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Interventions to improve system-level coproduction in the Cystic Fibrosis Learning Network

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ABSTRACT

Background Coproduction is defined as patients and clinicians collaborating equally and reciprocally in healthcare and is a crucial concept for quality improvement (QI) of health services. Learning Health Networks (LHNs) provide insights to integrate coproduction with QI efforts from programmes from various health systems.

Objective We describe interventions to develop and maintain patient and family partner (PFP) coproduction, measured by PFP-reported and programme-reported scales. We aim to increase percentage of programmes with PFPs reporting active QI work within their programme, while maintaining satisfaction in PFP-clinician relationships.

Methods Conducted in the Cystic Fibrosis Learning Network (CFLN), an LHN comprising over 30 cystic fibrosis (CF) programmes, people with CF, caregivers and clinicians cocreated interventions in readiness awareness, inclusive PFP recruitment, onboarding process, partnership development and leadership opportunities. Interventions were adapted by CFLN programmes and summarised in a change package for existing programmes and the orientation of new ones. We collected monthly assessments for PFP and programme perceptions of coproduction and PFP self-rated competency of QI skills and satisfaction with programme QI efforts. We used control charts to analyse coproduction scales and run charts for PFP self-ratings.

Results Between 2018 and 2022, the CFLN expanded to 34 programmes with 52% having ≥1 PFP reporting active QI participation. Clinicians from 76% of programmes reported PFPs were actively participating or leading QI efforts. PFPs reported increased QI skills competency (17%–32%) and consistently high satisfaction and feeling valued in their work.

Conclusions Implementing system-level programmatic strategies to engage and sustain partnerships between clinicians and patients and families with CF improved perceptions of coproduction to conduct QI work. Key adaptable strategies for programmes included onboarding and QI training, supporting multiple PFPs simultaneously and developing financial recognition processes. Interventions may be applicable in other health conditions beyond CF seeking to foster the practice of coproduction.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Engagement of patients and families with clinicians in health service design as equal partners is associated with improved health outcomes, but can be challenging to incorporate broadly in health systems.

⇒ Learning Health Networks, like the Cystic Fibrosis Learning Network, are communities of patients, clinicians, researchers and others from multiple programmes that use an actor-oriented network organisational architecture to orchestrate improved care delivery and health outcomes for patient populations.

WHAT THIS STUDY ADDS

⇒ We demonstrate improved and sustained ratings of coproduction from patient and family partners (PFPs) working in quality improvement alongside various CFLN programmes.

⇒ This report showcases adapted and integrated practices from CFLN programmes such as processes for inclusive recruitment and quality improvement training for PFPs to enable effective partnerships.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Lessons from the integration of best practices in the CFLN to maintain coproduction in QI work are poised for adaptation by other health systems to advance patient/family-clinician partnerships to orchestrate improvement and collaborations at scale.

INTRODUCTION

Coproduction refers to collaboration between patients and clinicians to engage as equal and reciprocal contributors in shared work as a service user and a service provider and can be applied to improve care delivery and health outcomes.[1] Coproduction principles connect patient voice to quality improvement (QI) and organisational design at a system level.[2]

Organisational mechanisms that support patient and family engagement are associated with improved healthcare outcomes with reported successes among individuals

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with acute and chronic conditions.[2] For people with cystic fibrosis (CF), a genetic disorder associated with multi-organ dysfunction, frequent clinic visits and a high level of self-care are routine aspects of disease management.[3] Drawing from the Chronic Care Model, partnership in care including the incorporation of people with CF in QI has long been promoted by the CF Foundation.[4–7] QI efforts are supported by a robust Care Centre Network that shares a patient registry for transparency of outcomes and benchmarking.[4–7] While many programmes in the Care Centre Network can apply QI methods and incorporate patients and family members in these efforts, these efforts are often localised to individual programmes and lack orchestrated means to support engagement for broad service improvement across diverse settings.[8]

Healthcare organisations struggle with patient and family involvement, often involving patients to provide token feedback instead of involving patients as reciprocal partners to share the work for improved health service design.[9] Meaningful patient engagement is stymied by barriers such as inadequate processes to train patients in health service improvement methods or to prepare clinicians to facilitate engagement.[9–11]

Learning health networks have improved care delivery and outcomes over multiple conditions for large populations of patients.[12–15] Learning health networks are communities of patients, clinicians, researchers and others that use an actor-oriented network organisational architecture to enable effective partnerships and collaborations at scale to improve health and healthcare.[13 16] The design of learning health networks emphasises the equity of involvement for patients and families in all phases of improvement, including opportunities to design and co-lead QI initiatives with clinicians across multiple sites.[17–19] The lessons of patient and family involvement within a learning health network offer a unique opportunity to understand how to practice and sustain coproduction at a system level.[20]

The Cystic Fibrosis Learning Network (CFLN), launched in 2016, organises clinicians, patients and families across adult and paediatric programmes from various health organisations as a connected learning health network.[8 21] The CFLN's purpose is to improve medical outcomes and quality of life for all people with CF through consistent evidence-based chronic care delivery and data-driven collaborative learning.[21] In early improvement initiatives, the CFLN has demonstrated advances in care delivery for consistent interdisciplinary care and shared agenda setting with patients and families using telehealth during the COVID-19 pandemic[22] and early recognition and response to lung function decline.[23]

In the development of the CFLN, we conducted an improvement project to foster coproduction as it applies to collaborative service redesign and execution of QI initiatives through multiple programmes. We collected and refined interventions foundational to the culture of coproduction in the CFLN that may be useful strategies to support organisational change to collaborate at scale for other disease conditions.

The objective of this manuscript is to describe interventions that enhanced patient and family engagement in system-level coproduction to conduct QI initiatives in the CFLN. We aimed to improve patient and family partner (PFP) self-reported rates and programme perception of coproduction and maintain satisfaction in the working relationship with the PFP and clinicians. We report highlights of collected interventions in a dynamic change package adapted to:

1. increase the percentage of CFLN programmes with at least one PFP rating at 5 or higher on a PFP scale, representing a self-rating of a PFP's active participation in a programme's QI work;
2. increase the percentage of CFLN programmes that rate the collaboration with the PFPs at 5 or higher on the programme scale, representing a rating of QI team's perceived PFP participation within the QI team and project support.

METHODS

Context

The CFLN is a community of clinicians, people with CF, families and researchers representing CF Foundation accredited care programmes.[8 21] Three cohorts of programmes were recruited from 2016 to 2020, and as of 2023, 34 programmes participated, representing both adult and paediatric care programmes (online supplemental appendix A). The CFLN is governed by a leadership team of clinicians and PFPs and is co-chaired by a physician and a PFP. The CFLN was funded by the CF Foundation and facilitated by Cincinnati Children's Hospital through June 2023 with operations transitioning to the CF Foundation beginning July 2023. In 2024, 42 programmes (24 paediatric and 18 adult) participated in the CFLN.

Participating programmes are required to designate clinical and PFP leaders to guide engagement and participation of the local team members in network and QI activities.[21] Adult care programmes identify patient or family partners, and paediatric programmes identify parent and other family partners. Programme leaders (clinicians and PFPs) are provided with role descriptions and financial support to participate in network activities and events, such as conferences. Patient/Family partnership constitutes regular attendance in local programme QI meetings, participating in CFLN events, presenting data and leading QI work as desired. Each programme has the option to participate in core CFLN improvement initiatives such as multicentre innovation labs on prioritised topics like early detection of lung function decline as well as programmatic-focused improvement work.[21]

Interventions

A multistakeholder team of patients, parents and clinicians, led by CFLN PFP leaders, developed network-wide

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coproduction measures and set an improvement goal to increase PFP active participation. The workgroup discussed barriers and gaps from their experience partnering with programmes. The workgroup identified that adult programmes had fewer PFPs than paediatric programmes. Clinicians had concerns that patients may not have time, interest or stable health to serve as PFPs. The workgroup first tested a recruitment process by defining barriers with a single programme that were echoed among other CFLN programmes. These discussions led to the identification of network-wide needs for a more inclusive and transparent recruitment process and additional coproduction concepts. The workgroup organised ideas in a key driver diagram. The workgroup reviewed coproduction measures regularly and summarised framework, change concepts and tools into a change package.[24] The change package was refined with additional programmes in two multicentre learning laboratories, known as community of practices[21] and was accessible to all programmes in its iterations (online supplemental appendix B).

Change concepts were organised in five areas: (a) establishing clinician and patient readiness; (b) promoting an inclusive and open PFP recruitment process; (c) onboarding PFPs to the clinical team; (d) developing an ongoing mutually beneficial working partnership and (e) promoting opportunities for deeper engagement, ownership and leadership in the QI work. Key tools from the change package are highlighted for each area.

Establishing clinician and PFP readiness

For clinician readiness, two tools were tested in a small group of programmes and adopted to assist clinicians in reflecting on existing barriers to coproduction: a Clinical Team Readiness Assessment and a Barrier Gap Analysis (online supplemental appendix B). The Clinical Team Readiness Assessment was an 11-item tool, adapted from the Improve Care Now Network,[25] and aided clinicians to explore individual biases and assumptions and challenge conventions for hierarchy that may inhibit equal partnership with patients and families. The Barrier Gap Analysis tool was a 6-item tool developed by a multistakeholder group of PFPs and clinicians to catalogue institutional barriers to partnership.

To share and address barriers to PFP readiness for partnership, a workgroup encouraged all PFPs in the CFLN to meet monthly and provided a space for PFP peers to share their experiences working with their local programmes. PFPs could ask questions about the health system's structure, share insights and identify new ways of engaging with their team.

Promoting an inclusive patient and family partner recruitment process

The change package outlined an inclusive recruitment process for programmes to identify candidates who may be interested in fulfilling a PFP role (online supplemental appendix B). The process started by inviting all patients and families who receive care at the programme to apply for the open PFP position while providing critical information necessary for participation (time expectations, purpose of work, meeting date/times, etc). It continued with following up with interested candidates fielding surveys to indicate their interest and conducting multi-stakeholder interviews to narrow down and finalise selections.

Onboarding patient and family partners to the clinical team

Onboarding processes help CFLN programmes provide context and programme culture with newly recruited PFPs. Onboarding materials contained: (a) tips for how clinicians can welcome and include new PFPs at programme meetings; (b) a set of templated slides to describe roles and functions of the programme and the CFLN; (c) a one-page information sheet outlining important topics to be addressed when onboarding new PFPs (such as time commitment and expectations) and (d) a list of common acronyms used in QI and healthcare (online supplemental appendix B). Specific tips recommended for holding an onboarding meeting for introductions of PFPs and the team and reiteration of the team's goals, consideration of providing Health Insurance Portability and Accountability Act training for PFPs and defining the process to provide financial recognition for PFPs (as sponsored by the CF Foundation) in consideration of their time away from work and childcare obligations.

Developing an ongoing mutually beneficial working partnership

The change package summarised four principles to foster ongoing engagement and partnership between clinicians and PFPs: (a) emphasise clear and regular communication; (b) invite full membership to the QI team; (c) engage in continued QI training and (d) develop trust and positive relationships between clinicians and PFPs (online supplemental appendix B). Communication was promoted by recommending programmes to designate a clinician member to serve as a primary point of contact to support the PFP. The primary contact confirmed the PFP was receiving communication and met regularly to reflect on project contributions, assess needs and changing time commitments. Types of communication included providing agendas and notes before and after QI meetings to all team members, including the PFP.

Clinicians were encouraged to offer PFPs full membership to the QI team such as giving PFPs responsibilities at or between meetings if they were interested. Inclusion of PFPs was encouraged at all QI project phases from design to dissemination. Recruitment of multiple PFPs on a team helped to distribute workload and promoted sustained partnership despite health status. Prioritised QI projects were recommended to be of high interest, accessible and acceptable to both clinicians and PFPs. Programmes were encouraged to train PFPs who have varying levels of QI skills through local training, network-wide organised sessions or peer workgroups. Clinicians provided space for PFPs to share opinions without fear of repercussions,

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and to address barriers to trust. Creating space was encouraged by setting aside agenda time during QI team meetings, preferably at the beginning of meetings, to listen to the needs and concerns of the PFPs. Trust was also deepened through recognition of PFPs, their lived experiences and additional professional experiences and skills they often bring to the programme.

Promoting opportunities for deeper engagement, ownership and leadership

The change package provided examples of PFP leadership and opportunities for further engagement. Examples of PFP leadership included facilitating programme QI meetings, leading QI projects and writing conference abstracts or manuscripts as part of an authorship team (online supplemental appendix B). Programmes were encouraged to elicit feedback from their PFP regarding interest, time commitment and bandwidth. Programmes were recommended to share PFPs' contributions widely and navigate barriers that may limit a PFP's role as a leader.

Measures

Two scales, a PFP scale and a programme scale, were developed in 2018 to measure coproduction (table 1). The PFP scale was adapted from a civic and political engagement scale[26] to measure how PFPs report activity with their programme team. The scale was defined from 1 to 7 to represent a continuum of involvement (table 1). The programme scale was developed as a separate measure to assess the clinical programmes' involvement with PFPs, where 1=no programme PFP and 7=multiple PFPs take QI leadership roles in a programme (table 1). The scales aided the network to measure coproduction over time.[21] A rating ≥5 was determined by the PFP workgroup as the goal level of PFP partnership.

Table 1 Scales for coproduction for (A) PFP; (B) clinical programme; (C) PFP QI skills assessment

Rating	Description
(A)	PFP engagement scale
7	Leading an effort; teaching others
6	Taking ownership in a project
5	Actively participating in the work
4	Recognising my part
3	Understanding more deeply how QI, partnership and transparency of data matter
2	Appreciating the value of QI, or I have a voice and value of QI
1	Learning about a project
(B)	Programme Coproduction Scale
7	Multiple partners make significant contributions to our team, including leading or co-leading initiatives, generating ideas and partnering to cocreate and coproduce improvement
6	1 or 2 partner(s) make significant contributions to our team, including leading or co-leading initiatives, generating ideas and partnering to cocreate and coproduce improvement
5	Partner(s) participate in our team's work, help us with our projects and support our ideas. Not assuming leadership
4	Beginning to get comfortable involving partner(s) in QI
3	Partner(s) in training, not yet started
2	Planning to get partners involved
1	No PFP involvement yet
(C)	PFP QI Self-Assessment Scale
6	Expert—I have knowledge of this skill/tool/method AND I have a high degree of experience correctly applying and adapting it AND I can teach others the theory behind it and coach them in its use
5	Highly experienced—I have knowledge of this skill/tool/method AND I have a high degree of experience correctly applying and adapting it in various situations AND I can explain my decisions for doing so
4	Analysis and application—I have knowledge of this skill/tool/method AND I can analyse a situation and determine if it is needed AND then independently and accurately apply it
3	Basic application—I have knowledge of this skill/tool/method AND given a defined situation I can apply it with assistance
2	Knowledge—I can tell you what this skill/tool/method is AND give you facts about it
1	No knowledge—I cannot tell you what this skill/tool/method is

PFP, patient and family partner; QI, quality improvement.

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PFPs self-rated their competency of QI skills through a QI skills assessment tool (rating 1–6) adapted from Institute for Healthcare Improvement's 'Improvement Advisor Knowledge Self-Assessment Form'.[27] PFPs set a QI competency goal of being able to execute 'analysis and application' (4 out of 6) for three common QI skills (SMART aim, run charts and Plan-Do-Study-Act (PDSA) cycles).

Likert scales ratings from 1 to 5 (high satisfaction) were collected monthly from 2018 to 2022 from PFPs to rate satisfaction of the working relationship with their programme and to rate how valued in the work they felt by their programme.

Data collection and intervention timing

The coproduction scales were collected monthly across all programmes and PFPs as part of network-wide reporting starting in 2018. In 2019, the workgroup created a key driver diagram and started recruitment process testing. QI training with PFPs began in June 2019. The QI skills measure was collected until 2023 at least annually at PFP workgroup meetings. In 2020, CFLN programmes experienced the COVID-19 pandemic, expanded to a new cohort of CFLN programmes and many participated in a telehealth-focused innovation lab.[22] A coproduction change package was part of onboarding new programmes and was made more accessible to all programmes in January 2021. Community of practices focused on refining change package tools in June 2021 and March 2022. The change package was last revised in July 2023 (online supplemental appendix B).

Analysis

The study used Shewhart control charts, specifically p-charts, to evaluate the proportion of programmes with at least 1 PFP scale rating ≥5, indicating participation in a programme's QI work and the proportion of programmes rating ≥5, representing programme perception of PFP participation within the QI team and project support. A subgroup analysis of the PFP scale rating was conducted to determine the proportion of programmes where PFPs rated themselves as taking a leadership role (rating ≥6). Control charts were chosen over inferential statistics as a visual depiction of system variation and performance over time as the learning network expanded. statistical process control (SPC) charts were shared across the network to illustrate special cause variation and emphasise learning across PFPs and clinical teams. Control limits were adjusted if the system was stable and met special cause variation determined a priori as 8 points above or below the centre line.[28] This rule was chosen to identify small, sustained changes and applied for all network-wide measures.[21] Rating of QI skills and satisfaction of working with the programme were collected less frequently over time to decrease data collection burden from PFPs in the network. Run charts were used given limited data analysis resources needed to construct control charts for these measures and still provide some real-time assessment of data trends over time.

Patient and public involvement

Patients and family members were intimately involved in all parts of this QI project, designing the aim and measurements to improve coproduction across programmes, data review and analysis, adapting and implementing strategies and were central to its dissemination including recognition as shared authors of this work. Coproduction measures and progress were shared widely with all CFLN programmes at interval network-wide meetings. Patients and families had direct roles such as developing the coproduction change package, developing PDSA cycles, teaching QI, participating in publication policy creation and serving as champions in the learning laboratories focused on PFP recruitment, onboarding and partnership.

Ethical considerations

Similar to other learning health networks, each programme and embedded PFPs have independent experiences with QI work and were not considered to be human subjects research. Programmes and PFPs submitted the measures to CFLN as part of QI activities. Information was summarised, de-identified and aggregated for sharing across the network to facilitate improvement learning.

RESULTS

As of January 2023, 73 PFPs were participating in the CFLN. PFPs were patients (n=19) and family members (n=54) (online supplemental appendix A). Of 29 programmes in the early years of the CFLN (2018–2020), an average of 18 PFPs responded to PFP scale and QI self-assessment monthly. From June 2020 onwards, the CFLN expanded to 34 programmes. In 2022, 65% (22 of 34 programmes) had at least one PFP who completed the monthly scale and assessment. Data were anonymised so the duration of individual PFPs responding was not ascertained.

The average PFP rating for coproduction was 5.2 from 2018 through 2022. Among 27 programmes in 2018, 46% of programmes had at least 1 PFP report a level of coproduction of 5 or higher indicating active QI participation at the programme. By December 2022, 52% of programmes had at least 1 PFP report coproduction as 5 or higher (figure 1A). The proportion of programmes where PFPs reported leading in collaborative QI activities (PFP scale ≥6) increased from 25% to 33% (figure 1B). Positive and negative shifts were identified as special cause (8 points above or below the centre line) over time, including the context of the COVID-19 pandemic and personnel changes in programmes and the CFLN. PFPs reported working at a range of different levels of coproduction particularly as new programmes and PFPs joined the CFLN in 2020 (figure 2). Clinicians at 76% of 34 programmes acknowledged PFPs were actively participating or leading QI efforts (programme scale ≥5) at their respective programmes (figure 3). There was

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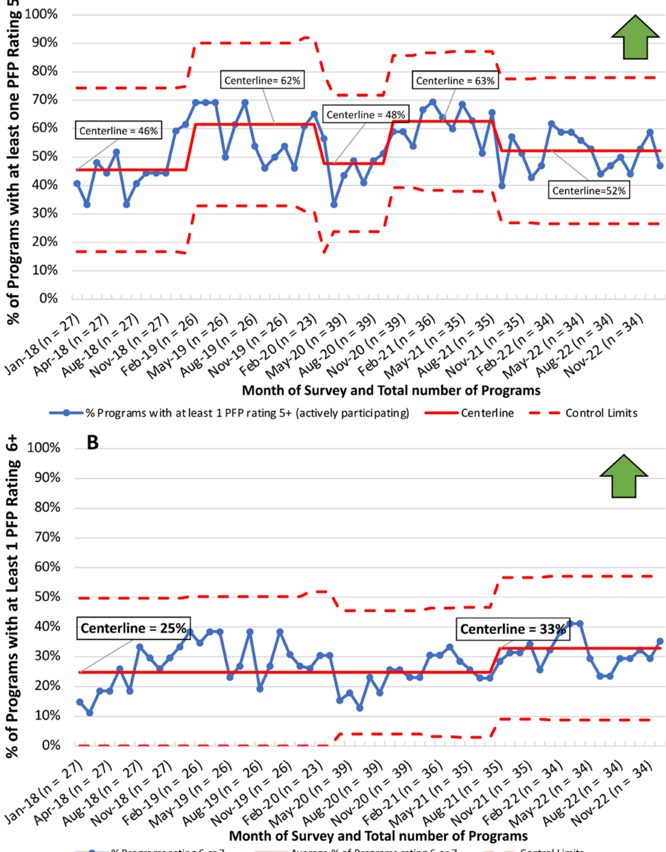

Figure 1 Patient and family partner (PFP) scale over time. P-chart for proportion of programmes with at least 1 PFP that (A) is actively participating in quality improvement (QI) (scale 5+) and (B) is leading QI initiatives (scale 6+).

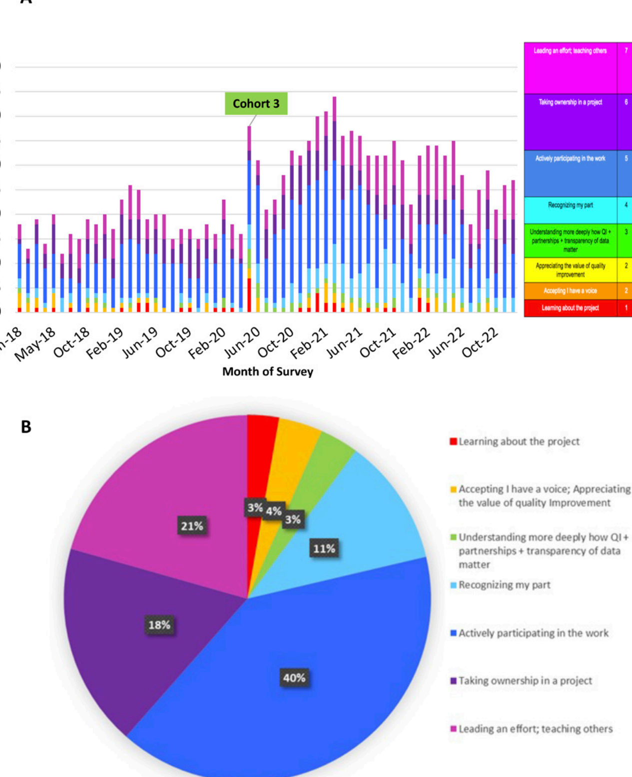

Figure 2 Reported range of patient and family partner (PFP) coproduction scale from 2018 to 2022. (A) Stacked histogram representing range of monthly PFP engagement scale responses from learning to leading and (B) pie chart of average proportion of scale responses. QI, quality improvement.

overlap in introduction and iterative testing for multiple change concepts, such as supporting PFP recruitment and initiating QI skills training, limiting analysis to determine which concepts contributed most to improvement for rated coproduction.

PFPs rated competence to analyse and apply common QI skills through a QI skills assessment of 4 or higher. The proportion of programmes with PFPs rating a 4 or higher increased annually from 17% to 32% of programmes from 2019 to 2023, representing a growing QI capacity among PFPs embedded in CFLN programmes (figure 4). PFPs also consistently rated 'high satisfaction' of the working relationship with their programme (4.6 of 5) and feeling valued in their work (4.7 of 5) (online supplemental appendix C).

DISCUSSION

We demonstrate improvement in rated scales of coproduction from patients, families and clinicians to engage in health service improvement efforts across diverse healthcare settings from over 30 programmes participating in the CFLN. Through coproduced development of a comprehensive package with five core areas that promote readiness, recruitment, onboarding, partnership and leadership, we maintained the capacity for system-level coproduction and high PFP satisfaction scores, even as new programmes joined the network.

Coproduction is central to improving patient-centred healthcare but remains a challenge to implement across various health systems.[29–31] Prior studies have acknowledged barriers to coproduction such as unclear roles and expectations, negative clinician attitudes and lack of support and resources to promote meaningful patient

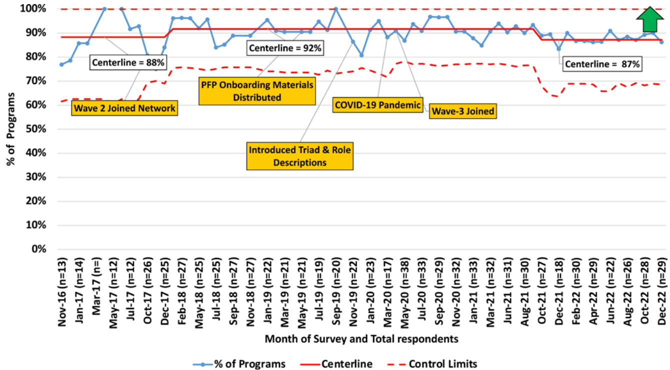

Figure 3 Programme coproduction scale. P-chart for proportion of programmes rating patient and family partners (PFPs) actively participating in quality improvement (QI) work (scale 5+).

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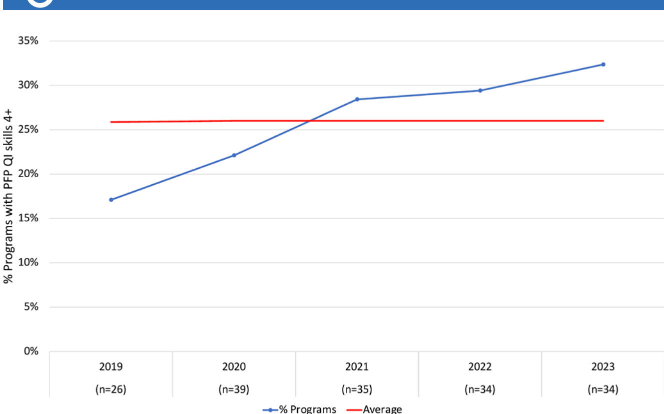

Figure 4 Patient and family partner (PFP) quality improvement (QI) Self-Assessment Scale. Run chart of annual percentage of programmes with a PFP rating comfort in application and analysis (scale 4+) for QI skills (SMART aim, run charts, Plan-Do-Study-Act cycles). N is the median number of programmes with responding PFPs. Red line—average across years.

involvement, ultimately hindering the advancement of a patient's role to influence service planning and lead decision-making.[32] A strength of this report is the collected practical summary of best practices, including outlines for recruitment and onboarding of a new PFP onto an improvement team. Other studies have also emphasised strategies for defining roles and responsibilities and recruitment to increase patient involvement to redesign care.[33–35] The summarised change concepts developed in the CFLN build on these prior studies and provide practical and adaptable tools that have been successful on a large scale to address such barriers across programmes from various health systems and aid in management of organisational complexity.

Patient and clinician partnerships in collaborative service design and improvement play a fundamental role in supporting the continuous learning culture and applications of learning health systems.[36] The value and practice of coproduction is active in learning health systems for various chronic conditions, emphasising a growing audience for supportive tools.[5 36–38] As we learnt in developing coproduction practices, PFPs reported a range of QI engagement, from learners to leaders. PFPs felt valued and satisfied in this partnership, regardless of their engagement level. We have leveraged our experiences with developing these strategies across multiple programmes to sustain a culture of coproduction across a growing and evolving learning health network. We believe sustaining coproduction practices requires a commitment to coproduction measures for learning health systems when adapting strategies to improve partnerships with patients and families. Learning health networks are attuned to revisit measures and interventions to identify areas of improvement and refine the working relationship between PFPs and clinicians. The CFLN has expanded QI training opportunities and continues to cross-share practices in learning laboratories and workgroups. We continue to assess coproduction culture within the network through inclusive learning using central measures as people within a network experience collaboration together. Such themes align with other reports of community engagement in research, QI and learning health networks.[32 37 39 40] Future work is needed to standardise and validate measures of coproduction to add knowledge to the generalisability of coproduction practices.

The core work of coproduction in the CFLN has advanced productive partnerships with patients and families and increased visibility, leadership and accountability of improvement projects. PFPs share authorship in increasing numbers of projects.[21–23] PFPs participating in the CFLN may be more practised to engage in healthcare improvement, research and advocacy, all vital, particularly as new evidence emerges impacting the health of many individuals with CF.[3 41] Adaptable mechanisms for coproduced health service design and delivery are timely strategies in the changing landscape of CF chronic care. The CFLN provides an important platform to coproduce implementation and narrow evidence and innovation practice gaps.[3 41] Furthermore, the inclusivity of coproduction also suggests exciting applications of this work with patients and families from underserved communities, where active commitment exists from the CF Foundation and others to bring out the voices of all PFPs to collaborate to address inequities from racial, ethnic or other systemic injustices in healthcare and health.[42 43] Our work suggests the following takeaways to support successful partnerships with patients, families and clinicians dedicated to quality care improvement:

1. Identify clinician readiness to support shared discussion and include commitment from leadership to reduce barriers to coproduction.
2. Facilitate an open call recruitment process for all patients and families. An open call is less likely to limit biased selection and exclude interest and skill from candidate PFPs willing to join.
3. Support multiple PFPs on a team simultaneously. Multiple PFPs can provide a sense of community for the PFP and are more likely to provide the team with consistent involvement, even if health challenges temporarily preclude a patient or family member from active work.
4. Provide basic QI methods training and promote PFPs to practice applications of methods across projects.
5. Share QI project selection that reflects urgency and priorities inclusive of PFPs' perspectives.
6. Facilitate access to information necessary for PFPs to contribute in identifying areas for improvement and participating in analysis of trends.
7. Encourage an inclusive and safe environment for clinician-PFP discussions.
8. Budget for financial recognition of PFPs as a mechanism for more equitable engagement. For example, the Patient-Centred Outcomes Research Institute requires budgeting for fair financial compensation for

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patients and caregivers as standard practice for engaging them as research partners.[44]

9. Disseminate learnings in open-access journals to facilitate shared access for evidence review.

Limitations

There are important limitations to this work. Participating programmes in the CFLN received financial support from the CF Foundation to participate in the Network and practice coproduction. It is unclear how reports of engagement would change without such resources. The self-reported measures of coproduction in the CFLN are subject to reporting bias. PFP responses were also de-identified to promote sharing and transparency for the coproduction improvement process. As such, the duration of an individual PFP reporting was not tracked. However, in a separate study involving interviews with PFPs and clinicians in the CFLN, self-reported measures echoed themes of high-value partnership and shared purpose.[8] We also tested multiple change concepts simultaneously and concurrently with external factors such as the COVID-19 pandemic limiting analysis for singular interventions. We present all tested concepts (online supplemental appendix B) to provide organisations an opportunity to adapt to local systems. We recognise that we had more paediatric programmes and a greater representation of family partners compared with adult partners. We were not scoped to assess potential differences in these responses. As the CFLN has expanded in 2024 to 42 sites, including 18 adult programmes, we continue to refine the change package to promote PFP coproduction.

CONCLUSION

Improvement in patient-centred healthcare necessitates partnership between clinicians and patients and families. The CFLN set out to augment and sustain system-level coproduction between clinicians and PFPs in multiple programmes through shared resources, processes and tools. PFPs and programmes reported high partnership in scales of coproduction, and PFPs reported overall high satisfaction in their participation with their respective programmes. Interventions and material presented in the manuscript are poised for adaptation by other health systems to advance coproduction.

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