

Accelerating the rate of improvement in cystic fibrosis care: contributions and insights of the learning and leadership collaborative

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ABSTRACT

Introduction The Learning and Leadership Collaborative (LLC) supports cystic fibrosis (CF) centres' responses to the variation in CF outcomes in the USA. Between 2002 and 2013, the Cystic Fibrosis Foundation (CFF) designed, tested and modified the LLC to guide front line staff efforts in these efforts. This paper describes the CFF LLC evolution and essential elements that have facilitated increased improvement capability of CF centres and improved CF outcomes.

Methods CF centre improvement teams across the USA have participated in 11 LLCs of 12 months' duration since 2002. Based on the Dartmouth Microsystem Improvement Curriculum, the original LLC included face to face meetings, an email listserv, conference calls and completion of between learning session task books. The LLCs evolved over time to include internet based learning, an electronic repository of improvement resources and examples, change ideas driven by evidence based clinical practice guidelines, benchmarking site visits, an applied QI measurement curriculum and team coaching.

Results Over 90% of the CF centres in the USA have participated in the LLCs and have increased their improvement capabilities. Ten essential elements were identified as contributors to the successful LLCs: LLC national leadership and coordination, local leadership, people with CF and families involvement, registry data transparency, standardised improvement curriculum with evidence based change ideas, internet resources with reminders, team coaching, regular progress reporting and tracking, benchmarking site visits and applied improvement measurement.

Conclusions The LLCs have contributed to improved medical and process outcomes over the past 10 years. Ten essential elements of the LLCs may benefit improvement efforts in other chronic care populations and health systems.

INTRODUCTION

The Learning and Leadership Collaborative (LLC) supports cystic fibrosis (CF) centres' responses to the variation in CF outcomes in the USA.¹ Between 2002 and 2013, the Cystic Fibrosis Foundation (CFF) designed, tested and modified the LLC to guide front line staff efforts in these efforts. We report here the implementation and outcomes of 11 sequential CFF supported improvement collaboratives that involved over 90% of the US CF care centres during this 10 year period. We include essential elements to consider in designing, executing and assessing improvement collaboratives.

METHODS

Leading improvement in CF centres at a national level across the USA posed unique challenges. Each CF centre had its own local culture, patient population and interprofessional staff, and was influenced by the larger healthcare system in which it existed. It was critical to identify an improvement programme and process that could be adapted to suit the complex CF community broadly and each specific CF centre. A variety of healthcare improvement methods were considered, and after an early sampling of three improvement methodologies, the CFF leadership adopted the Dartmouth Clinical Microsystem applied theory and curriculum.^{2 3} The rationale for this selection was based on the practicality, feasibility, adaptability and applicability of the Dartmouth curriculum for busy novice improvers in a variety of contextual settings.



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Learning and Leadership Collaborative framework

The Improvement Breakthrough Series, originally designed and tested by the Institute for Healthcare Improvement in the late 1990s, and Kolb's experiential learning theory, provided the initial framework for the LLC that was launched in 2002.^{4 5} To address time constraints of busy front line staff, the LLCs consisted of face to face learning sessions, monthly learning session conference calls, an email based listserv and structured task books to guide improvement teams' action periods between learning sessions (figure 1).

The improvement method was grounded in the Dartmouth Clinical Microsystem Curriculum, described in detail in table 1.³ Important elements include patient and family involvement in the CF centre improvement teams, the use of evidence and practice based change ideas, regular CF centre progress reports, optimising the workplace using '5s' processes (sort, straighten, shine, standardise and sustain),^{6 7} measurement and gaining new customer knowledge (patients and families) through observation and inquiry skills.⁷ The CF Foundation Patient Registry (CFFPR) provided capability to track individual CF centre clinical and process outcomes longitudinally.^{1 8}

Customisation of the LLC

Customisation of the LLC involved a 2 year iterative process with the teams of the first two LLC cohorts explicitly selected for the design phase. In subsequent years, the CFF issued an 'LLC request for applications', inviting all CF centres to apply for review and selection by the national CF leadership team using selection criteria of CF centre CFFPR reporting,

diversity, geography (equitable), centre size and completeness of applications.

CF improvement team composition

The CF centre improvement teams were led by a physician director and a nurse coordinator, and included representation of multiple professional roles, including receptionists, pulmonologists, dieticians, social workers, respiratory and physical therapists, nurses and other roles in the CF centre. People with CF and/or family members also began to participate as full members of improvement teams in 2003. Each CF centre improvement team created a 'travel team' limited to 4–6 interprofessional members and a family member or caregiver representative to travel to the face to face learning sessions (financially supported by CFF grants).⁹ Due to infection prevention and control concerns, individuals with CF could participate by telephone during the face to face events.¹⁰

LLC curriculum

During each 12 month LLC (table 1), interprofessional improvement teams learned to assess the current state of their CF centre care and processes, identify strengths and improvement opportunities in their delivery of care, and make improvements.³ Each CF centre improvement team started with a broad knowledge of their centre's performance, and in each learning session narrowed their initial improvement theme, such as nutrition, pulmonary care or core processes, including access to appointments, length of clinic visits or coordination of interprofessional care during the clinic visits, to more focused improvement goals. A global improvement aim was derived from

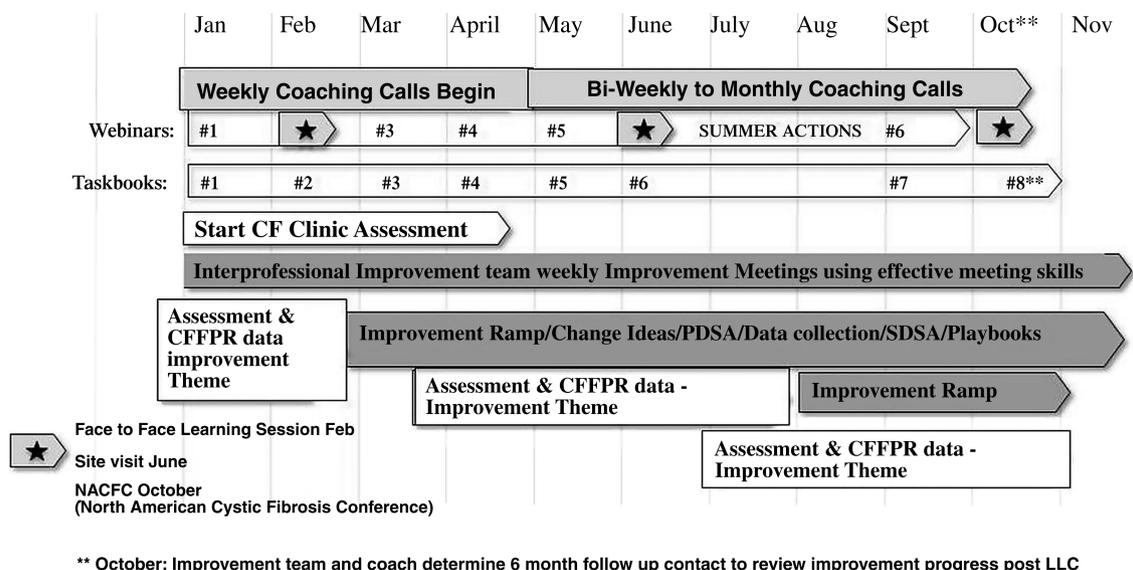


Figure 1 Cystic Fibrosis Foundation Learning and Leadership Collaborative (CFF LLC) structure and process. CFFPR, CF Foundation Patient Registry; PDSA, plan-do-study-act; SDSA, standardise-do-study-act.

Table 1 Dartmouth Microsystem Improvement Curriculum for cystic fibrosis Learning and Leadership Collaboratives: topics and processes

Learning session	Method	Topic	Key aspects, tools and processes
1 'Getting started'	Adobe connect	Assessing your CF centre	Accelerating improvement of CF care action guide
2 'Getting to know the LLC community and curriculum'	Face to face meeting	DMIC overview: ▶ Effective meeting skills ▶ Themes and aim statements ▶ Flowcharts and fishbones ▶ Change ideas ▶ PDSA–SDSA ▶ Playbooks ▶ Measurement ▶ Patients and family involvement	Link CFFPR data with CF centre assessment data to inform improvements. Practice the curriculum tools and processes with the help of faculty and coaches. Link practice guidelines to change ideas. Practice effective meeting skills, including brainstorming and multi-voting. Introduction to improvement measurement and homework.
3 'Journey begins'	Adobe Connect	Progress reports and template, DMIC review, run charts	Progress report template DMIC materials and tools Run chart templates, homework
4 'Journey continues'	Adobe Connect	Progress reports 5s to standardise the workplace Measurement: SPC	Progress report template 5s worksheets. Measurement SPC templates and homework
5 'Getting ready to do a site visit'	Adobe Connect	Progress reports Ethnography and observation skills Benchmarking Executive summaries	Progress report template Observation worksheets Executive summary template
6 'The site visit and preparing for the summer'	Face to face meeting	Progress reports: PowerPoint Observing CF clinic in operation, patient and family advisory board Gaining customer knowledge Mesosystems Presenting/writing skills Measurement computer labs	PowerPoint presentation templates Observation worksheets Gaining customer knowledge worksheets CFRD change ideas Mesosystem worksheets Computers for measurement labs
7 'Reconnecting'	Adobe Connect	Progress reports	Progress report template Review of DMIC
8 'Preparing for NACFC'	Adobe Connect	Progress reports Poster presentation	Progress report template Poster template
9 'NACFC and preparing for transition'	Face to face meeting	Progress reports via posters Sustaining improvement SDSA and playbooks Advanced measurement Plan for coach 6 month check in	Posters SDSA worksheet Playbook checklist Measurement templates Action plan and Gantt chart
10 '6 month post LLC check in'	Telephone, email or face to face	Progress report Needs assessment Select future 'check in' with coach	Progress report template Needs assessment tool

5s, sort, straighten, shine, standardise and sustain; CF, cystic fibrosis; CFRD, cystic fibrosis related diabetes; CFFPR, CF Foundation Patient Registry; DMIC, Dartmouth Microsystem Improvement Curriculum; LLC, Learning and Leadership Collaborative; NACFC, North American CF Conference; PDSA, plan-do-study-act; SDSA, standardise-do-study-act; SPC, Statistical Process Control.

the selected theme and described the rationale for improvement, including potential benefits. Participants created flowcharts to understand their current processes and then created cause and effect (fishbone) diagrams to understand potential causes of current results. Change ideas (interventions) based on evidence based guidelines and benchmarking were then adapted and tested using plan-do-study-act (PDSA) cycles, including quantitative measures to assess if the change resulted in real time improvement in that particular setting. Finally, the successful change idea and process was 'standardised' through the

standardise-do-study-act (SDSA) process, including a 'playbook' illustrating the new standardised process.³

The LLC evolved over 10 years (table 2) informed by participant verbal and internet based survey feedback, results of the LLCs, the changing teaching and electronic environment, the economy and faculty and leadership reflection on action.¹¹ Consistent national CF leadership participation in all aspects of the LLC planning, execution and evaluation, along with a dedicated national LLC coordinator and faculty, contributed to a disciplined approach to improvement.

Table 2 Evolution of the cystic fibrosis Learning and Leadership Collaborative (2002–2013)

LLC	Focus	Centres	Methods	Lessons Learned
2002–2003 NICHQ	Paediatric Nutrition and smoking cessation	16	National Initiative Children's Healthcare Quality Demonstration Project	CF centre data and measures were centralised
2003–2004 LLCI	Paediatric Nutrition, CFRD and pulmonary	10	Intermountain Healthcare Mini-Advanced Training Program specific to CF for invited CF centres	Programme based in hospital systems. More CF specific examples and connection to chronic care needed
2004–2005 LLCII	Paediatric Nutrition, CFRD and pulmonary	12	DMIC learning collaborative offered to accredited CF centres. Conference calls, listserv, adapted microsystem action guide for CF	Standardised improvement methodology and language awkward but good fit with CF centres and content customised to CF
2005–2006 LLCIII	Paediatric Nutrition and pulmonary	17	21 coaches Action guide, public reporting, paediatric benchmarking	Coaches selected and developed from CF community and past LLCs to help CF centres. Prior participants provided CF specific improvement examples
2006–2007 LLCIV	Paediatric Pulmonary	16	22 coaches Mentoring programme, adult benchmarking, QI toolkit on http://www.cff.org Registry data now transparent	Discipline specific mentoring programme further supported staff QI tools and examples on CFF website
2007–2008 LLCV	Paediatric Pulmonary improvement	15 plus Toronto, Canada	18 coaches CF specific change ideas QI toolkit posted at http://www.cff.org	Change ideas (pulmonary and nutrition) created from guidelines and benchmarking. CF specific improvement action guide created
2008–2009 e-LLCVI	Paediatric Nutrition and pulmonary	9	10 coaches First site visit (Hartford, CT) Web sessions replaced conference call learning sessions	Transformative experience to visit high performing CF centre. Positively influenced the adaptation of best practices
2009–2010 AQI/ CFRD	Adult CFRD	10	First adult series Second topic specific focus Web based action guide Site visit (Minneapolis, MN) Online learning and resources	Identified leaders to develop adult care change ideas. CFRD change ideas created and distributed
2010–11 Self study	Nutrition/pulmonary	4	4 coaches	CF action guide online with coaching with limited results
2011–2012 AQI2	Adult Nutrition and pulmonary	14	10 coaches National patient and family care experience survey Site visit (Minneapolis, MN) Online learning and resources	Growing body of knowledge, tools, checklists and topics specific to transition and referrals. New measurement modules developed
2012–2013 AQI3	Adult Nutrition, pulmonary, transition of care, end of life, referrals	10	10 coaches Site visit (Minneapolis, MN) Online learning and resources 3 part measurement curriculum	Adult CF healthcare professionals from past AQI session teach examples and experiences. Measurement faculty adds coach and CFFPR registry specialist, special interest groups
2012–2013 LLC8	Paediatric/adult Nutrition and pulmonary	10	12 coaches Site visit (Minneapolis, MN) Online learning and resources 3 part measurement curriculum	Aimed to include smaller CF practices

AQI, adult quality improvement; CF, cystic fibrosis; CFF, CF Foundation; CFRD, cystic fibrosis related diabetes; CFFPR, CF Foundation Patient Registry; DMIC, Dartmouth Microsystem Improvement Curriculum; LLC, Learning and Leadership Collaborative.

Team coaching

Team coaching is defined as one person coaching an entire improvement team rather than individual coaching.¹² Team coaching was added to the LLCs in 2005 as a result of participant feedback identifying support needed to learn and practice improvement in daily delivery of care to people with CF.¹³ Participants who had participated in previous LLCs were invited to coach subsequent CF improvement teams. These coaches participated in coaching development workshops based on the Dartmouth Institute Coaching programme during the LLC face to face meetings and were supported with monthly coaching calls to share their coaching experience and to provide a supportive community for their team coaching.¹⁴ Pairs of coaches were matched to LLC CF centres based on geography and time zones to provide weekly coaching conference calls to support the CF centre improvement teams' progress through the action period task books. As the improvement teams increased their improvement capabilities over the course of the LLC, coaching transitioned to every other week and then monthly coaching sessions (figure 1).

Coaches established relationships with their assigned teams through telephone coaching between the face to face learning sessions. At these learning sessions they further developed their relationships through spending time with the team, reinforcing the Dartmouth Microsystem Improvement Curriculum (table 1) to develop improvement skills and habits, creating action plans and timelines, and offering encouragement. After the face to face learning sessions, telephone coaching provided further encouragement and reminders about improvement tools and timelines to help the team stay focused on specific action period goals.

RESULTS

Between 2002 and 2013, over 90% of US CF centres participated in the LLC programmes (table 2).⁹ The LLCs focused primarily on improving paediatric outcomes and in 2009 added an adult care focus. Clinical and process outcomes have improved during this period of time. Clinical outcomes which have been influenced by multiple factors are extensively discussed in companion articles in this supplement.^{1 8 15-17} Process performance improvements measured at the front lines of care during the LLCs and tracked through the CFFPR may be most closely linked to the effect of the LLCs.

Process improvement

Three process measures tracked over the past decade in the CFFPR have shown improvements on a national scale. First, the percentage of patients seen by a physical or respiratory therapist each year increased from 69% in 2006 to 86.7% in 2012. Second, the percentage of patients seen by a dietician each year

increased from 70.2% in 2003 to 87.5% in 2012. Finally, the percentage of patients seen by a social worker increased from 60.5% in 2003 to 82.3% in 2012. Site specific process improvements have also been observed. Some examples include improvements in clinic cycle times and patient flow through a CF clinic session, increase in volume of patients seen in the CF clinic four times a year, increase in identification of people with CF being at nutritional risk, increase in proper utilisation of respiratory equipment and nutritional enzymes, and more consistent treatment of pulmonary exacerbation.^{8 15 16 18-20}

Perceived benefit of team coaching

In 2008, the perceived benefit of team coaching was evaluated by 198 CF team members from 49 CF centres (internet based survey), a focus group of coaches and 12 CF leader telephone interviews.¹³ All three groups reported coaching actions that were perceived to support improvement work, including the coach understanding CF centre context, building relationships, offering helping behaviours and finally supporting the improvement team through reinforcement of improvement processes and tools. Many CF leaders reported that prior to their involvement in the LLC, their improvement knowledge and skills were often absent or minimal and they were able to learn improvement as a member of the interprofessional improvement team while maintaining legitimacy and credibility as a leader. Leaders also described new leadership styles and processes to consider as a result of the interprofessional team members' new capabilities and the coach role modelling.

DISCUSSION

Over the past decade there has been substantive utilisation and spread of the LLC, with over 90% of US CF centres participating, with some participating multiple times due to staff changes, leadership or having a perceived need to recharge their improvement efforts. If considering exposure to the LLCs is an intervention, as is discussed in accompanying articles in this supplement, that exposure may have contributed to the improvement in process and outcomes performance in CF care.^{1 8 15-17} However, it is not possible at this time to discern the relative effects of the LLC and other contributing factors, such as medical treatment advances or local context.

Researchers have explored more vigorous evaluation of improvement methodologies to better understand what improvement actions work in which settings and under which conditions.²¹⁻³⁰ Detailed descriptions that support replication in other settings are rarely described.²⁵ Understanding the 'how and why' of the LLC intervention can potentially lead to deeper understanding of improvement interventions and programme replication in other settings.²⁵

Dixon-Woods *et al* argue that developing an understanding of the ‘how and why’ of the LLC intervention can potentially lead to the successful replication of the programme in other settings. They describe an ‘ex post theory’ approach to understanding how improvement programmes work through a three step process: (1) developing an understanding of the programme leader’s initial model of improvement; (2) identifying contributing factors that modify the existing understanding; and (3) developing a new modified version of the theory.²⁵ Consideration of this approach to deepen the understanding of the CF LLC experience is useful. The initial improvement model employed by the CF LLC was modelled after the Institute for Healthcare Improvement Breakthrough Series, Kolb’s experiential learning theory⁵ and clinical microsystems² (step 1). This was modified over time based on reflection on the LLC experiences and improvement literature resulting in a modified improvement model that includes standardised evidence based change ideas, team coaching, more active use of the CFFPR and an applied measurement curriculum (step 3). We have identified 10 ‘essential elements’ which have contributed to the developmental evolution towards the current LLC model (step 2) and may provide aspects of the ‘how and why’ for future replication and evaluation.

The LLC how and why: 10 essential elements

Box 1 provides 10 ten essential elements of the LLC.

1. National leadership and coordination

Leadership at all levels of the healthcare system makes a difference in accelerating CF improvement. The nationally based CFF leadership group initiated and supported 10 years of improvement and featured a persistent passionate and engaging visionary leader

who provided the leadership and development of the mission, vision and worthy goals since 2002.^{8 9 17} There was a constant awareness in the CF community that the improvement vision was about ‘adding tomorrows’. The CFF also provided support for front line CF centre improvement through provision of one central coordinator who was an information resource for any LLC questions, tracked all CF improvement, posted LLC schedules, resources and reminders, and provided regular consistent communication to all members of the CF community.

2. CF centre front line leadership

As reported in the Dartmouth Clinical Microsystems Research, local high performing front line units are often lead by a leadership dyad (usually a physician and a nurse).² In the CF LLCs, the leader dyad, a centre or programme director physician and nurse coordinator were members of the improvement team and were able to create the conditions in the clinical microsystem to support regular time to learn and practice improvement in the daily care of people with CF. These leaders were able to learn improvement knowledge through participation in the LLCs and reported being better leaders of improvement as a result of the experience.¹³

3. Participation of people with CF and families

Considering that the origin of the CFF was a group of parents in 1955, and the first of the CFF seven worthy goals is that patients and families are full partners, it is now common practice that patient and family members are involved in the LLCs.^{8 9 17} Patient and family contributions to the improvement process and the CF centre team dynamics have been invaluable, and create a ‘true north’ for improvement activities.^{17 31 32}

4. Registry data transparency and public reporting

Schechter *et al* reported the identification of outcomes variation across the US CF centres that provided the stimulus to engage in quality improvement.¹ The collection and transparency of the CFFPR data contributed to the benchmarking activities of the CF community and stimulated curiosity among the LLC members to learn *how* the high performing CF centres achieved the results they did to then adapt in their own CF centre.

5. Standardised improvement curriculum and CF specific change ideas

The use of the Dartmouth Microsystem Improvement Curriculum (table 1) provided a standardised improvement language within the CF community.³ This standard improvement method for the improvement teams resulted in easy and understandable sharing of experiences and improvement results, and simplified the teaching modules in the LLCs. CF specific change ideas drawn from evidence based guidelines and observations from CFF sponsored benchmarking site visits

Box 1 Ten essential elements of the Cystic Fibrosis Foundation Learning and Leadership Collaborative (CFF LLC)

Essential elements

1. National leadership and coordination
2. CF centre front line leadership
3. Participation of people with CF and families
4. Registry data transparency and public reporting
5. Standardised improvement curriculum and evidence based SmartChange ideas
6. Internet resources, reminders and task books
7. Team coaching
8. Regular progress reports and tracking of improvement
9. Benchmarking site visit by LLC travel team
10. Applied improvement measurement: ‘Making it easy and practical’

were shared during LLC learning sessions to stimulate CF centre improvements.

6. Internet resources, reminders and task books

The capabilities of internet based software evolved over time and resulted in conference calls being changed to internet learning sessions and creation of an online resource centre to provide open access to all CF improvement materials, resources, learning session materials and tools, examples of CF specific improvement and change ideas. The email based listserv provided a virtual forum to post questions and seek clarifications in improvement. The task books provided focus, clarity and prioritisation of tasks to be completed between learning sessions. These have evolved to a central electronic learning platform with discussion boards, automated reminders and electronic task books to complete the between learning session actions.

7. Team coaching

Participants who had received team coaching in the LLC reported generally favourable results.¹³ Eighty per cent of the reported supportive coaching actions were related to the improvement experience and hard work of making improvements while providing care. Coaching actions included exploring the context where the team provides care and service, building relationships and communication processes with the improvement team and leaders, offering helping actions to support making improvements and reinforcing the process by offering technical support. The coaches' goals were to develop improvement capability of the interprofessional improvement teams to eventually 'work themselves out of a job' as a result of the team's new improvement capabilities. CF quality coaches now attend the Dartmouth Institute Microsystem Academy formal team coaching programmes to advance their coaching skills.¹⁴

8. Regular progress reports and tracking of improvement

Regularly scheduled progress reports helped create a rhythm and pace of improvement and balance while providing care to people with CF. The progress reports helped the improvement teams reflect on their learning and improvement achievements to energise their continued improvement journey. Collection of the LLC improvement team progress reports also contributed to easy sharing of lessons learned and tips for all the CF centres.

9. Benchmarking site visit by LLC travel team

Starting in 2008, the LLC travel teams travelled to a high performing CF centre to see processes and interactions that contributed to their high performance level. A high performing CF centre was identified to host up to 14 CF centres to observe their CF clinic operations and a Patient and Family Advisory Committee meeting, talk with staff and patients, and at the same time attend specific topic learning sessions

(table 1, sessions 5 and 6). The site visit is reported to be one of the most highly satisfying and inspiring experiences of the LLC members due to the tools, resources, sharing of experiences and improvement stories, and building of relationships that make CF improvement more real and more doable.

10. Applied improvement measurement: 'making it easy and practical'

Applied measurement education and skills training is a critically important aspect for overall improvement success.²² In 2010, the LLC faculty recognised a gap between measurement training and evidence of applied measurement in improvement practice. In iterative cycles, a new measurement curriculum was developed to better meet the practical learning needs of the front line interprofessional improvement teams. By 2011, a three module measurement curriculum was developed which featured stronger integration with CFFPR and practical easy to use tools which allowed participants to more effectively apply skills and techniques in their daily improvement work (table 3).

Measurement homework assignments with faculty feedback and the development of measurement special interest groups further advanced measurement interests and resources for the LLCs. An essential ingredient of the improved curriculum was a collaboration between an improvement measurement expert, a CFFPR data specialist and a CF quality coach using a team teaching process. This 'making it easy and practical' strategy has accelerated improvement measurement skills applications and utilisation of measurement in the front line quality improvement efforts.

LLC evaluation

Parry *et al* recognised the difficulty in evaluating the effectiveness of improvement interventions, and recommended approaches to improve the degree of linkage between phases of programme development and measurement activities.²⁹ Drawing heavily on the Kirkpatrick model of programme evaluation,³³ they proposed that improvement programmes move through three stages: (1) *innovation*, where small scale novel approaches are first trialled; (2) *testing*, where approaches that have been found to be initially successful are trialled for efficacy and applicability in a moderate sample; and (3) *scale up and spread*, where a model that has been well vetted is assessed for effectiveness in a large sample. Rapid cycle change methodologies (such as PDSA) and the use of statistical process control (SPC) are recommended components of all three stages. They further suggest longitudinal quantitative analyses such as those discussed elsewhere in this supplement to bolster capacity for process and outcomes assessment. Formal cluster randomised or step wedge interrupted time series designs are recommended in the scale up and spread stage to be able to scientifically

Table 3 Applied quality improvement measurement curriculum

Module	Core skills	Materials	Learning activities
Fundamentals	Global and specific aims Defining measures Data collection plan Variation Run charts	<i>Article:</i> 'Run charts' ³⁴ <i>Videos:</i> 'Practical data collection' [*] 'How to use the run chart Excel template' [†] <i>Excel templates:</i> Run chart template [‡] <i>Worksheets:</i> 1. Measurement definitions 2. Data collection plan 3. Completed examples of worksheets	<i>On-site session:</i> Lecture with table exercises and audience response questions (with accompanying PowerPoint slide set). <i>Homework assignment:</i> Define measures, create a data collection plan, plot and analyse a run chart. <i>Webinar:</i> Review fundamentals content and questions, preview intermediate module.
Intermediate	Basic SPC: XmR and p charts Excel skills Intro to <i>Port CF</i> data registry Begin to identify measurement special interest groups	<i>Article:</i> 'Control charts 101' ³⁵ <i>Videos:</i> 'How to use the XmR Excel template' [§] 'How to use the p chart Excel template.' [¶] 'Port CF registry orientation.' ^{**} <i>Excel templates:</i> XmR chart template [‡] p chart template [‡]	<i>Webinar No 1:</i> Didactic with application exercises using online poll questions (interpreting SPC charts), with accompanying PowerPoint slide set. <i>Homework assignment:</i> Using assigned data sets or actual data from ongoing improvement work, plot a XmR and a p chart, assess descriptive characteristics and variation. <i>Webinar No 2:</i> Intermediate module review and questions, preview advanced module.
Advanced	Stratified SPC analyses 5P data displays Cascading measures from microsystem to mesosystem to macrosystem levels Finalise measurement special interest groups	<i>Excel templates:</i> 5P data display Excel template ^{††} Cascading measures XmR template ^{††}	<i>On-site session:</i> Didactic with table exercises and audience response questions (with accompanying PowerPoint slides), demonstrations of templates, lab period to work with templates. <i>Homework assignment:</i> Prepare data displays for posters for NACFC conference with option for faculty review.

^{*}Hess A. *Practical data collection*. http://clinicalmicrosystem.org/materials/video_player/?movie=09. Video 2006.

[†]Oliver BJ. *How to use the Excel run chart template*. Video 2012.

[‡]Splaine M, Trustees of Dartmouth College Microsoft Excel Templates for Run Charts, XmR Charts, and p charts. Dartmouth Institute for Health Policy and Clinical Practice, Hanover, NH, 2004.

[§]Oliver BJ. *How to use the Excel XmR chart template*. Video 2012.

[¶]Oliver BJ. *How to use the Excel p chart template*. Video 2012.

^{**}Petren K, Cystic Fibrosis Foundation. *Port CF Registry Orientation*. Video 2012.

^{††}Oliver BJ, Petren K, Messier R, *et al*, Trustees of Dartmouth College and US Cystic Fibrosis Foundation Excel 5P data display and XmR cascading measures templates, 2013.

CF, cystic fibrosis; NACFC, North American CF Conference; SPC, Statistical Process Control.

determine effectiveness attributable to the improvement interventions.

The LLC experience has preceded these suggested evaluation methods by many years and has not specifically followed this evaluation framework. However, it is significant to note that many aspects of the LLCs parallel Parry and colleagues' recommendations. For example, at the beginning of the LLC history, 2 years were spent piloting and testing the improvement interventions using rapid cycle change methodologies and SPC measurement as part of the CF centres' improvement efforts (stage 1). The CFFPR has also facilitated longitudinal cohort analyses (stage 2). However, the LLC has not yet addressed the stage 3 recommendations (formal scientific investigation utilising a cluster randomised or interrupted time series design) to allow for a rigorous investigation of the 'LLC effect'.

Because of this limitation we can report on general outcomes, but cannot specifically attribute these outcomes to LLC exposure. Other factors such as leadership, CF centre readiness and capacity for change, local culture, treatment advances and timing of implementation may also have contributed.

The LLC story is illustrative of the current state of the discipline of healthcare improvement science, which is burgeoning into a new era of evidence based improvement and robust outcomes research. Given that the LLC has demonstrated considerable scale up and spread in programme development, a clear opportunity now exists to progress to the next stage of formal scientific inquiry using a cluster randomised or step wedge time series design to assess process and outcomes performance attributable to the LLC intervention.

Future directions

The longitudinal sustainability of ongoing CF centre improvement is not clear. As a result of feedback from CF centre leaders seeking ongoing follow-up to sustain the new improvement efforts, each coach now contacts the CF centre improvement team 6 months after completion of the LLC. The annual centre report completed by each accredited CF centre to maintain their accreditation includes reporting of improvement activities that could be more robust and informative. There are current efforts to design more specific improvement assessments of CF centres to track improvement longitudinally and link to measured outcomes. More specific assessments of a CF centre may include evidence of regular improvement meetings, use of the Dartmouth Microsystem Improvement Curriculum and tools, improvement data displays, a self-reported survey and possible observations during accreditation site visits.

The CFF LLC improvement history and lessons learned coupled with emerging literature urging evaluative research designs will inform the next decade of CF improvement. The future focus of CF improvement work will span the continuum of care, starting with newborn screening and spanning a lifetime to advanced care at all levels of the healthcare system.²¹ The CFF envisions this lifelong integrated process of care and improvement focus as the 'OneCF centre'. The OneCF centre will take a whole system view of CF care, integrating paediatric, adult, specialists, inpatient and eventually community and home care. To be able to lead this new vision, a new leadership programme specifically designed to develop skills and knowledge to lead improvement of care and processes will be included in the LLC.

CONCLUSION

The LLCs have contributed to improved medical and process outcomes between 2002 and 2013. Ten essential elements of the LLCs may benefit improvement efforts in other chronic care populations and health systems. The LLC experience has enhanced our knowledge of improvement collaboratives and identified future opportunities to apply more robust scientific evaluations to gain a deeper understanding of what works in what context to best improve the care of people with CF.

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Contributors MMG has been the quality improvement expert over the course of 10 years and designed, executed and evaluated the LLC, including the team coaching study. BJO has been instrumental in leading and designing the measurement components and evaluation in the LLC. Both MMG and BJO drafted, discussed and revised the manuscript in partnership with Drs Marshall and Stevens. Both MMG and BJO agree to being accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

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