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Review

Using registry data to improve quality of care

Kieran McIntyre [a,*], Dominique Pougheon Bertrand [b], Gilles Rault [c]

[a] University of Toronto, Department of Medicine, Division of Respirology, Adult Cystic Fibrosis Program, St Michael's Hospital, Canada
[b] LEPS EA3412, Sorbonne Paris Cité University, Bobigny, France
[c] Cystic Fibrosis Center, Foundation Ildys, Roscoff, France

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Abstract

Patient registries provide clinicians, patients and families with the ability to track important health outcomes at a population, cystic fibrosis (CF) center, and patient level. International quality improvement (QI) work driven by registries has been effective at improving the health and the care delivered to the individual patient. In this review, we examine the role CF registries have played in the QI process over the years and discuss the inherent strengths and limitations that exist when using registry data for this purpose.

Keywords: Quality improvement; Patient registries; Cystic fibrosis

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1. Introduction

A registry is defined as any organized system that uses observational study methods to collect uniform data and evaluate specified outcomes for a population defined by a particular disease, condition, or exposure. The importance of collecting data on patient outcomes in cystic fibrosis (CF) was recognized back in 1964 with the Warwick report which highlighted variation in CF survival in the US and laid the groundwork for the CF Foundation Patient Registry which was established in 1966 [1]. Since then, many countries have created and maintained national CF registry data, as outlined in the first paper in this series [2]. Registries have been used to provide a deeper understanding of the epidemiologic changes in the population over time, to evaluate the associations between clinical characteristics and health outcomes, to further our understanding of the genotype-phenotype relationships in CF, as well as to provide evidence for advocacy strategies

* Corresponding author at: Adult Cystic Fibrosis Program, St. Michael's Hospital, 30 Bond Street, Toronto, Ontario M5B 1W8, Canada.
E-mail address: mcintyrek@smh.ca. (K. McIntyre).

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within the CF community. In addition, registry data are regularly used as the foundation upon which to build quality improvement (QI) initiatives aimed at ensuring the best outcomes and care practices for patients [3, 4]. By tracking health outcomes and care delivery processes over time, it is possible to identify under-utilization of evidence-based practices and areas for improvement.

The objectives of this review are to highlight the important role CF registries have played in the QI process over the years both at a population and patient level and to discuss the inherent strengths and limitations that exist when using registry data for this purpose.

1.1. Population and CF center-specific improvements

The drive for change requires an understanding of how each center and/or country is currently performing. As health care providers, our goal is to provide the best possible care to our patients and we often assume that the outcomes within our practice are the best they can be. However, assumptions are not always supported by the cold hard facts and at times, there may be a discrepancy between what we think is reality and what reality actually is.

Utilizing a patient registry to facilitate QI work is not exclusive to CF and there are examples within cardiac disease and stroke just to name a few [5, 6]. Like others conditions, analyses of national CF registry data have shown variations in practice patterns and outcomes between countries as well as between centers within a country [7–10]. Analyzing registry data can be a means of calling attention to practice gaps that do not meet evidence-based care recommendations or where health outcomes are below expectation [11]. CF care teams can develop targeted projects aimed at factors identified as sub-optimal and quantify the impact of directed QI initiatives using longitudinal registry data to showcase their success. For example, we see from Fig. 1 that the US CF care center values for median lung function and body mass index (BMI) have dramatically increased from 1986 to 2016 [12]. The population measurements have shifted upwards, at a national level, such that the most recent median values for lung function and BMI were higher than in prior years likely the result of several nation-wide Learning and Leadership QI Collaborative (LLC) initiatives supported by the US CFF.

The use of national CF registry data for QI purposes has expanded to countries beyond the US including Canada, UK, Germany, France and others [11]. The French PHARE-M project is an adaptation of the US program for Accelerating Improvement in CF Care developed by The Dartmouth Institute Microsystem Academy within 14 CF centres in France [13]. Within this project, the French CF registry data plays a key role in order to track national and center-specific outcomes for the 14 participating centers and ultimately compare outcomes to those centers not involved in the PHARE-M QI program [14]. A specific example of how registry data were used by the Roscoff pediatric program in France (which was one of the 14 participating centres in the PHARE-M project) is how they classified children into groups based on their nutritional status using colour coding (green, yellow, red) to indicate the level of risk of malnutrition [15]. The degree of nutritional intervention was adjusted depending on their risk group. By following the registry data over time (BMI z-scores, in particular), the CF teams were able to show a greater percentage of children with improved nutritional status after three years using registry data. In Germany, the Cystic Fibrosis Quality Assurance (CFQA) project has utilized demographic and longitudinal clinical measurements captured with the German CF Registry to quantify improvements in health outcomes and care both nationally and at individual CF centers due to QI efforts [3, 11, 16]. The CFQA project highlighted the importance of standardizing data definitions within the German registry in order to track key outcomes and show improvements over time between centers.

International comparisons of registry data can also be instrumental in identifying differences which can lead to

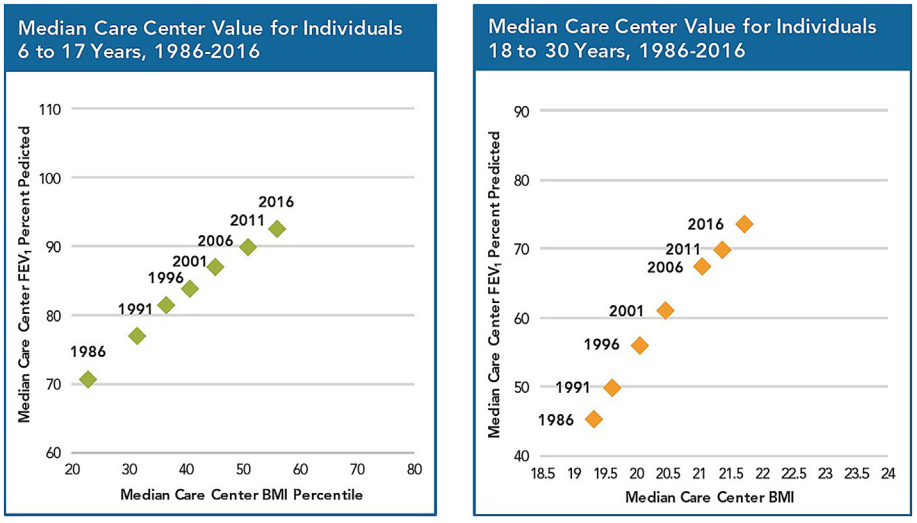

Fig. 1. Median care center values for FEV1 and BMI/BMI percentiles from 1986 to 2016. Source of data: Cystic fibrosis patients under care at CF Foundation-accredited care centers in the United States, who consented to have their data entered. Figure provided by the Cystic Fibrosis Foundation.

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