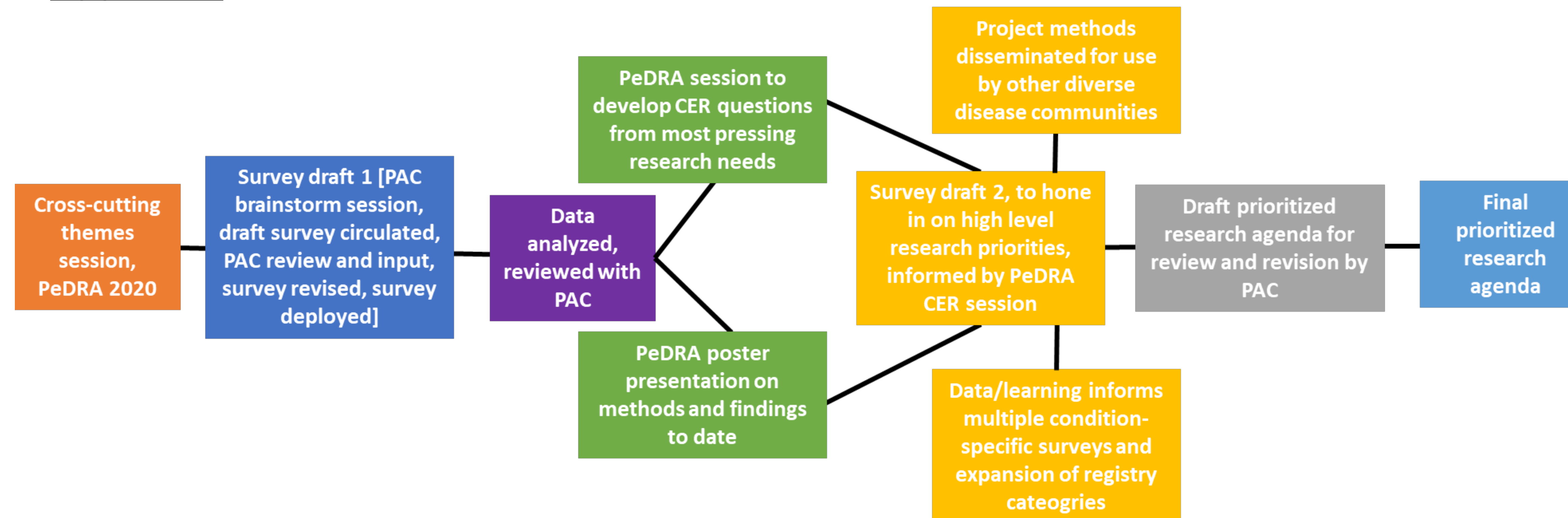
## Goal

To create a list of high-priority, patient-centric research questions relevant across multiple disease areas and actionable by PeDRA investigators. The hope is that the outcome of this work can influence near-term PeDRA studies, mid-term large scale studies (e.g., a **“Big” Study**) and future patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).

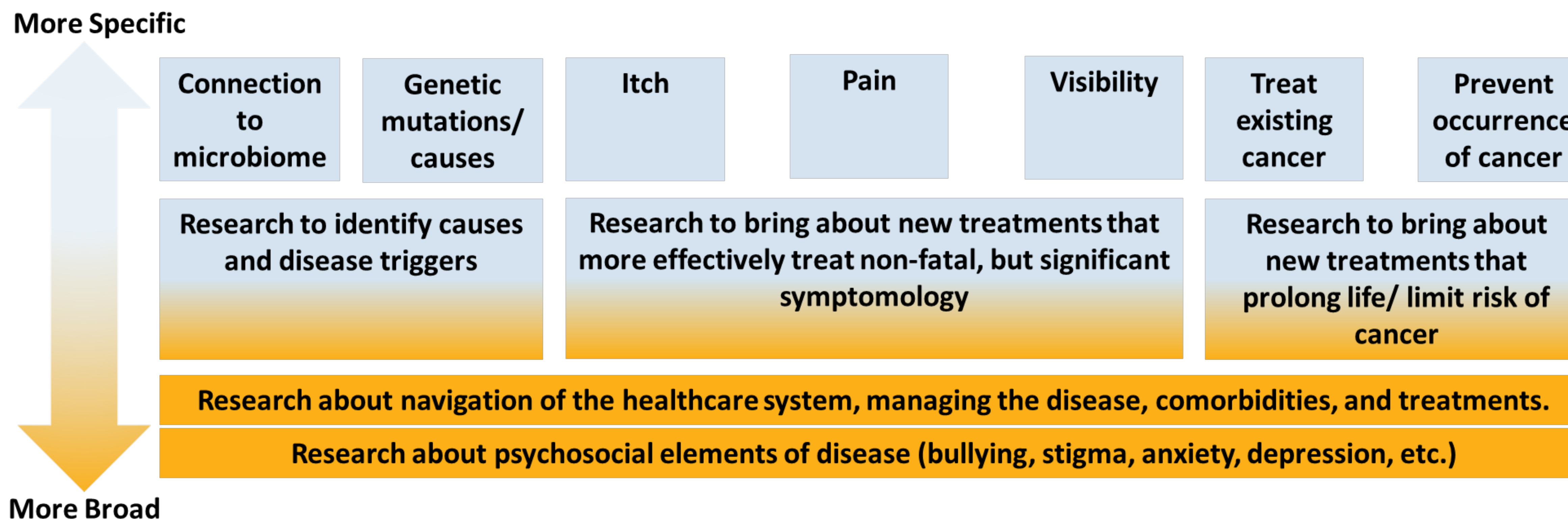
## Methods

**THIS IS AN ONGOING STUDY.** The PeDRA-PAC is conducting a consensus building exercise under the direction of an experienced facilitator. Following an introductory meeting, the PeDRA-PAC iterated via email to design a survey to identify shared disease burdens, curiosities, and priorities. An online version of the survey (created using Alchemer) was distributed by email to all 15 members of the PeDRA-PAC. Results from the survey were compiled and discussed during a virtual meeting of the PeDRA-PAC and are now being further refined into a second survey, which will be followed by a discussion during the patient breakout session at PeDRA 2021 and at least one more virtual meeting of the PeDRA-PAC to distill all information into actionable research questions.

## Approach



## Trending Priorities



## HOW YOU CAN HELP

Please use the chat window or send an email to [mike.siegel@pedraresearch.org](mailto:mike.siegel@pedraresearch.org).

### Researchers:

1. Ask questions.
2. Share ideas and interpretations of the data so far.
3. Express interest in leading or participating in a study based on outcomes from this initiative.

### Patients:

1. Ask questions.
2. Share ideas and interpretations of the data so far. Are we missing anything that matters to you?
3. Let us know if you’d like to get involved with the PeDRA-PAC or learn more.