Development of an electronic registry to determine prevalence and characteristics of anaphylaxis and epinephrine use: parent protocol
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Aims: Food allergy impacts 8% of children in the United States. Nearly 40% of children with food allergy have a history of severe reactions. To date, there is no comprehensive mechanism for reporting and tracking allergic reactions, including anaphylaxis. The objective of this study is to develop and pilot a web-based reporting tool for allergic reactions and management for parents.

Methods: To develop the tool, we solicited feedback from a wide variety of food allergy and anaphylaxis advocacy, research, and education experts via a focus group. This focus group gave us access to the collective experience and wisdom of a diverse sample of parents of children with food allergy in the Chicagoland area from the very initial stages of tool development. During this focus group, we asked the parents to comment on the content of a prototype and the feasibility of implementing a web-based reporting tool for allergic reactions and management practices.

Results: The important themes that were identified in focus groups of the parent-friendly registry were ease of use and providing ample details during the report. During the focus group and parental feedback on the prototype, it was found that the parents did not want a short-survey that they could fill out on the way to the hospital or in the waiting room. They much rather would prefer one that would be taken on a computer and was longer, so they could report the details of their child’s reaction. Many parents also would like the registry to be available for use to all allergic reactions, not just food-induced reactions.

Conclusions: The development of an electronic registry system requires the forging and sustaining of partnerships between researchers and parents. While it would seem that a more mobile-friendly format would have been preferred, the focus group steered the development into a more detail-oriented survey that would require parents to really think through their child’s reaction, regardless of severity. The parents were enthusiastic about the development of a web-based reporting tool for allergic reactions and management, so they too could better understand their child’s reactions throughout the course of the study.