Our CF team felt that there was opportunity to improve the experience for patients with new diagnoses of CF and their families. Survey data confirmed that patients with new diagnoses and their families had suboptimal experiences during their initial visits to our center. The objective was to increase the rate of patients and families reporting strong satisfaction in all areas of being a new patient at our center.

**Methods:** We assembled a multidisciplinary team of attending and fellow physicians, nurses, and social workers. We distributed surveys to families of patients with new diagnoses of CF at our center over the past 2 years to assess current impressions of families’ experiences, identify areas for improvement, and track progress over time. We then used quality improvement methods to define current processes, identify key drivers for improvement in the family experience, and identify possible interventions for improvement.

**Results:** Baseline survey data showed varying levels of satisfaction for new patients and families. Specific areas of low satisfaction included the sweat testing process, logistics with finding and moving through facilities, and the amount of information provided at the initial visit. We tested multiple interventions for improving the patient and family experience through plan-do-study-act cycles. Successful changes that we implemented included family welcome baskets and educational binders, greater previsit planning by the CF team, improving logistics of the sweat testing process, how-to-contact and frequently asked questions sheets for families, and checklists for providers for covering educational topics. Although we are still collecting data to assess for overall improvements, initial results are promising.

**Conclusions:** A standardized approach to identify weaknesses and improve care team processes can improve the experience of patients with new diagnoses of CF and their families.

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### 101 Investigation of educational needs of people with a new diagnosis of cystic fibrosis transmembrane conductance regulator–related disease

O. Goltsis1, D. Tullis2, K. Griffin1. 1School of Medicine, University College Dublin, Dublin, Ireland; 2Department of Medicine, University of Toronto, Ontario, Canada; 3Division of Respiriology, St. Michael’s Hospital, Toronto, Canada

**Background:** The cystic fibrosis transmembrane conductance regulator (CFTR) gene encodes the CFTR protein. Malformation or dysregulation of this protein as a result of CFTR gene mutations can lead to a broad range of clinical consequences. Individuals who present with clinical concerns associated with CFTR dysfunction but do not fulfill the diagnostic criteria for cystic fibrosis (CF) are identified as having CFTR-related disease [1]. The general population does not understand this condition well because of its variable clinical presentation, late age of onset, and quality of educational resources, which are limited in number, content, and readability. To address this knowledge gap, this study investigated the educational needs of people with a new diagnosis of CFTR-related disease to develop patient-centered health educational material.

**Methods:** Semi-structured interviews were conducted with consenting individuals with CFTR-related disease referred to the Adult Cystic Fibrosis Clinic at St. Michael’s Hospital in Toronto, Canada, in the last 5 years.

**Results:** Quantitative analysis revealed four common themes at the time of diagnosis: an understanding of the implications for family members, the amount of information provided at the initial visit, and expected quality of life. A proportion of patients also mentioned concern regarding the length of time it took to receive a referral to the CF clinic.

**Conclusions:** These findings substantially improved our ability to develop meaningful and accessible web-based and printed educational materials and reinforced the need to educate and strengthen communication with related specialties.

**Reference**