

AIM

we aim to improve the process of healthcare transition and health literacy of CF adolescents at UNC by creating a sustainable, streamlined approach to transition of CF patients beginning at age 8 and extending through the "hand-off" of patients to the adult care team (age \geq 18). By working on this process, we expect fewer delayed transitions, improved health literacy of this patient population, and improved patient and provider satisfaction. Our specific aim is to enroll 90% of eligible patients into CF RISE by July 1, 2017.

PROBLEM

The health of patients with cystic fibrosis (CF) has improved markedly over the last decade, with most patients now reaching adulthood. Consequently, there is a clear need for guided transition of patients from pediatric to adult care, since without systematic approaches, individuals with chronic illnesses face almost insurmountable barriers in sustaining healthcare. The pediatric CF clinic at UNC cares for approximately 350 patients, and each year, 10-20 new patients become age-appropriate for transition to the adult CF clinic.

IMPORTANCE

With >50% of US CF patients currently 18 years or older, CF can no longer be considered a pediatric disease, yet compared to age-matched peers, young adults who grow up with a chronic health condition achieve milestones later in life or not at all. This may be an unintended consequence of the family-focused care provided in pediatrics that can limit education, independence, and attainment of self-management skills for the adolescent with a chronic disease. Transition from pediatric to adult care overlaps with other, often tumultuous, life events, and this stressful period can lead to poor health outcomes, as patients struggle to cope with many simultaneous changes compounded by difficulties with access to care. A planned, structured transition is most appropriate for providing uninterrupted care and support for the young adult with CF. The CF Foundation has advocated for this approach since 1996, recommending that all CF Centers transition at least 90% of their patients 21 and older to adult providers.

EXPECTED OUTCOMES*Objectives:*

- Understand the patient perspective through more effective survey techniques. Empower our Patient Family Advisory Board (PFAB) to become more active in the center.
- Assess patient satisfaction with the current transition process by surveying those who transitioned or transferred prior to November 1, 2015
- Improve the quality of our transition program by structuring transition based on the CF R.I.S.E. toolset, including knowledge assessment and readiness tools. Incorporate a rewards system through Beads of Breath.
- Measure the effect of the CF R.I.S.E. toolset by studying outcomes including the number of patients enrolled in the program, the number of knowledge assessments completed by the patients, and change in assessment scores over time. Study the effect of our process change by patient and provider survey and measuring time to establishing care in the adult CF center.

Numerical Targets:

- >90% of eligible patients enrolled in CF R.I.S.E.
- Completion of at least 60% of available knowledge assessments by enrolled patients
- 20% improvement in individual scores after directed education
- 20% improvement in patient/provider satisfaction with the new transition program

- <56 days between last pediatric clinic appointment and first adult clinic appointment
- >30% of eligible patients transferred each year

MEASURES

Outcomes measures:

- Changes in CF R.I.S.E. scores from initial score to most current scores, assessed quarterly
- Provider and patient satisfaction scores, assessed annually
- Time to establish care in the adult CF clinic in days, assessed quarterly

Process Measures

- Percentage of patients transitioned each year, assessed annually
- Percent of eligible patients enrolled in CF R.I.S.E. each quarter
- Percent of total completed knowledge assessments, assessed monthly

Balancing Measures

- Time to first available adult CF clinic appointment for non-internal transfers, assessed quarterly
- Time to first available return visit, assessed quarterly

RISKS/BARRIERS

The major barrier is time involved in completion of the modules (for both patients and providers) as well as attitudes regarding “taking another test” for the enrolled subjects. An additional barrier is lack of computer access at home for subjects.

STAKEHOLDERS

Key stakeholders in the process include the patient, their caregivers, and the multidisciplinary CF team. Interprofessional input is incorporated at weekly team meetings where individual patients are discussed with their goals, barriers, and timeline to transition. Patient/family preferences will be incorporated through the involvement of the Patient-Family Advisory Board (PFAB), who meet monthly via teleconference with meetings facilitated by the CF Social Worker. The multidisciplinary team also has a patient and a parent of a patient involved in weekly team meetings.

SCOPE

In Scope:	Out of Scope:
Patients aged 16 and older followed in the pediatric CF clinic for regular CF care.	Patients younger than age 16 or not routinely followed in the pediatric CF clinic. Patients with diseases other than cystic fibrosis.

SCHEDULE

Kick-off date: July 18 (subject to change based on hiring status of CF transition coordinator)
 Blue Belt Training: July 29
 Sept 15, Dec 15, March 15, June 15: deliverables due

PROJECT TEAM

Team Member	Project Role (<i>sponsor, lead, SME, coordinator, etc.</i>)
Jennifer Goralski	Lead
Jennifer Leandro	Member

IHQI - CF Transition

rev. 06-13-16

Martha Taylor	Member
Jaimee Watts	Member
Margaret Leigh	Sponsor
TBN	Project Coordinator