



January 28, 2022

Nakela L. Cook, MD  
Executive Director  
Patient-Centered Outcomes Research Institute  
1828 L Street NW, Suite 900  
Washington, DC 20036

RE: PCORI's Research Agenda: Proposed Agenda for Public Comment

Dear Executive Director Cook,

Thank you for your leadership of the Patient-Centered Outcomes Research Institute (PCORI) and your ongoing efforts to promote community collaboration and advance a timely research agenda. I write today on behalf of the Coalition of Skin Diseases (CSD) to offer community feedback on the proposed research plan and encourage greater emphasis on skin disease research.

The Coalition of Skin Diseases (CSD) is a national non-profit which serves as the largest consortium of dermatological patient organizations in the United States. Collectively, CSD represents 84 million Americans (over 25% of the population) living with a skin condition. It is our mission to advocate on behalf of individuals with skin disease by supporting basic scientific and clinical research, fostering physician and patient education, generating awareness of the skin disease, and supporting our patient advocacy organization members in their efforts to improve the quality of life for those living with one of 20 represented skin diseases.

Skin diseases are historically under-represented in federal and quasi-federal research efforts and available resources are inadequate given the size of the affected patient population. For example, while there are 3,000 dermatological diseases (including many rare conditions), there are only eleven initiatives focused on skin conditions in PCORI's searchable portfolio, representing only four dermatological diseases. Further, while we appreciate that PCORI places specific emphasis on representing rare conditions, this hasn't translated into meaningful resources for skin diseases with a qualifying prevalence.

One opportunity to deepen the engagement across dermatological conditions could be through the PCORI focused grant submission (RFP) process. Given the prevalence of dermatological conditions, dermatology focused research could go a long way in advancing PCORI goals. Similarly, the Engagement Awards category, which is intended to broaden the catalogue of represented diseases, has grant requirements that remain unattainable for many, who would benefit greatly from an even lower required initiative scope. A \$50,000 grant, for example, would be more accessible across the dermatology landscape. In addition to expanding the influence of PCOR/CER, this would also allow for more rare diseases to be represented in the

PCORI system, which would allow for an expansion of impact over time through access to future grant opportunities.

Regarding the core elements of the proposed research plan, skin disease patients face many of the same access-driven barriers to care as other communities and can play a meaningful role in efforts to address health disparities and promote health equity. Our communities and talented researchers are also working on identifying knowledge/evidence gaps for the field and advancing implementation science in key areas. There is a great deal of synergy between PCORI-identified priorities and emerging skin disease research efforts, and our stakeholder community can play an important role in identifying timely collaborative opportunities and mutual areas of interest. In the spirit of community engagement, we welcome a dialogue with PCORI to review general and specific opportunities in more detail.

The dermatological care landscape is quickly advancing. For many skin diseases, the next decade will usher in new, more effective treatments, first in class treatments, and first treatments all together. The excitement and ongoing innovation in the dermatology space is palpable, yet for many specific skin conditions, established best practices for patient centered outcomes research are not known and/or the means to translate successful models in other disease areas not available. Please let CSD know if you or your colleagues have any questions or require any additional information.

Sincerely,

A handwritten signature in black ink, appearing to read "Kelly Barta", with a stylized flourish at the end.

Kelly Barta  
President  
[Coalition of Skin Diseases](http://www.skincoalition.org)

