

# A decade of healthcare improvement in cystic fibrosis: lessons for other chronic diseases

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From 2002 to 2012, the median predicted survival age for people with cystic fibrosis (CF) increased nearly 10 years—from 31.3 years to 41.1 years.<sup>1 2</sup> Strategic efforts to improve care for CF marked this remarkable era. These efforts were supported by expert leadership among CF healthcare improvement professionals and resources from the CF Foundation. While process outcomes improved substantially—for example, more timely clinic visits, increased influenza immunisation rates, and more effective screening for associated problems such as depression and diabetes,<sup>1 2</sup> clinical outcomes improved even more dramatically—notably, pulmonary function, nutritional status and predicted survival.

This supplement, *Ten Years of Improvement Innovation in Cystic Fibrosis Care*, captures the larger perspective of this comprehensive improvement initiative and reports representative CF care centre-level examples. It also identifies strategies to widen the circle of improvement professionals who successfully publish their innovative work in scholarly journals.<sup>3</sup>

## WHAT CAN BE FOUND IN THIS SUPPLEMENT?

Institution-based improvement reports in this supplement describe better airway clearance linked to patient education,<sup>4</sup> successful strategies to meet guidelines for regular CF clinic visits,<sup>5</sup> local care improvement to meet and sustain goals for nutritional status,<sup>6</sup> reduced airway infection rates through improved infection prevention and control measures,<sup>7</sup> implementation of care redesign to improve the management of acute exacerbations of CF,<sup>8</sup> and an initiative to facilitate the continuum of care for patients moving from paediatric to internal medicine specialists, important as CF increasingly becomes a disease of both children and adults.<sup>9</sup>

Additional commissioned papers describe overarching improvement approaches that include strategic benchmarking,<sup>10</sup> development of a transparent patient registry to track outcomes at the individual patient and CF care centre (system) levels,<sup>11</sup> effective integration of patients and families into improvement processes,<sup>12 13</sup> and a series of improvement collaboratives to spread knowledge for improvement among CF care centres.<sup>1 14</sup>

## WHAT WORKED TO IMPROVE CF CARE?

Disaggregating the relative contributions of these various improvement strategies is difficult.<sup>15</sup> Schechter *et al* make a strong case for the influence of a patient registry,<sup>11</sup> while Boyle *et al* craft a compelling argument for the role played by benchmarking—the analysis and spread of improvement strategies from highly achieving institutions to the wider CF centre network.<sup>10</sup> In addition, there is face value for the strong role that patients and families perform in improving CF care.<sup>12 13</sup> Finally, participation by care centre personnel in improvement collaboratives has been associated with demonstrably improved process outcomes.<sup>14</sup>

Recent reviews have provided empiric evidence for the impact of selected elements of context in effective improvement initiatives<sup>16 17</sup>—for example, leadership, culture and information systems. In their critical review, Kaplan *et al*<sup>17</sup> found a particularly positive role for institutional and microsystem quality improvement team leadership, with the strongest case being made for active participation by senior leaders in improvement initiatives, and the effective communication by leaders of their vision and expectations.

We argue for the strong contribution provided by effective integrated leadership from the CF Foundation as well as national



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leaders represented by many of the authors in this supplement. Other contributing contextual elements<sup>16 17</sup> in the CF improvement story include effective data management, substantial physician involvement, a pervasive culture of improvement among CF care centres, and microsystem-level motivation for change.

## CONCLUSIONS

While we do not underestimate the impact of recent scientific and therapeutic advances in CF,<sup>1</sup> we argue that healthcare improvement strategies such as those reported here—tested and adopted in CF care centres over a decade—have had a profound role in the improvement of life and predicted survival for people with CF. Moreover, we suggest that the aggregate effects of these combined efforts—a widely available and transparent patient registry, benchmarking of best improvement practices, active involvement of patients and their families in improvement initiatives, and dissemination of improvement methodologies among CF healthcare professionals—may be transferrable to improving care for others with serious chronic illnesses.

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### **CF Foundation and CF care expert partnership yields striking progress for people with cystic fibrosis**

*Healthcare improvement strategies serve as model for improving care in other chronic disease*

**[A decade of health care improvement in cystic fibrosis: lessons for other chronic diseases doi 10.1136/bmjqs-2014-002871]**

A decade of strategic efforts to improve care has had a key role in improving quality of life and added years to predicted survival for people with cystic fibrosis (CF) in the United States, according to the editors of a BMJ Quality & Safety supplement dedicated to the disease.

Health outcomes for CF have improved dramatically following implementation of an innovative and aggressive plan to promote quality improvement at CF care centres.

This includes benchmarking comparisons of current care with best practice; use of a patient registry to track outcomes; patient and family involvement in improvement processes; and collaborative improvement networks to foster standardisation and improvement of care practices.

This "remarkable era" has been driven by concerted efforts to improve care, as well as strong leadership among health care professionals treating people with the disease, and resources from the Cystic Fibrosis Foundation, write David Stevens of the Dartmouth Institute for Health Policy and Clinical Practice in New Hampshire and Bruce Marshall of the Cystic Fibrosis Foundation.

Ten Years of Improvement Innovation in Cystic Fibrosis Care includes reports on a range of improvement initiatives, ranging from the impact of patient education on improving adherence to critical daily treatments, and strategies for boosting nutritional status.

It also covers better management of worsening symptoms and infections and enhanced continuity of care as children with the condition increasingly survive into adulthood and transition to adult care services.

Process outcomes, such as more timely clinic visits, higher rates of flu vaccination, and more effective monitoring of associated problems, including diabetes and depression, have all improved. So too have key clinical outcomes, such as improved lung function and nutritional status, write Stevens and Marshall.

Kathryn Sabadosa, author of one of reports in the supplement states: "As the mother of an adolescent with CF, I am grateful for the CF Foundation's leadership in creating a culture that sets the bar high, strives for exemplary care, and values my son as a partner in improving care and maintaining his health."

Brent James, vice president for medical research and executive director, Institute for Health Care Delivery Research, Intermountain Healthcare, and known internationally for his innovative work on improving the quality and safety of health care delivery, comments: "Progress in CF-related care delivery provides a model for clinician-scientists' massive opportunity to improve health care delivery and patient outcomes in the future."