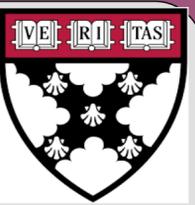




VALID-CF Study



VALue In Delivery of care for children with Cystic Fibrosis An international collaborative paediatric study

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Introduction

Cystic Fibrosis (CF) is a chronic, progressive disease that primarily affects the lungs and digestive system. Advances in clinical care have been sequential and added years to life expectancy and quality of life. In recent years, highly effective disease modifying drugs have been introduced to therapy. These agents, termed CFTR modulators, are highly expensive, prompting questions about the affordability of new treatments worldwide and how the multidisciplinary team may adapt to care for changing phenotypes and an ageing population of PWCF.

Novel therapeutics are showing promise in up to 90% of people with CF (PWCF) but drug development requires substantial investment which contributes to the high cost of these modulator drugs and delays in funding in many countries unable to afford them. The application of Value Based Healthcare has become a global movement in order to find ways to control and prevent further disease i.e. optimise patient outcomes in a system of rising costs. European centres are moving toward this model and our study will be the first paediatric centre in Ireland to conduct research in this area with the collaborative input and experience in Value Based Healthcare of Boston Children's Hospital and Harvard Business School.

We conduct this research with ICHOM's mission statement in mind – "to unlock the potential of Value-Based Healthcare by defining global standard sets of outcome measures that matter most to patients and driving adoption and reporting of these measures worldwide to create better value for all stakeholders." We focus on outcomes that matter most to patients and care-givers so that we can use them to guide our decision-making in a way that will empower the patient and optimise benefit from care received. We explore new ways to deliver patient reported outcome measures (PROMs) in an evolving, ageing population of PWCF.

Aims and Objectives

1. To conduct a comparative analysis of the care pathways for children with CF in Ireland and Boston in an era of modulator therapy
2. To apply Time Driven Activity Based Costing (TDABC) to paediatric CF care in Ireland and Boston in order to evaluate and compare direct and indirect costs of healthcare utilisation in an era of CFTR modulator therapy
3. To investigate the use of patient reported outcome and experience measures in optimising the care we deliver to PWCF

Methods

This is a prospective observational study. Participants are paediatric patients attending specialist CF centres at Children's Health Ireland, Dublin and Boston Children's Hospital, Massachusetts.

Participants are stratified by age (0-1 year; >1-<7 years; 7-<12 years; 12 years+). The patient journey is recorded by direct observation of ambulatory and inpatient care. The steps in this journey are documented at all stages to record activities, interventions and resources required. Costing analysis of the care received by children with CF will be estimated using the seven steps of TDABC for healthcare organisations (Table 1) (Kaplan & Porter, 2011).

Step 1	Select the medical condition
Step 2	Define the care delivery value chain i.e. chart all key activities performed within the entire care cycle
Step 3	Develop process maps that include each activity in patient care delivery, and incorporate all direct and indirect capacity-supplying resources
Step 4	Obtain time estimates for each process. i.e. obtain time estimates for activities and resources used
Step 5	Estimate the cost of supplying patient care resources, i.e. the cost of all direct and indirect resources involved in care delivery
Step 6	Estimate the capacity of each resource and calculate the capacity cost rate
Step 7	Calculate the total cost of patient care

Table 1: Seven steps of TDABC for healthcare organisations

Patient reported outcomes are measured from the patient and primary care-giver perspective as we move into an era of high impact modulator therapies. Combinations of general and condition specific PROMs will be developed. We explore alternative ways to measure health outcomes in paediatric patients where benefits of CFTR modulator therapy may not be clinically apparent.

Results

This is an ongoing study

Conclusions

Never before has a prospective international study of this kind been conducted to evaluate healthcare utilisation and costs using key principles of Value Based Healthcare in an era of CFTR modulator therapy. Our timely, novel contribution to the literature will build on existing cost analysis studies to include value based measures (PROMS, experience measures, direct, indirect and societal costs) that are critical to facilitate improvements in the delivery of patient centred care, the health of our patients as a whole and the optimum use of resources under existing financial constraint.