MANUALE PER L'AUTOVALUTAZIONE E LA REVISIONE TRA PARI

SLIDE KIT 1:INTRODUZIONE GENERALE E LINGUAGGIO

Elisabetta Bignamini e Domenico Tangolo

per la commissione «Accreditamento» SIFC-LIFC

Nota introduttiva e conflitti di interesse

Queste slide sono messe a disposizione dei Centri di riferimento e supporto per la diagnosi e cura della fibrosi cistica per favorire l'utilizzo del Manuale per l'autovalutazione e la revisione tra pari e promuovere le fasi di autovalutazione ed eterovalutazione, che sono oggetto di altri due slide kit , dedicati.

Per ogni informazione relativa scrivere a accreditamentofc@gmail.com

Gli Autori non hanno conflitti di interesse sui temi trattati

Agenda

1

Il linguaggio della qualità

2

La storia del «Manuale»

3

Il ciclo di Deming:applicazioni pratiche

1

Il linguaggio della qualità: vocabolario di base

Struttura

Processo

Esito

Criterio

Indicatore

Standard

Benchmarking

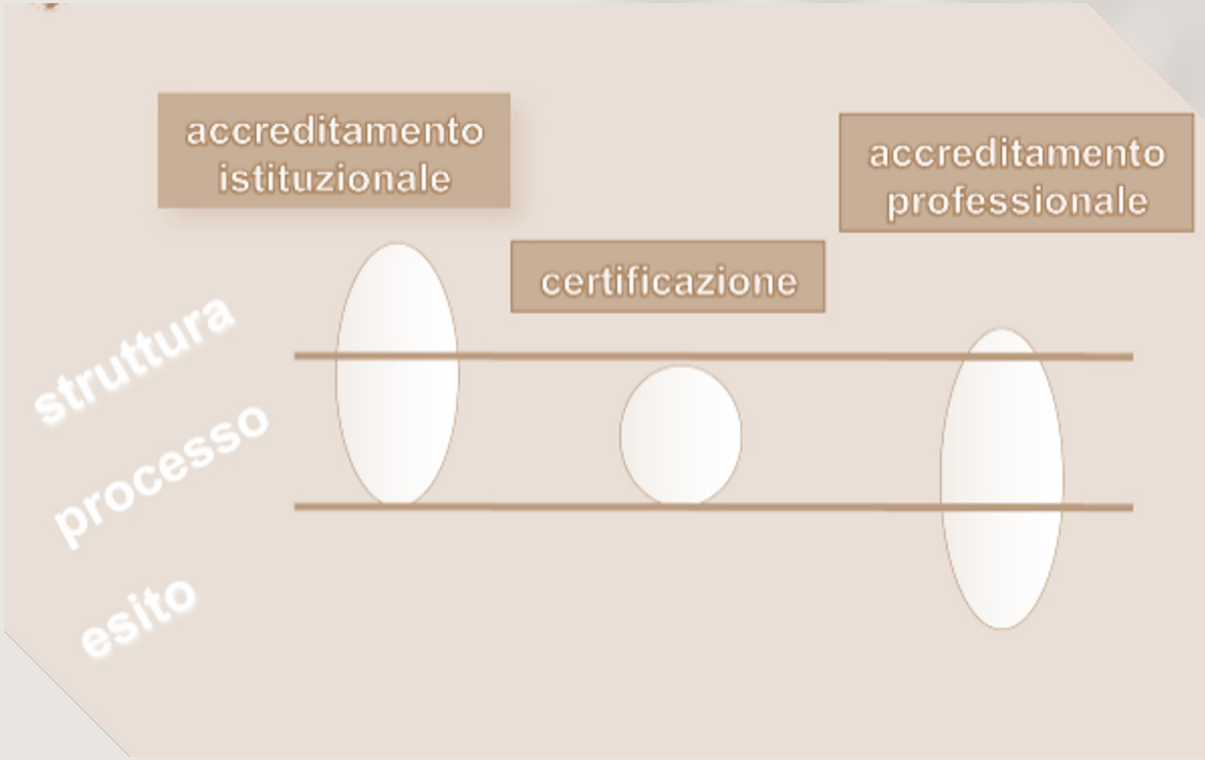
- STRUTTURA: elementi statici dell'ambiente in cui l'assistenza viene fornita
- PROCESSO: modalità di effettuazione delle attività professionali
- ESITO: cambiamento dello stato attuale e futuro dell'oggetto del nostro intervento, che può essere attribuito all'intervento stesso

Q&A

Q. Di cosa si dispone? A. Struttura

Q. Che cosa si fa? A. Processo

Q. Che cosa si ottiene? A. Esito



L’osservato/atteso risponde alla domanda : dove sono? Cosa voglio ottenere?

Quali elementi osservabili descrivono il mio atteso? CRITERIO

Come posso misurare questi elementi? INDICATORE

A che livello mi dichiaro soddisfatto? STANDARD

CRITERIO

"Norma, fondamento per giudicare, distinguere, valutare"

Galileo Galilei

κρινειν = distinguere, giudicare

Regola che viene assunta come norma di giudizio

Zanichelli

Elemento riferito alla struttura, al processo o agli esiti dell'assistenza sanitaria che corrisponde a un giudizio di buona qualità

Donabedian, 1989,

Argomento, tema, aspetto da prendere in considerazione per valutare e decidere.

P. Morosini – F. Perraro, 1999

INDICATORE

Indice rappresentativo dell'andamento di un particolare settore, unità di misura del criterio

Zanichelli

misura riproducibile del criterio nella situazione analizzata

STANDARD

Valore di riferimento

Zanichelli

Percentuale di azioni o di esiti che si ritengono debbano soddisfare l'indicatore

BENCHMARKING

Il termine è stato introdotto in un periodo non definito dagli agrimensori che lo utilizzavano per indicare punto preciso che serviva da base per partire per tutte le altre misurazioni

- Un segno su un oggetto che indica un riferimento topografico nel rilievo delle maree
- Un punto di riferimento da cui possano essere prese delle misure
- Qualcosa che serve da standard da cui altri prendano delle misure
- Dagli anni 50 è stato utilizzato in Giappone
- Dagli anni 70 ha diffusione in campo aziendale anche in USA e Europa
- In medicina entra nell'ambito delle qualità delle cure dagli inizi degli anni novanta

Mean and median age at death
Proportion of patients living with lung transplant
Proportion of patients living with liver transplant
Mean, minimum, maximum, quartiles of FEV_1% predicted
FEV_1% predicted groups (<40/40–80/>80%)
Prevalence of chronic infection by *Pseudomonas aeruginosa*
Prevalence of chronic infection by *Burkholderia* spp.
Prevalence of chronic infection by *Staphylococcus aureus*
Prevalence of infection by non-tuberculous mycobacteria
Prevalence of infection by *Stenotrophomonas maltophilia*
Mean, minimum, maximum, quartiles of Z-scores for height
Mean, minimum, maximum, quartiles of Z-scores for weight
Mean, minimum, maximum, quartiles of Z-scores for BMI
Proportion of patients with BMI <18.5
Prevalence of allergic bronchopulmonary aspergillosis
Prevalence of pneumothorax
Prevalence of haemoptysis
Prevalence of malignancy
Prevalence of liver disease
Number of patients living with transplanted lung(s)
Number of patients living with transplanted liver
Number of deaths in current year
Age at death groups for deaths occurred in current year
Cause of death for deaths occurred in current year

Percentage of new cases diagnosed by newborn screening in current year
Median age at diagnosis
Median age at diagnosis for new diagnoses
F508del genotype (homozygote/heterozygote/other/not genotyped)
Mean, minimum, maximum, quartiles of age at diagnosis
Age at diagnosis groups
Proportion of patients who underwent neonatal screening
Proportion of patients with DNA analysis

CHE COSA MISURARE ? ESITI CLINICI

Benchmarking

What to compare?

1. Median Age of all patients
2. Proportion of patients aged 18 years or more
3. Number of deaths in current year – as a proportion of total number of patients averaged over 3 years
4. Median age at death (deaths in current year)
5. Median (IQR) FEV1 predicted with boxplots:
   Ages (6, 10, 16, 18, 22, 26)
6. Median (IQR) BMI percentile with boxplots
   Ages (6, 10, 16)
7. Mean BMI (aged 18 years and more) with boxplots
   Ages (18, 22, 26)

Need to be able to assess these measures in real time and compare trends across time (annually at least)

2

La storia del Manuale

ELSEVIER

Journal of Cystic Fibrosis 4 (2005) 7–26

Journal of Cystic Fibrosis

www.elsevier.com/locate/jcf

Standards of care for patients with cystic fibrosis: a European consensus

Eitan Kerem*, Steven Conway, Stuart Elborn, Harry Heijerman

For the Consensus Committee[1]

Department of Pediatrics and CF center, Mount Scopus, Jerusalem 91240, Israel

1. Introduction

Cystic fibrosis (CF) is caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene [1,2]. This results in dysfunction of the apical membrane CFTR protein which regulates chloride and sodium transport in secretory epithelial cells [1], with abnormal ion concentrations across the apical membranes of these cells. The clinical consequences include multi-system disease characterised by progressive pulmonary damage leading to respiratory failure, pancreatic dysfunction, liver disease that may progress to cirrhosis, gut motility problems, and elevated sweat electrolytes. Virtually all men with CF are infertile due to atresia or complete absence of the vas deferens.

Cystic fibrosis is a complex disease requiring a holistic approach to treatment [3]. Center care by a team of trained and experienced health professionals is essential for optimal patient management and outcome [4]. Specialist care in dedicated CF centers is associated with improved survival and quality of life [4,5]. Such care involves frequent clinical evaluations and monitoring for complications, by physicians and other healthcare workers specifically trained in the management of CF and early treatment interventions.

Standards of care define the optimal service provision necessary to deliver the best outcomes possible for patients. Several guidelines have been written to assist CF caregivers in the evaluation and monitoring of patients, detection of complications and prevention of clinical deterioration [6–9]. However there is lack of uniformity in many of the agreed European recommendations e.g.; the necessary infrastructure for a CF center; the minimum standards for routine evaluation and assessment of patients; the documentation of results in a standard database and; the management of complications. We are convinced that intensive treatments, both prophylactic and as a response to acute events, decrease morbidity and increase survival and quality of life.

The aim of this consensus document is to define standards for the routine evaluation, monitoring and treatment of patients with CF in Europe. We hope that these will be adopted by all European CF centers to provide a quality assurance instrument and a basis for audit of CF care.

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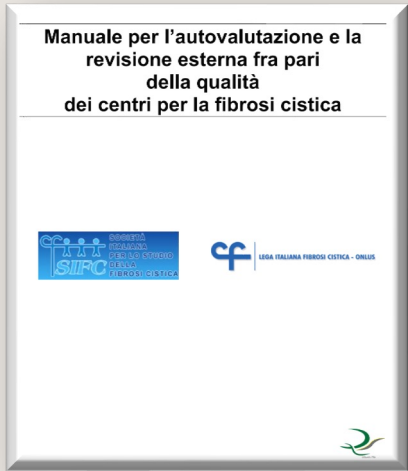
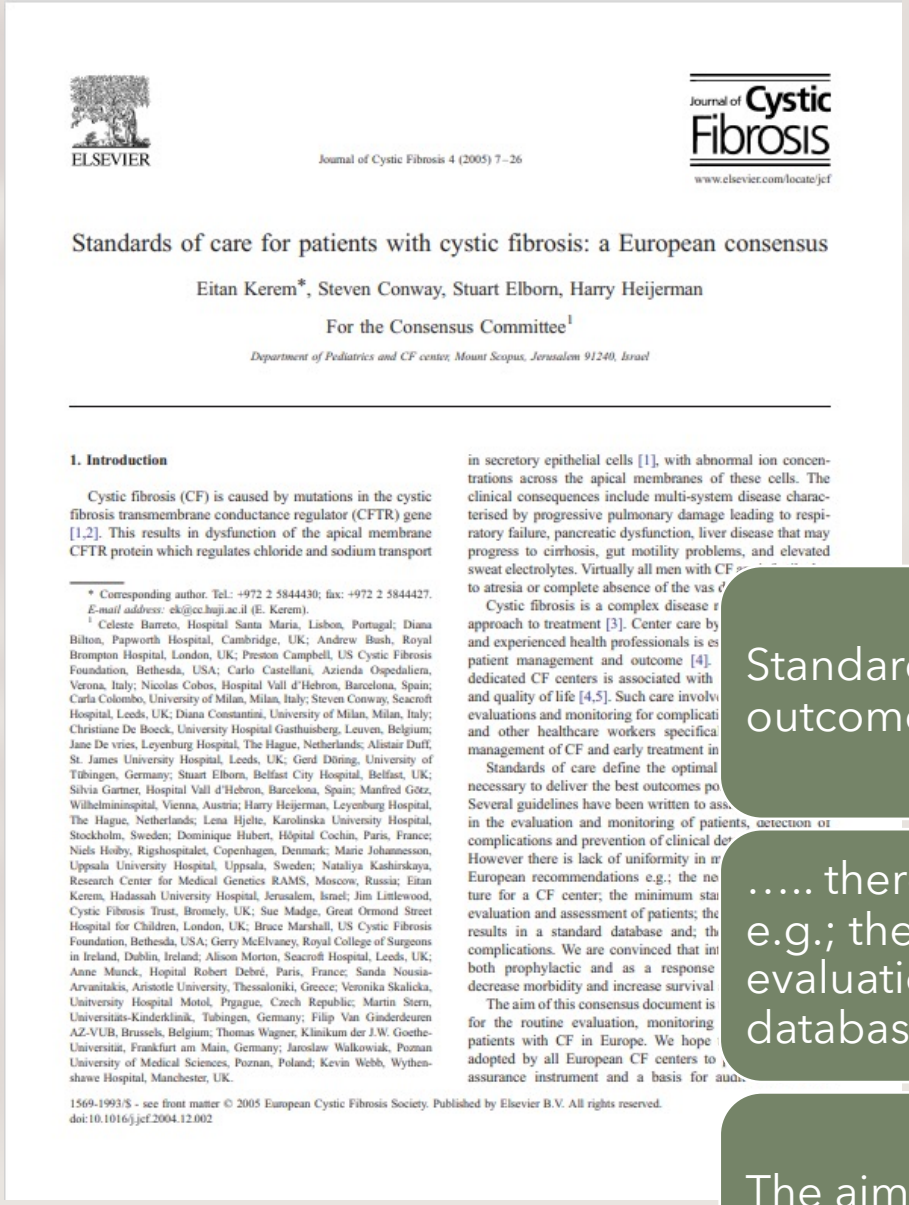
- Nel 2006 , in seguito a questa pubblicazione nasce la commissione Standard of Care della SIFC
- Nel 2010, si capisce che non è solo una questione di «misure», ma che bisogna guardare alla qualità: coinvolgimento delle persone affette da fibrosi cistica e delle loro famiglie e inizio del percorso per la Valutazione tra pari della qualità dei centri Fibrosi Cistica
- Nel 2012 nasce il primo manuale per l' autovalutazione e la valutazione tra pari per i Centri Fibrosi cistica





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doi:10.1016/j.jcf.2004.12.002

Il primo documento di consenso europeo

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ACCREDITAMENTO

In ambito sanitario, e specificamente nel nostro paese, distinguiamo, parlando di accreditamento due forme:

Accreditamento Istituzionale

Accreditamento Professionale

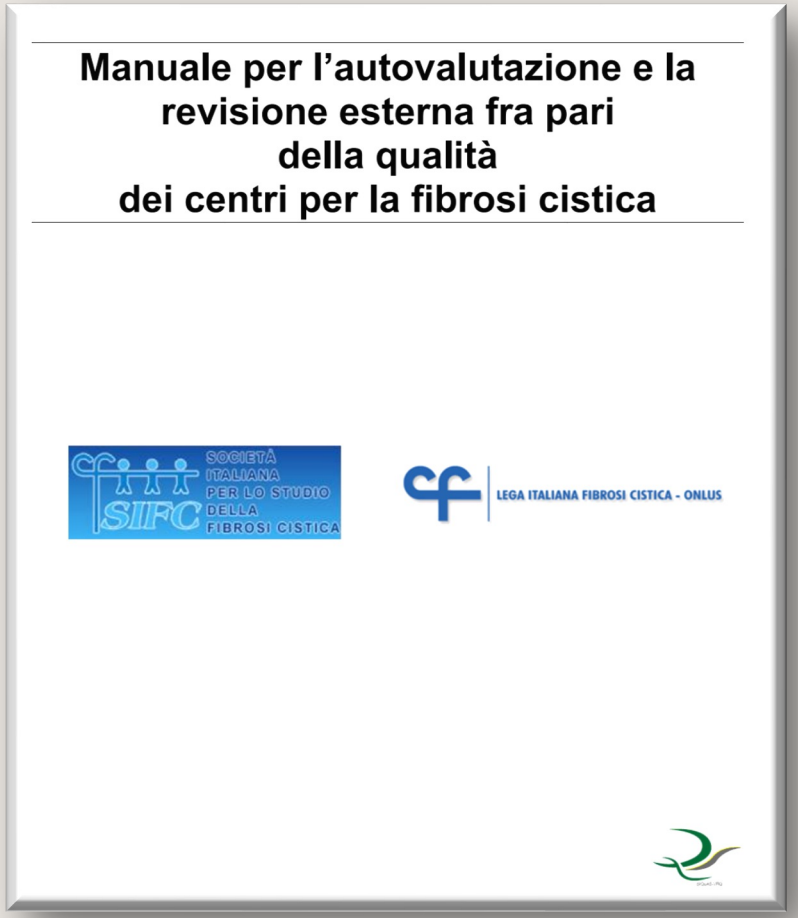
l'Accreditamento professionale nasce con questa finalità:

"…. standardizzare la struttura e il modo di lavorare degli ospedali per far sì che le istituzioni con ideali più elevati abbiano il giusto riconoscimento davanti alla comunità professionale e che le istituzioni con standard inferiori siano stimolate a migliorare la qualità del proprio lavoro. In tal modo i pazienti riceveranno il trattamento migliore e la gente avrà qualche strumento per riconoscere quelle istituzioni che si ispirano ai più alti ideali della medicina."

American College of Surgeon 1918

- Numerose società scientifiche nel nostro paese hanno prodotto “Manuali di Accreditamento”, o meglio “Manuali di autovalutazione e revisione esterna fra pari della Qualità” (Liva, 1999), che recentemente hanno visto fra i protagonisti della definizione dei requisiti, e del processo valutativo, anche i pazienti ed i familiari.

Ciò che resta nodale in questo approccio è la volontarietà del processo, mentre nel caso dell’accreditamento istituzionale i processo è obbligatorio.



10 centri valutati

15% di requisiti probabilmente non utili

50% di requisiti da rivedere

2012

2016

In Europa si arriva un po' dopo…

ELSEVIER

Journal of Cystic Fibrosis 13 (2014) S43 – S59

Journal of Cystic Fibrosis
www.elsevier.com/locate/jcf

Review

European Cystic Fibrosis Society Standards of Care: Quality Management in cystic fibrosis

Martin Stern [a,*], Dominique Pougheon Bertrand [b], Elisabetta Bignamini [c], Mary Corey [d], Birgit Dembski [e], Christopher H. Goss [f], Tanja Pressler [g], Gilles Rault [h], Laura Viviani [i], J. Stuart Elborn [j], Carlo Castellani [k]

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Abstract

Since the earliest days of cystic fibrosis (CF) treatment, patient data have been recorded and reviewed in order to identify the factors that lead to more favourable outcomes. Large data repositories, such as the US Cystic Fibrosis Registry, which was established in the 1960s, enabled successful treatments and patient outcomes to be recognized and improvement programmes to be implemented in specialist CF centres. Over the past decades, the greater volumes of data becoming available through Centre databases and patient registries led to the possibility of making comparisons between different therapies, approaches to care and indeed data recording. The quality of care for individuals with CF has become a focus at several levels: patient, centre, regional, national and international. This paper reviews the quality management and improvement issues at each of these levels with particular reference to indicators of health, the role of CF Centres, regional networks, national health policy, and international data registration and comparisons.

Keywords: CF registries; Standards; Models of care; Quality management; Outcomes in CF

Contents

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2014

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Journal of Cystic Fibrosis

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Review

European Cystic Fibrosis Society Standards of Care: Framework for the Cystic Fibrosis Centre

Steven Conway [a,*], Ian M. Balfour-Lynn [b], Karleen De Rijcke [c], Pavel Drevinek [d,e,f], Juliet Foweraker [g], Trudy Havermans [h], Harry Heijerman [i], Louise Lannefors [j], Anders Lindblad [k], Milan Macek [l,m], Sue Madge [n], Maeve Moran [o], Lisa Morrison [p], Alison Morton [q], Jacquelien Noordhoek [r], Dorota Sands [s], Anneke Vertommen [t], Daniel Peckham [u]

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Abstract

A significant increase in life expectancy in successive birth cohorts of people with cystic fibrosis (CF) is a result of more effective treatment for the disease. It is also now widely recognized that outcomes for patients cared for in specialist CF Centres are better than for those who are not. Key to the effectiveness of the specialist CF Centre is the multidisciplinary team (MDT), which should include consultants, clinical nurse specialist, microbiologist, physiotherapist, dietitian, pharmacist, clinical psychologist, social worker, clinical geneticist and allied healthcare professionals, all of whom should be experienced in CF care. Members of the MDT are also expected to keep up to date with developments in CF through continued professional development, attendance at conferences, auditing and involvement in research. Specialists CF Centres should also network with other Centres both nationally and internationally, and feed Centre data to registries in order to further the understanding of the disease. This paper provides a framework for the specialist CF Centre, including the organisation of the Centre and the individual roles of MDT members, as well as highlighting the value of CF organisations and disease registries.

Keywords: CF Centre; Multidisciplinary team; Continuing professional development

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Review

European Cystic Fibrosis Society Standards of Care: Best Practice guidelines

Alan R. Smyth [a,*], Scott C. Bell [b,c], Snezana Bojcin [d,v], Mandy Bryon [e], Alistair Duff [f], Patrick Flume [g], Nataliya Kashirskaya [h], Anne Munck [i,j], Felix Ratjen [k,l], Sarah Jane Schwarzenberg [m], Isabelle Sermet-Gaudelus [n,o,p], Kevin W. Southern [q], Giovanni Taccetti [r,s], Gerald Ullrich [t], Sue Wolfe [u]

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Abstract

Specialised CF care has led to a dramatic improvement in survival in CF: in the last four decades, well above what was seen in the general population over the same period. With the implementation of newborn screening in many European countries, centres are increasingly caring for a cohort of patients who have minimal lung disease at diagnosis and therefore have the potential to enjoy an excellent quality of life and an even greater life expectancy than was seen previously. To allow high quality care to be delivered throughout Europe, a landmark document was published in 2005 that sets standards of care. Our current document builds on this work, setting standards for best practice in key aspects of CF care. The objective of our document is to give a broad overview of the standards expected for screening, diagnosis, pre-emptive treatment of lung disease, nutrition, complications, transplant/end of life care and psychological support. For comprehensive details of clinical care of CF, references to the most up to date European Consensus Statements, Guidelines or Position Papers are provided in Table 1. We hope that this best practice document will be useful to clinical teams both in countries where CF care is developing and those with established CF centres.

Keywords: Cystic fibrosis; Standards of care; Multidisciplinary management

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Review

European Cystic Fibrosis Society Standards of Care: Quality Management in cystic fibrosis

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Abstract

Since the earliest days of cystic fibrosis (CF) treatment, patient data have been recorded and reviewed in order to identify the factors that lead to more favourable outcomes. Large data repositories, such as the US Cystic Fibrosis Registry, which was established in the 1960s, enabled successful treatments and patient outcomes to be recognized and improvement programmes to be implemented in specialist CF centres. Over the past decades, the greater volumes of data becoming available through Centre databases and patient registries led to the possibility of making comparisons between different therapies, approaches to care and indeed data recording. The quality of care for individuals with CF has become a focus at several levels: patient, centre, regional, national and international. This paper reviews the quality management and improvement issues at each of these levels with particular reference to indicators of health, the role of CF Centres, regional networks, national health policy, and international data registration and comparisons.

Keywords: CF registries; Standards; Models of care; Quality management; Outcomes in CF

Contents

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MANUALE
PER L'AUTOVALUTAZIONE
E LA REVISIONE ESTERNA
FRA PARI
DELLA QUALITÀ DEI CENTRI
PER LA FIBROSI CISTICA
EDIZIONE 2021

Agenzia Nazionale per i Servizi Sanitari Regionali

Proposta di modello per l'accreditamento istituzionale

delle strutture ospedaliere

Giugno 2015

Presidenza del Consiglio dei Ministri

CONFERENZA PERMANENTE PER I RAPPORTI
TRA LO STATO, LE REGIONI E LE PROVINCIE AUTONOME
DI TRENTO E DI BOLZANO

Intesa, ai sensi dell'articolo 8, comma 6, della legge 5 giugno 2003, n. 131, tra il Governo, le Regioni e le Province autonome in materia di adempimenti relativi all'accreditamento delle strutture sanitarie.

Rep. n. 32/CSR del 19 febbraio 2015

LA CONFERENZA PERMANENTE PER I RAPPORTI TRA LO STATO, LE REGIONI E LE PROVINCE AUTONOME DI TRENTO E BOLZANO

modello incrementale a più livelli

8 criteri

Presidenza del Consiglio dei Ministri

CONFERENZA PERMANENTE PER I RAPPORTI
TRA LO STATO, LE REGIONI E LE PROVINCE AUTONOME
DI TRENTO E BOLZANO

Intesa, ai sensi dell'articolo 8, comma 6, della legge 5 giugno 2003, n. 131, tra il Governo, le Regioni e le Province autonome sul documento recante "Disciplina per la revisione della normativa dell'accreditamento", in attuazione dell'articolo 7, comma 1, del nuovo Patto per la salute per gli anni 2010-2012 (Rep. Atti n. 243/CSR del 3 dicembre 2009).

Rep. n. 258/CSR DEL 20/12/2012

LA CONFERENZA PERMANENTE PER I RAPPORTI TRA LO STATO, LE REGIONI E LE PROVINCE AUTONOME DI TRENTO E BOLZANO

Nell'odierna seduta del 20 dicembre 2012:

VISTA la delega a presiedere l'odierna seduta conferita al Sottosegretario di Stato alla Presidenza del Consiglio dei Ministri Prof. Giampaolo Vittorio D'Andrea;

VISTO l'articolo 8, comma 6 della legge 5 giugno 2003 n. 131, che prevede che Il Governo può promuovere la stipula di intese in sede di Conferenza Stato-Regioni o di Conferenza unificata, dirette a favorire l'armonizzazione delle rispettive legislazioni o il raggiungimento di posizioni unitarie o il conseguimento di obiettivi comuni;

VISTA l'intesa di questa Conferenza del 3 dicembre 2009 (Rep. n. 243/CSR) concernente il nuovo Patto per la salute 2010-2012 che, all'articolo 7, comma 1, prevede la stipula, nel rispetto degli obiettivi programmatici di finanza pubblica, di un'intesa in sede di Conferenza Stato-Regioni, ai sensi del predetto articolo 8, comma 6, della legge n. 131 del 2003, finalizzata a promuovere una revisione normativa in materia di accreditamento e di remunerazione delle prestazioni sanitarie;

VISTA la nota in data 26 ottobre 2012, con la quale il Ministero della salute ha inviato, ai fini del perfezionamento della prescritta intesa in sede di Conferenza Stato-Regioni, la proposta d'intesa indicata in oggetto;

VISTA la lettera in data 2 novembre 2012, con la quale la proposta di intesa è stata diramata alle Regioni e Province autonome di Trento e Bolzano;

VISTA la nota in data 5 novembre 2012, con la quale la Regione Veneto, Coordinatrice della Commissione salute, ha chiesto il differimento della riunione tecnica convocata per il giorno 7 novembre 2012 al fine di poter svolgere ulteriori approfondimenti;

1. Attuazione di un sistema di gestione delle strutture sanitarie	6
2. Prestazioni e servizi	5
3. Aspetti strutturali	2
4. Competenze del personale	2
5. Comunicazione	5
6. Appropriatezza clinica e sicurezza	4
7. Processi di miglioramento ed innovazione	3
8. Umanizzazione	1

8 criteri

requisiti 28

Fattore/criterio	Descrive il fattore/criterio di qualità di riferimento.
Requisito	Descrive l'obiettivo da raggiungere.
Campo d'applicazione	Descrive il livello dell'organizzazione che deve provvedere a implementare e a soddisfare il requisito.

La struttura dei requisiti (1)

I requisiti per l'accreditamento sono caratterizzati dalla seguente struttura:

- Il fattore/criterio di riferimento;
- Il requisito;
- Il campo d'applicazione;

- I livelli di compliance del requisito: ad ogni requisito sono attribuite, ai fini della valutazione, delle evidenze che possono essere attinenti:
  - al processo: focalizzate sul modo in cui si realizza una certa attività;
  - all'esito: focalizzate sul risultato che si ottiene.

requisiti 28

requisiti 28

Fase 1: Documenti di indirizzo e pianificazione	La fase 1 richiede la presenza e i contenuti dei documenti di indirizzo e pianificazione. Questi possono essere la missione, le politiche, i piani o le linee guida, le istruzioni o le checklist a seconda del campo di applicazione del requisito. *Definire una politica, organizzare un'attività, definire un piano delle attività, ecc.* Il requisito non fa riferimento al livello dell'organizzazione responsabile per la preparazione di questi documenti. La responsabilità è pertanto identificata dalla Direzione.
Fase 2: Implementazione	La fase 2 richiede la conoscenza, la consapevolezza e l'implementazione di quanto progettato, pianificato e identificato nella fase precedente sia da parte della Direzione che del personale. *Realizzare un'attività, rispettare le esigenze e i bisogni del cittadino/ paziente, mettere in atto un piano delle attività, formare, educare, sensibilizzare, ecc.* La valutazione del soddisfacimento dei requisiti previsti da questa fase viene effettuata attraverso l'osservazione sul campo, interviste o la valutazione delle cartelle cliniche dei pazienti, dei dati e di altri documenti.
Fase 3: Monitoraggio	La fase 3 richiede che i risultati dell'implementazione delle evidenze delle fasi precedenti siano documentati. *Monitorare un'attività, valutare l'efficacia delle azioni ecc.*
Fase 4: Miglioramento della qualità	La fase 4 presuppone che i dati raccolti in base alle evidenze definite nella fase 3 siano analizzati e valutati e, sulla base di questi, vengano definite le priorità, pianificate e implementate opportune iniziative/ attività per il miglioramento della sicurezza e della qualità delle strutture, dei processi e degli esiti. *Mettere in opera azioni di miglioramento, ecc.*

La struttura dei requisiti (2)

…..

Ciascun requisito è declinato secondo la logica del ciclo di Deming

Ogni organizzazione implementerà i requisiti secondo le proprie necessità e nel modo che maggiormente si adatta alle modalità con cui eroga prestazioni. Per il soddisfacimento dei requisiti risulta importante che:

- Le organizzazioni siano in grado di dimostrare in che modo soddisfano l'obiettivo e lo scopo del requisito;
- Le organizzazioni siano in grado di dare **evidenza** del soddisfacimento del requisito.

	Fase 1	Fase 2	Fase 3	Fase 4	Totale evidenze per singolo requisito
FATTORE/CRITERIO 1 Fornisce garanzia di buona qualità della assistenza socio-sanitaria, una gestione della organizzazione sanitaria che governi le dimensioni più fortemente collegate alla specifica attività di cura e assistenza in una ottica di miglioramento continuo					
Requisito 1.1 Modalità di pianificazione, programmazione e organizzazione delle attività di assistenza e di supporto	1	3	4	1	9
Requisito 1.2 Programmi per lo sviluppo di reti assistenziali	1	3	1	1	6
Requisito 1.3 Definizione delle responsabilità	1	2	2	1	6
Requisito 1.4 Le modalità e gli strumenti di gestione delle informazioni (sistemi informativi e dati)	2	2	2	1	7
Requisito 1.5 Le modalità e gli strumenti di valutazione della qualità dei servizi	1	4	1	1	7
Requisito 1.6 Le modalità di prevenzione e di gestione dei disservizi	2	2	1	2	7
N° totale evidenze per singola fase	**8**	**16**	**11**	**7**	**42**

requisiti 28

La struttura dei requisiti (3)

.....

Ciascun requisito è declinato secondo la logica del ciclo di Deming

Ogni organizzazione implementerà i requisiti secondo le proprie necessità e nel modo che maggiormente si adatta alle modalità con cui eroga prestazioni.

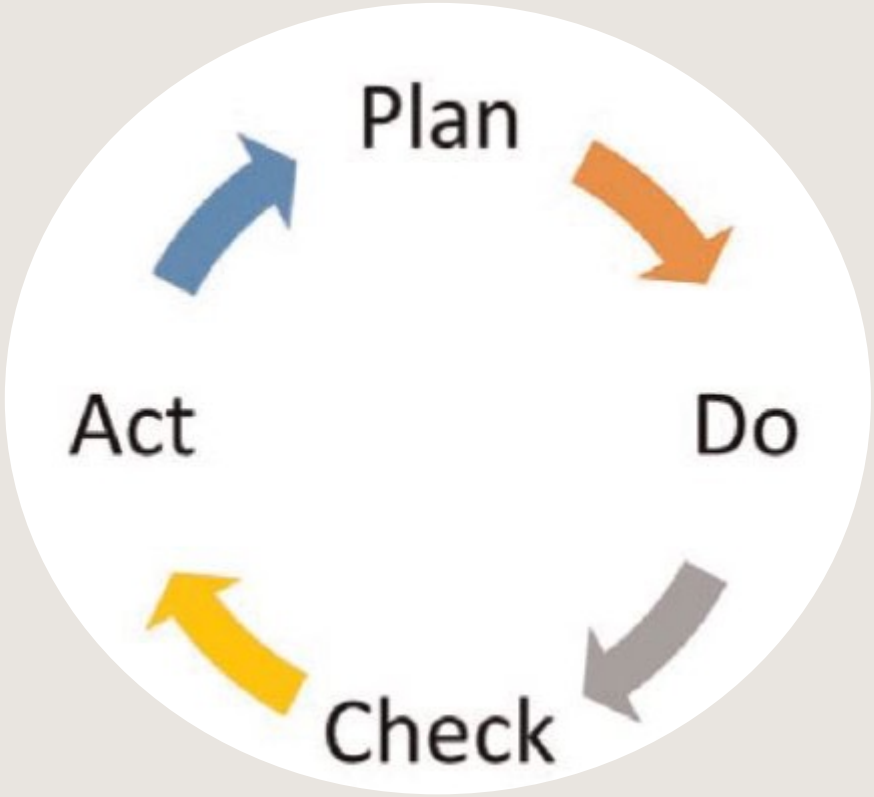
Per il soddisfacimento dei requisiti risulta importante che:

- Le organizzazioni siano in grado di dimostrare in che modo soddisfano l'obiettivo e lo scopo del requisito;
- Le organizzazioni siano in grado di dare **evidenza** del soddisfacimento del requisito.

Correggere e/o resettare gli obiettivi e i processi

PLAN :stabilire obiettivi e processi necessari per ottener eil risultato prefissato

Pianificare il miglioramento



DO : dare attuazione ai processi

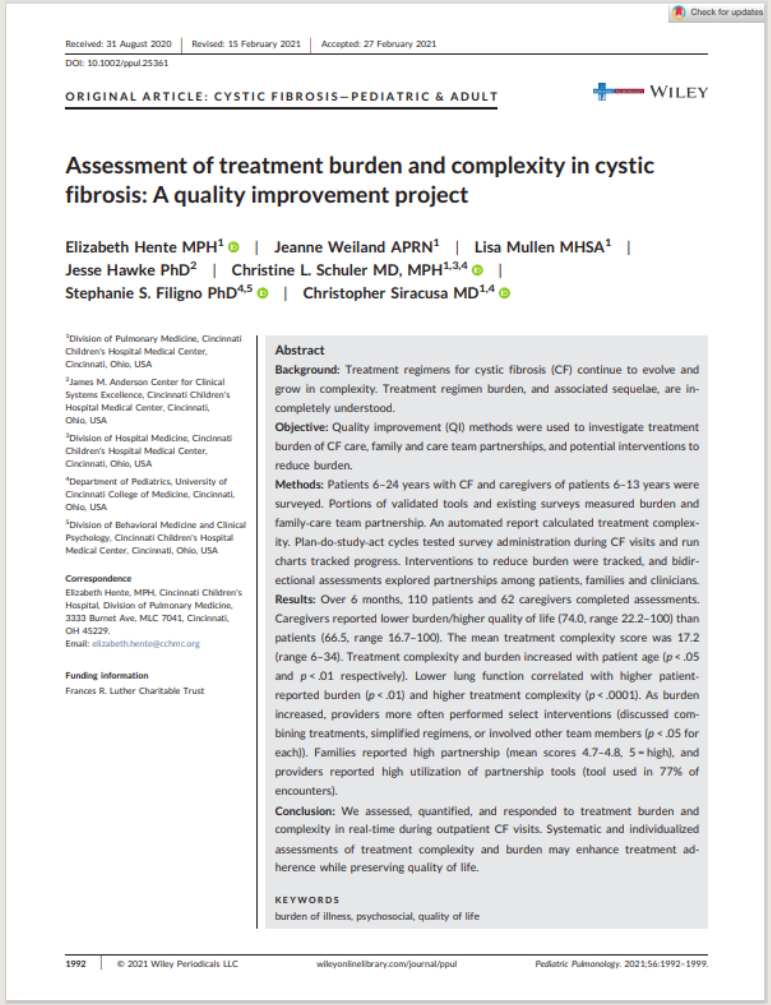
AìCT: adottare azioni per migliorare in modo continuo le prestazionii

Analizzare le cause dei problemi riscontrati e i lati positivi delle azioni intraprese

CHECK: i e misurare i processi e riportarne i risultati

EB

Esempi di applicazione del ciclo di Deming in letteratura



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ORIGINAL ARTICLE: CYSTIC FIBROSIS–PEDIATRIC & ADULT

WILEY

Assessment of treatment burden and complexity in cystic fibrosis: A quality improvement project

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Abstract

Background: Treatment regimens for cystic fibrosis (CF) continue to evolve and grow in complexity. Treatment regimen burden, and associated sequelae, are incompletely understood.

Objective: Quality improvement (QI) methods were used to investigate treatment burden of CF care, family and care team partnerships, and potential interventions to reduce burden.

Methods: Patients 6–24 years with CF and caregivers of patients 6–13 years were surveyed. Portions of validated tools and existing surveys measured burden and family-care team partnership. An automated report calculated treatment complexity. Plan-do-study-act cycles tested survey administration during CF visits and run charts tracked progress. Interventions to reduce burden were tracked, and bidirectional assessments explored partnerships among patients, families and clinicians.

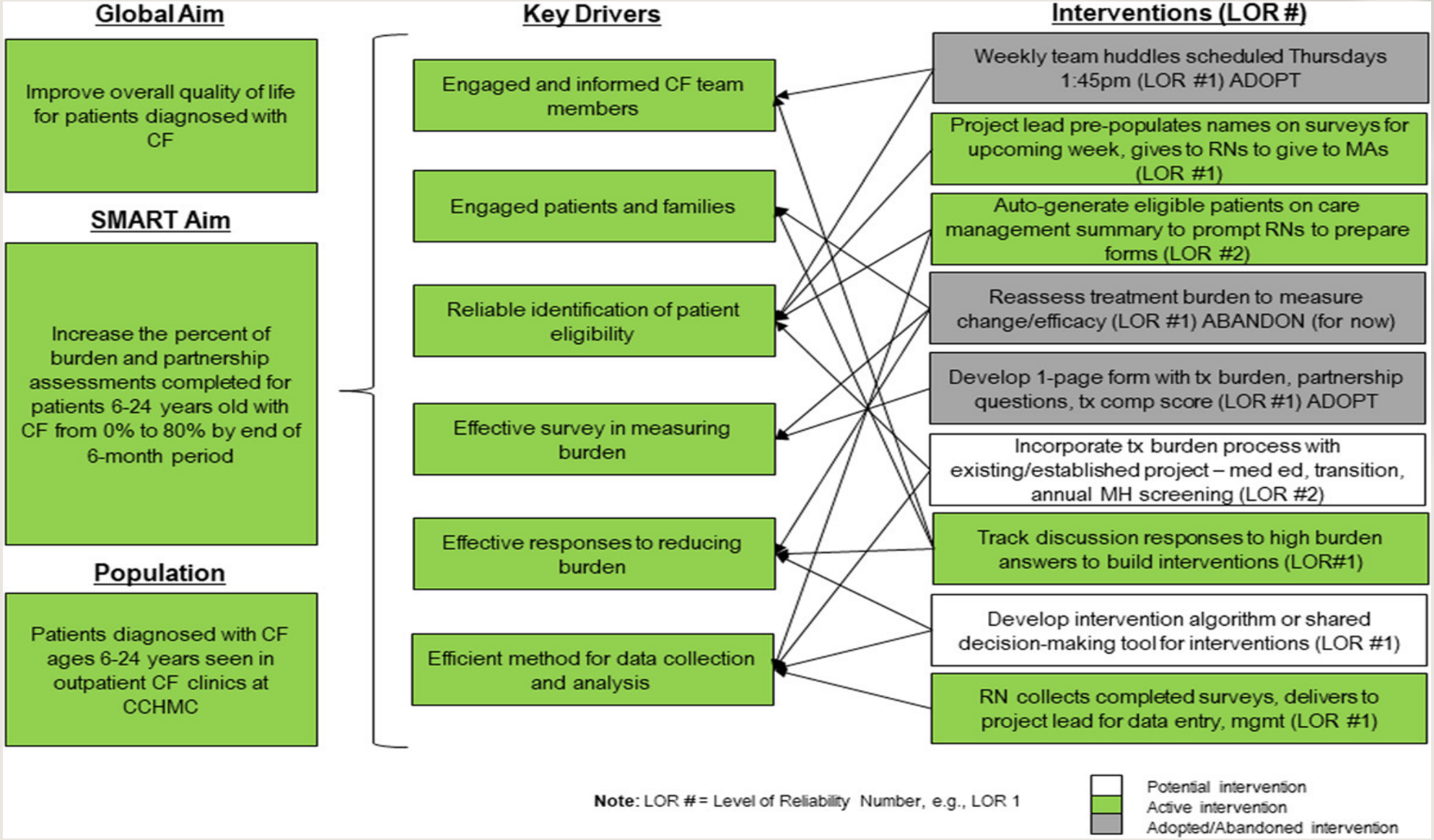
Results: Over 6 months, 110 patients and 62 caregivers completed assessments. Caregivers reported lower burden/higher quality of life (74.0, range 22.2–100) than patients (66.5, range 16.7–100). The mean treatment complexity score was 17.2 (range 6–34). Treatment complexity and burden increased with patient age ($p < .05$ and $p < .01$ respectively). Lower lung function correlated with higher patient-reported burden ($p < .01$) and higher treatment complexity ($p < .0001$). As burden increased, providers more often performed select interventions (discussed combining treatments, simplified regimens, or involved other team members ($p < .05$ for each)). Families reported high partnership (mean scores 4.7–4.8, 5 = high), and providers reported high utilization of partnership tools (tool used in 77% of encounters).

Conclusion: We assessed, quantified, and responded to treatment burden and complexity in real-time during outpatient CF visits. Systematic and individualized assessments of treatment complexity and burden may enhance treatment adherence while preserving quality of life.

KEYWORDS
burden of illness, psychosocial, quality of life

- Assessment of treatment burden and complexity in cystic fibrosis: A quality improvement project
- Pediatric CF Center at Cincinnati Children's Hospital : 250 pazienti
- CFQ-R

110 pts 6-24 anni e 62 caregiver dei pts 6-13 aa in 6 mesi



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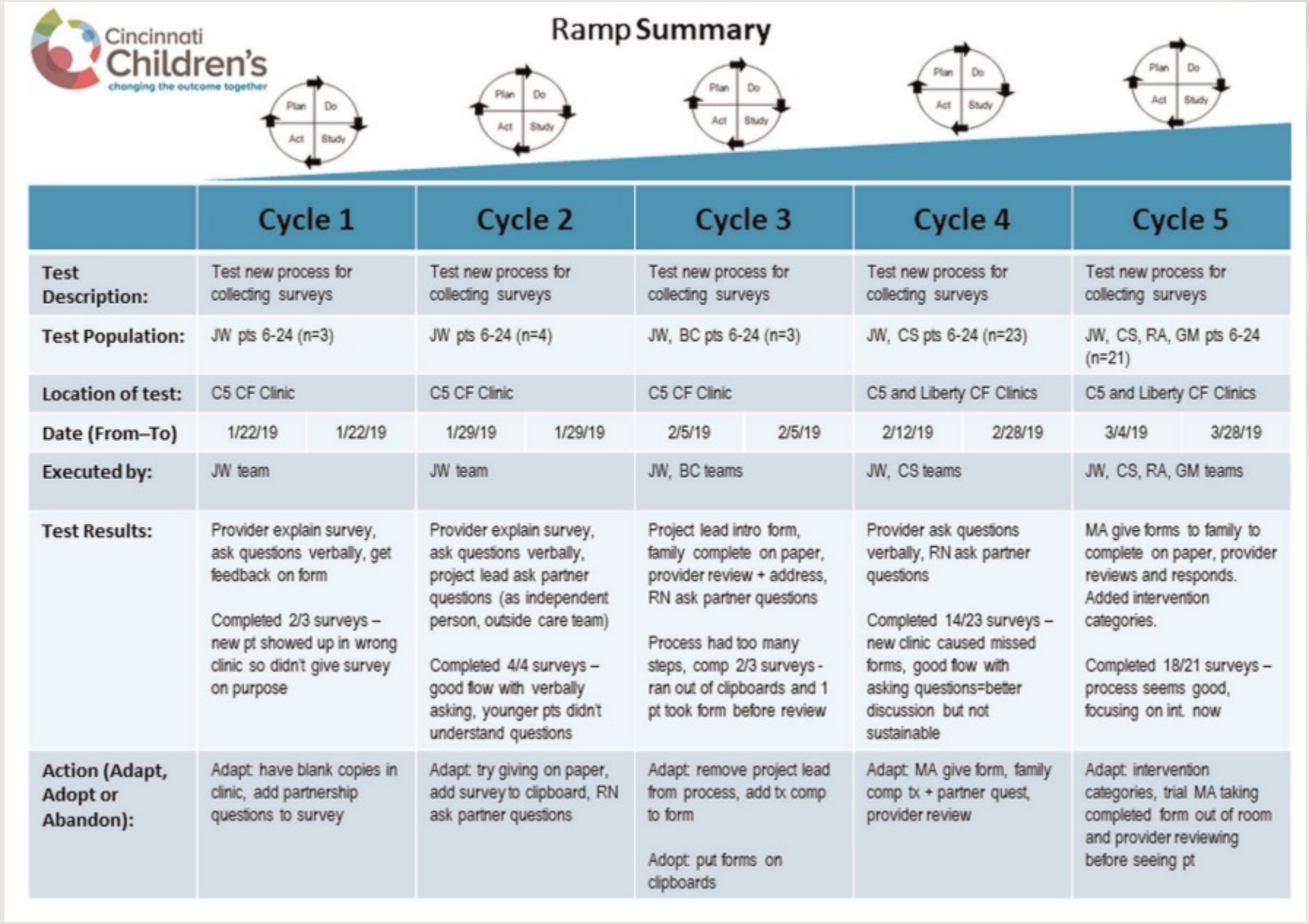

	Cycle 1	Cycle 2	Cycle 3	Cycle 4	Cycle 5
Test Description:	Test new process for collecting surveys	Test new process for collecting surveys	Test new process for collecting surveys	Test new process for collecting surveys	Test new process for collecting surveys
Test Population:	JW pts 6-24 (n=3)	JW pts 6-24 (n=4)	JW, BC pts 6-24 (n=3)	JW, CS pts 6-24 (n=23)	JW, CS, RA, GM pts 6-24 (n=21)
Location of test:	C5 CF Clinic	C5 CF Clinic	C5 CF Clinic	C5 and Liberty CF Clinics	C5 and Liberty CF Clinics
Date (From–To)	1/22/19 – 1/22/19	1/29/19 – 1/29/19	2/5/19 – 2/5/19	2/12/19 – 2/28/19	3/4/19 – 3/28/19
Executed by:	JW team	JW team	JW, BC teams	JW, CS teams	JW, CS, RA, GM teams
Test Results:	Provider explain survey, ask questions verbally, get feedback on form Completed 2/3 surveys – new pt showed up in wrong clinic so didn't give survey on purpose	Provider explain survey, ask questions verbally, project lead ask partner questions (as independent person, outside care team) Completed 4/4 surveys – good flow with verbally asking, younger pts didn't understand questions	Project lead intro form, family complete on paper, provider review + address, RN ask partner questions Process had too many steps, comp 2/3 surveys - ran out of clipboards and 1 pt took form before review	Provider ask questions verbally, RN ask partner questions Completed 14/23 surveys – new clinic caused missed forms, good flow with asking questions=better discussion but not sustainable	MA give forms to family to complete on paper, provider reviews and responds. Added intervention categories. Completed 18/21 surveys – process seems good, focusing on int. now
Action (Adapt, Adopt or Abandon):	Adapt: have blank copies in clinic, add partnership questions to survey	Adapt: try giving on paper, add survey to clipboard, RN ask partner questions	Adapt: remove project lead from process, add tx comp to form Adopt: put forms on clipboards	Adapt: MA give form, family comp tx + partner quest, provider review	Adapt: intervention categories, trial MA taking completed form out of room and provider reviewing before seeing pt

Hente E, Weiland J, Mullen L, et al. Assessment of treatment burden and complexity in cystic fibrosis: A quality improvement project. Pediatric Pulmonology. 2021;56:1992-1999