

2. SPECIFIC AIMS Parents of very young children with type 1 diabetes (VYD) often experience distress, anxiety and burnout that can impede T1D care, threatening the child's current and future adaptation to T1D. The health care system may not equip parents to contend with these issues well, but VYD parents can offer reciprocal support and guidance in promoting effective parenting and coping skills. The many obstacles to face to face interaction among parents suggest that a social media approach may be a very effective way of facilitating timely, meaningful and needed social support in the forms of parenting guidance, affective support, provision of information, and sharing of creative solutions to common T1D management problems in VYD. While many excellent social media resources exist, there is not a single portal that facilitates parents' access to these resources, nor have the potential benefits been validated empirically. We propose to apply crowdsourcing methods to achieve the iterative development and initial evaluation of a social media platform designed by and for VYD parents with extensive input from health professionals and technical expertise in crowdsourcing and application development provided by Appirio, Inc. and Nemours web development team.

Crowdsourcing is a flexible category of online activity that has been applied to diverse problems in many fields, including public health, that includes four elements: 1.) An organization that has a task it needs to be performed, (e.g., development of a social media resource that meets the needs of parents of VYD); 2.) A community, "the crowd", that agrees to perform the necessary tasks voluntarily (here selected parents of VYD, T1D clinicians, and professional application developers); 3.) An online environment that allows the work to take place by enabling collaboration between the crowd and the organization, (the infrastructure that will be developed if this grant is funded); and 4.) Mutual benefit for the organization and members of the crowd (better glycemic control, improved quality of life and decreased burden of care for VYD and their families).

To our knowledge, crowdsourcing methods have not been applied to the design and development of online health behavior resources such as that proposed in this application. We will design the portal with our stakeholders based on principles of User-Centered Design and then collect preliminary data needed to justify and then conduct a rigorous controlled trial of the effectiveness of a social media resource that will provide parents of VYD (<6 years old) with timely, responsible, safe and effective support and guidance regarding parental management of common behavioral, affective and cognitive barriers to effective T1D care in this age group. The proposed work will address these specific aims:

Aim 1: We will use crowdsourcing methods to 1.) Identify the most important concerns about management of VYD from key stakeholders (parents, pediatric endocrinologists, diabetes nurses, dietitians, psychologists and social workers) to specify problem areas that a social media portal should address; 2.) Collaborate with parents (with available input from T1D professionals) to design the optimal structure, functions and outcomes of a social media resource for parents of VYD to improve daily management of T1D, to enhance parental coping with sources of distress and care burden that uniquely affect this clinical population and to facilitate parents' access to and use of other beneficial resources within the diabetes online community.

Aim 2: Relying on Appirio's crowdsourcing platform engaging more than 700,000 expert application developers, and ongoing stakeholder input, we will iteratively incorporate the knowledge, experience and perspectives gained in Aim 1 to systematically build and refine a social media resource enabling parents of very young children with T1D to obtain real-time emotional support, information and parenting guidance, enabling them to cope more effectively with the daily demands of diabetes management in this population.

Aim 3: We will conduct a randomized controlled trial of a final, fully functional version of the platform with 120 parents of children <6 years old who receive T1D care at any Nemours Children's Health System site in the Delaware Valley and Florida, to permit careful tracking of key T1D outcomes, patterns of portal utilization by parents and further refinement of the resource based on user feedback during and after the trial.

Aim 4: We will compile taxonomic libraries of common T1D management problems and associated empirically validated protocols (as reported by parent users of the resource) for parents to apply to those problems.

Having designed, created, validated and refined the proposed portal, we will be well-positioned to plan and complete a rigorous randomized controlled trial to evaluate effects of portal access on metabolic, behavioral and affective outcomes of T1D care in the VYD population. During the completion of Aims 3 and 4, we will concurrently cultivate relationships with such entities as the Juvenile Diabetes Research Foundation (JDRF), the www.childrenwithdiabetes.com website, the American Diabetes Association, the T1D Exchange and the PedsNet Clinical Data Research Network to enable economical completion of such a trial.