Development of an electronic registry to determine prevalence and characteristics of anaphylaxis and epinephrine use: ED protocol

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**Aims:** An estimated 8% of children in the United States have a food allergy, and nearly 40% of children of these children have a history of severe reactions. To date, there is no comprehensive mechanism for reporting and tracking anaphylactic incidents. To address this gap, we are developing and piloting an Anaphylaxis and Epinephrine Use Registry in a pediatric emergency department. To develop our tool, the first step was to collaborate with ED personnel to identify critical issues for registry implementation.

**Methods:** We conducted two focus groups, one with 5 ED physicians and the other with 5 observation unit healthcare providers, to gain insight into the content of the registry and the feasibility of implementation. During the focus group, we asked how each group diagnosed and treated an anaphylactic patient and how implementing a registry would impact their workflow. Based on this input, we then collaborated with ED physicians and clinical informatics experts at the hospital to further develop a reporting tool in the electronic medical record.

**Results:** Major themes from the focus group and development process identified were data security in the transfer, ease of implementation and ease of data extraction. Transferring the data into the registry required the implementation of a new process to ensure data security between the hospital and the academic institution, where the data was to be stored. To de-identify the information, a “hashing” technique, which electronically de-identifies the data, was implemented. Another feasibility issue that was identified was that the data that was to be used for the registry was not standardized, so “smart-text” phrases were developed within the electronic medical record to help collect the data in a standardized way. These phrases would hopefully alleviate the amount of “free-text” found in a patient’s chart, resulting in improved standardized charting practices in the ED and data extraction for the registry.

**Conclusions:** The successful development of an electronic registry system requires the forging and sustaining of partnerships between clinicians, clinical informatics experts and researchers. Major issues to be resolved will be the issues of data security, ease of implementation into the physician’s workflow and the ease of data extraction for the registry. Each hospital system will most likely be different but the knowledge gained through a registry can offset the obstacles in development.