

**NACT 2017
INDIANAPOLIS
&
Terzo Circle
of Care
Vertex
&
Milton Park
Laboratori
Vertex**

V° Forum sulla Fibrosi Cistica

Napoli 25-26 Novembre 2017



Marco Magri
Consiglio direttivo
LIFC

Messaggio principale della CFF Foundation:

- OTTIMISMO ed ENTUSIASMO
- Entro 5 anni il 95% delle mutazioni avranno una terapia
- Entro 10 anni il 100% delle mutazioni avranno una terapia

Terapia non vuol dire cura definitiva ma un trattamento specifico

Nuove classificazione delle mutazioni

Man mano che gli studi con i nuovi farmaci avanzano appare evidente che la classificazione delle differenti mutazioni a 6 Classi non è sufficiente a spiegare il difetto funzionale della proteina CFTR

Evoluzione

- Nuovi farmaci e nuovi players si affacciano all'orizzonte
- Nuovi meccanismi di attacco al difetto base vengono proposti
- Forte competizione tra le Aziende

Vertex

- Esiste una certa % di pazienti che evidenzia risultati deludenti con ORKAMBI ma Vrtx sta sviluppando altri farmaci che possono significativamente migliorare la efficacia

Vertex sviluppo

- TEZACAFTOR + IVACAFTOR (Fase III)
- Vx 440 + TEZACAFTOR +IVACAFTOR (Fase II)
- VX 152 + TEZACAFTOR +IVACAFTOR (Fase II)
- Vx 371 + LUMACAFTOR + IVACAFTOR

Galapagos altro attore

Area	Pre-clinical	Ph 1	Ph 2	Ph 3
IPF	'3499	Autotaxin	'1690	
Undisclosed	'2384	GPR84	'1205	
CF	Potentiators	'3067	'2451	'1837
CF	C1	'2851	C1	'2222
CF	C2	'3221	C2	'2737
OA	ADAMTS-5		'1972	
Atopic dermat	'2534	IL-17C	MOR106	
Inflammation	'3121			
	'3312			
Pain	'3535			

 partnered

PROTEOSTASIS

- Propone un ulteriore step nella terapia del difetto di base quello di affiancare al potenziatore e al correttore un AMPLIFICATORE
- Queste nuove molecole hanno un meccanismo differente in pratica aumentano la biosintesi della proteina CFTR
- L'aumento intra cellulare della proteina migliora anche l'efficienza ed il beneficio clinico dei correttori e potenziatori.
- Il vantaggio degli amplificatori è che sono potenzialmente efficaci indipendentemente dalla classe di mutazione

IONIS pharmaceutical

- Oligo nucleotide antisense

Tecnologia target su m RNA dei canali ENAC

Farmaco nasce dall'idea di bloccare la funzionalità dei canali del sodio ENAC inibendone il gene.

Enzimi pancreatici

In USA non sembrano esserci i problemi che abbiamo vissuto in Italia legati alla carenza di Creon. Nuovi enzimi:

- Zenpep
- Pertzye
- Relizorb (terapia enterale)

Sono disponibili come alternativa a Creon. Purtroppo non sembrano essere interessati a rendere disponibili i loro prodotti in UE. Probabilmente perchè l'Italia non è un paese che gli garantisce buoni profitti.

Terapia antibiotica inalatoria

- In USA sono disponibili solo 2 farmaci per via inalatoria:
 - Tobramicina
 - Aztreonam

La Levofloxacinina dovrebbe essere approvata nel 2018.

Purtroppo non sembrano esserci altri farmaci in arrivo per il trattamento dell'infezione cronica da *Pseudomonas a.*

Terapia antibiotica inalatoria

- E' invece in fase III un nuovo farmaco inalatorio per l'infezione cronica da MRSA (Stafilococco aureo meticillino resistente). Questo batterio è di crescente riscontro nell'escreato dei pazienti FC
- Il farmaco contiene Vancomicina in formulazione polvere inalatoria.
- Altre molecole in fase iniziale di studi clinici sono per il trattamento del micobatterio.

Terapia antibiotica inalatoria

- Una forte raccomandazione è stata data circa l'utilizzo di **sistemi inalatori validati** (farmaco+ nebulizzatore)
- I farmaci generici inalatori non sempre danno garanzie di pari efficacia rispetto ai farmaci originali.
- La riduzione della efficacia può essere anche superiore al 30-40%

Iniziativa per la comunità FC

How the Community shapes CF Initiatives

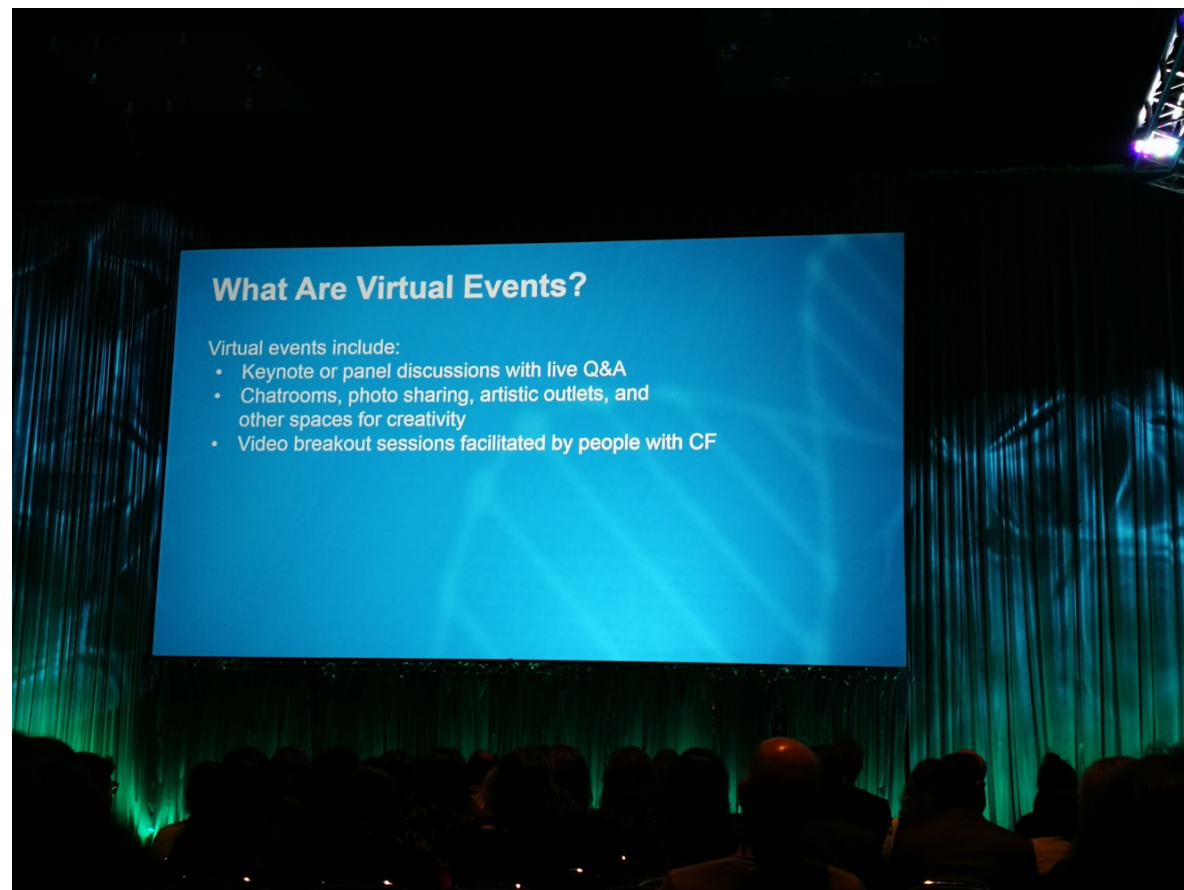
COMMUNITY VOICE
CYSTIC FIBROSIS FOUNDATION

The CF Community shapes our work by providing input on the design, development, and expansion of many CF initiatives, including:

- Adult Advisory Council**
Members of this council inform the Foundation on current topics and recommends strategies that ensure excellent programs
- Virtual Events**
These events are designed for and by adults with CF to create a virtual space to connect, learn, share, and inspire from one another
- Impact Grants**
Provides individuals or organizations up to \$10,000 per year for innovative programs that benefit people with CF and their families
- CF Peer Connect**
A program that provides people with CF the opportunity to connect one-to-one virtually with a peer mentor for topic-based mentoring related to managing life with CF

Community members get involved through surveys, focus groups, committees, and more!

Eventi virtuali per la comunità FC



Advocate - Portavoce (CFF Foundation)

I governi federali e statali svolgono un ruolo fondamentale nella ricerca sulla FC, nello sviluppo di farmaci e nell'accesso per le persone affette da FC di accedere alle cure e alle terapie di cui hanno bisogno.

Stiamo responsabilizzando i membri della comunità CF a parlare di questioni importanti per le persone con fibrosi cistica.

Il nostro obiettivo è quello di aiutare a educare i responsabili politici sui bisogni delle persone affette da FC in modo che prendano decisioni intelligenti sulla ricerca, sul trattamento e sull'accesso alle cure correlate alla

Terzo Circle of Care - Vertex

La LIFC ha avuto finanziato un progetto dal titolo:

Telemonitoraggio per i pazienti in pre e post trapianto polmonare

Si rivolge a 60 pazienti, 20 saranno seguiti dal Centro Trapianti della Lombardia e 40 in altri centri come: Torino, Padova, Firenze e Palermo.

Progetti presenti

I vincitori del bando sono stati 15, i temi trattati variavano dalle APP di video giochi per i bambini, alla raccolta fondi, alla divulgazione dell'informazione sulla malattia, alla formazione di centri medici in paesi meno organizzati, alla transistion care.

Il progetto LIFC è stato molto apprezzato per essere rivolto a chi ne ha più bisogno, per essere innovativo e concreto ed immediatamente fruibile dai pazienti.

Meeting di presentazione - Indianapolis

Lo scorso 13 Novembre, si è svolto un meeting organizzato dalla VERTEX per presentare i progetti e lo stato dell'arte degli stessi.

Ho presentato il progetto durante una piacevole serata che ci ha consentito di rafforzare i rapporti con la VERTEX e con gli altri partner presenti, del mondo economico, medico-scientifico e associativo anche europeo.

Self-monitoring healthcare devices addressed to pre and post transplant CF patients

Objective

Evaluate if self-telemonitoring can be useful for early diagnosis of major adverse events that complicate the course of lung transplant

Assess the impact of telemonitoring on patients' quality of life, pre and post-transplant hospitalization, onset of chronic rejection

Detect multiple vital parameters of the patient at home in the pre-transplantation phase

Avoid the risk of infections for immunodepressed CF patients when attending hospitals for medical checks

Make patients play an active role in the management of their own health

Audience

- 60 CF patients
 - 20 followed by Lombardia Regional Transplant Center
 - 40 followed by other Italian Regional Transplant Center

Parameters Evaluated

- FEV1 and FVC (forced vital capacity)
- Discomfort assessment according to MRC (Medical Research Council)
- SpO2 during programmed maximum physical activity
- Axillary body temperature
- Body weight
- Glycemia; mean and median of daily blood glucose
- Quality of life (self-assessment with St. George's Respiratory Questionnaire SGRQ)

Project Status and Challenges

- The project started in Ospedale Maggiore Policlinico – Milan on 01/09/2017 after the approval of the Ethics Committee. By now the project has 10 patients and 1 physiotherapist to read and analyze the data
- Other National Transplant Centers have been contacted to join the project and involve CF patients: Florence, Palermo and Padua
- The difficulty was starting the project due to the lack of qualified staff who could read and analyze the data. Once equipped with the staff, the project finally started in Ospedale Maggiore Policlinico - Milan

Impact

- After a year from the start up of the project, reports will be produced, based on which the benefits expected will emerge

Next Steps

- Increase the number of patients
- Involve in the project other National Transplant Centers

Devices



NONIN WristOx2 3150



Spirometer Thor Otthon



Home Medical Assistant



Patients interface



LIFC
Lega Italiana
Fibrosi Cistica



Fondazione IRCCS Ca' Granda
Ospedale Maggiore Policlinico



Sistema Socio Sanitario
Regione
Lombardia



LIFC
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Fibrosi Cistica

I progetti vincitori:

1

An Innovative Smartphone App to Enhance Social Connectedness and Support Well-being in Young People Living with CF

Cindy Branch-Smith, PhD¹; Donna Cross, EdD¹; Andre Schultz, PhD^{1,2}; Rebecca Nguyen¹; Jacinta Francis, PhD¹; Liz Balding²; Stephanie Chen³
 1. Telethon Kids Institute, Perth, Australia; 2. Princess Margaret Hospital, Perth, Australia; 3. Monash Children's Hospital, Victoria, Australia

OBJECTIVE

- To develop and pilot a smartphone app that is engaging, usable and helpful to young people living with CF
- To evaluate the acceptability and usability of a smartphone app designed to support social connectedness and well-being

Young people with CF have fewer social interactions and the risk of cross-infection means they're isolated from one another

Smartphone technologies allow young people with CF to stay connected with each other and school peers regardless of location

Frequent hospitalisation
Daily treatments
Treatment side-effects

School absences
School engagement
Social contact & support

Social isolation
Academic achievement
Mental illness

Mental health issues are significantly higher for people living with CF than the general population*

AUDIENCE

- The smartphone app is targeted at young people with CF aged 12 – 17 years
- Study findings will inform practice recommendations and policy guidelines to help CF clinics and organisations across Australia support social connectedness and well-being in young people living with CF

DELIVERABLES

APP DELIVERABLES

- Discovery session - planning key functionality of app, completed 03 October
- Wireframes - mock version of the app, completed 31 October
- Completion of user acceptance testing - final testing and acceptance of app by project team, due 17 January 2018
- Deployment of app - ready for trial, due 06 February 2018

PROJECT DELIVERABLES

- Recruitment December 2017 - January 2018
- Pilot-testing the app February - March 2018
- Administer online survey to evaluate app March - April 2018
- Online group interview (E-summit) April - May 2018
- Data analysis and report writing May - July 2018

IMPACT

FOR YOUNG PEOPLE WITH CF

- Moderated social chat room function may increase young people's health and well-being by forming friendships and support networks with other young people who have CF (or who are experiencing something similar)
- Medication reminders mean young people manage their own medications which may increase autonomy and independence
- Interactive CyFi Buddy asks users how they are feeling, and provides additional tips and uplifting videos, may also positively affect user's well-being
- Young people may feel more supported by their parents & the CF team because they will know how young people are feeling

FOR PARENTS AND THE CF MULTI-DISCIPLINARY TEAM

- The CyFi Buddy communicates with the CF team, so they are more aware of how their patients are feeling before they come to clinic, which means they can communicate more effectively with them
- Parents can feel confident in knowing their child is being supported socially
- Our app is designed to provide parents with peace of mind, given notifications will be sent to them if users do not take their medication or continuously indicate they are experiencing low mood

CHALLENGES

- We need to workshop with young people who can't be in the same room together, but we have successfully conducted e-Summits in the past
- Translating health research through technology requires collaboration across a number of different agencies. We are fortunate to have support from an app developer and also CF Western Australia and CF Victoria, who will help us to promote the app throughout the CF community

IDEAL NEXT STEPS

- Taking the app to commercial production and conducting an efficacy trial to assess whether using the app has a positive effect on social connectedness and well-being
- Ensuring that all young Australians with CF who have a smartphone know about the app by the end of 2018, and eventually to disseminate the app internationally to the young CF community
- Applying the app more widely for young people living with other chronic health conditions

Figure 1: CyFi Spaces Smartphone App

Young people from across Australia at Princess Margaret Hospital (Western Australia) and Monash Children's Hospital (Victoria) will test the app for 6 weeks. The Cystic Fibrosis Associations in each state are involved in promoting the app February-March 2018.

Figure 1: CyFi Spaces Smartphone App

TELETHON KIDS CHILDREN'S HOSPITAL aresta CYSTIC FIBROSIS WESTERN AUSTRALIA

2

Transition to Lung Transplant: Developing National Standards in Canada to Successfully Transition Patients with Cystic Fibrosis

Joanna Williams, MHA, CHE¹; Kate Gent, MN, NP-PHC, CDE²; Cecilia Chaparro, MD³
 1. Cystic Fibrosis Canada, Toronto, Canada; 2. St. Michael's Hospital, Toronto, Canada; 3. University Health Network, Toronto, Canada

Objectives

The collaborators set out to develop a national program to optimize the transition to transplant process and each patient's transplant journey.

The four-tiered program aims to:

- Conduct an environmental scan to understand current challenges and gaps in care
- Develop and host virtual patient and caregiver educational webinars
- Develop and host on-site and virtual workshops for healthcare professionals
- Develop standardized protocols for transplant management in CF clinics

Deliverables

1. Environmental Scan

Feedback was gathered through three independent surveys distributed via Cystic Fibrosis Canada's social media channels, direct to clinics, and direct to patients through clinic distribution lists. Survey results provided insight into current gaps in care and a roadmap for webinar topics. Surveys were completed by:

- 53 Adult Patients
- 6 Transplant Coordinators
- 31 Nurse Coordinators

2. Virtual Patient & Caregiver Educational Webinar Program (In development)

- Webinar 1: Preparing for a Transplant
- Webinar 2: Financial Considerations & Relocation
- Webinar 3: Psychosocial Challenges

3. Virtual Healthcare Provider Webinar Program

- Webinar 1: Overview of Transplant (Speaker: Dr. Cecilia Chaparro)
- Webinar 2: Pharmacy Overview (Speaker: Daniel Cortes)
- Webinar 3: Relocation & Financial Considerations (Speakers: Annie Thomas-Dieman & Laura Middleton)
- Webinar 4: CF-Related Diabetes (Speaker: Kate Gent)
- Webinar 5: Vaccines (Speaker: Kevin Curly)
- Webinar 6: Mental Health (Speaker: Dr. Kien Dang)
- Webinar 7: GI & Liver Disease (Speakers: Dr. Paul Pencharz, Brooke Stewart, & Dr. Tanja Gonska)
- Webinar 8: Infection Control Guidelines (Speaker: Dr. Shahid Husain)
- Webinar 9: Physiotherapy & Exercise (Speakers: Kenneth Wu & Lisa Wickerson)
- Webinar 10: Bone Health (Speaker: Dr. Erin Norris)
- Webinar 11: Sexual Health Issues (Speaker: Dr. Elizabeth Tullis)
- Webinar 12: Paediatric Transplantation (Speaker: Dr. Melinda Soimoon)

4. Development of Standardized Protocols (In development)

Protocols for CF-related issues pre- to post-transplant will be developed based on webinar content and discussions on the following topics after consultation and consensus with the other transplant centers in Canada:

- Cystic Fibrosis-Related Diabetes
- Gastrointestinal Complications
- Vaccines
- Fertility & Pregnancy

Audience

The environmental scan was targeted to:

- Adult (18 years +) post-transplant patients
- Caregivers of paediatric transplant patients
- Lung transplant coordinators at the four Canadian transplant centers
- CF Nurse coordinators from 42 clinic sites

The virtual patient and caregiver educational webinars are targeted towards:

- Post-transplant patients & caregivers

The virtual and on-site workshops for healthcare professionals, and the standardized protocols are targeted towards:

- The lung transplant team
- The CF clinic team

Other groups have expressed interest in the virtual webinars, namely, pre-transplant patients and patients not yet listed for transplant.

Figure 1: Number of Annual Transplants for CF Patients¹

Figure 2: Survey Question: What Was the Most Stressful Aspect of Being on the Transplant List? Selected Patient Responses Include:

The wait – an emotional rollercoaster	The long wait from testing to approval
Not being able to plan anything	Out of pocket costs
Relocating – being away from home and family	Nightmares – not knowing if I would get the lungs in time
Not knowing what to expect	The fear of it going badly
Feeling too sick to exercise but fearful of being removed from the list	Fear of not being ready and declining surgery

Impact

- Survey responses indicated great appreciation from both patients and healthcare providers for a focus on this topic and for the opportunity to engage in the development of the program.
- Based on feedback, a new webpage has been developed on Cystic Fibrosis Canada's website dedicated to the pre- to post-lung transplant transition process. Traffic to this page will be monitored and evaluated at the end of the project.
- Recorded webinars will be made freely available on Cystic Fibrosis Canada's website and will be accessible by the global CF community. Metrics on viewings of recordings will be tracked.
- Post-webinar follow-up surveys will gather feedback from participants on the value of the webinars and opportunities for improvements.

Challenges

Challenges encountered while developing this program included:

- Wait times for translating survey and website content
- Survey participation rates and follow-up reminders, which delayed the development of program content
- Scheduling convenient times to discuss webinar content with the expert speakers and convenient times to host the webinars, given the desire to engage a national audience across multiple time zones

Ideal Next Steps

- Develop a more robust peer mentorship program for patients
- Greater outreach to the French-speaking community
- Global collaboration (LLC QI project) – in progress

References

¹ Cystic Fibrosis Canada (2017). The Canadian Cystic Fibrosis Registry 2016 Annual Report in press

Acknowledgments

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Presented at the 3rd Annual Circle of Care Colloquium, Indianapolis, IN, USA, November 1, 2017

Marco Magri, Consiglio direttivo LIFC, V Forum FC Napoli

I progetti vincitori:

3

Simplification of CF-Related Diabetes Screening by the Use of a Home-Based Oral Glucose Tolerance Test (OGTT): A Pilot Study to Evaluate Validity and Patients' Perceptions (AtHome)

Marjolaine Mailhot, RD, MSc¹; Valérie Boudreau, RD, PhD cand²; Katherine Desjardins, RD, MSc²; Martin Ladouceur, PhD³; François Tremblay, MD, MSc²; Rémi Rabasa-Lherot, MD, PhD^{1,2}

¹ Centre hospitalier de l'Université de Montréal (CHUM), Montreal, Canada; ² Montreal Central Research Institute (IRCM), Montreal, Canada; ³ Ecole de santé publique, Université de Montréal, Montreal, Canada

Objective
We propose a pilot study to evaluate the diagnosis performance of a simplified home-based OGTT to screen for CF-related diabetes (CFRD) in a population of patients with CF, we will compare results obtained from the:

- Standard hospital-based OGTT with measures of plasma glucose and the use of 75 g glucose beverage
- Home-based OGTT with measures of glucose with continuous glucose monitoring system (CGMS) and capillary blood glucose (BG) and the 75 g glucose beverage
- Home-based OGTT with measures of glucose (CGMS and capillary BG) and 75 g of glucose from candies

We believe that a simplified version of the OGTT would be more attractive, would make it more acceptable for patients and has the potential to improve their adherence to screening tests, simplify CF-team works and reduce costs.

Audience

- We are recruiting adult patients with CF without known diabetes to participate into this pilot study (n=20).
- We can take advantage of our large screening program for diabetes (over 200 CF patients included with at least 90 OGTT each year).
- Inclusion criteria are: adult CF-patient without known diabetes, in stable condition at least 1 month apart from the last exacerbation.
- Exclusion criteria are: known CFRD, recent exacerbation, pregnancy, cancer, transplantation and use medications known to interfere with glucose metabolism such as oral steroids.
- A multicenter project including pediatric patients will be conducted after this pilot study.

Deliverables

- The project was accepted by our research ethic committee in September 2017.
- Patients' recruitment is ongoing.
- Expected date of completion of study: June 2017

Study Protocol and Data Collection

Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	...	Day 14
Cystic Fibrosis Clinic Standard-OGTT with plasma glucose values Questionnaires (acceptability) CGMS training and installation Medical history retrieved from medical chart			At home Home-based OGTT with measures of glucose with CGMS and capillary BG Patient should follow standardized conditions		At home Home-based OGTT with measures of glucose with CGMS and capillary BG Patient should follow standardized conditions		End of study participation CGMS removed by the patient at home and send back to the study team for data compilation	

One home-based OGTT performed with 75g glucose from candies and the other one with the 75g glucose beverage; random order.

Challenges

- It is difficult to recruit patients for studies requiring participants' high involvement.
- We are limited with the low number of person with CF without known CFRD at our center.

Impact

We know that the OGTT is associated to several frustrations in patients:

- Blood samples are not appreciated;
- The OGTT must be integrated into many other test, appointments and complex medical;
- The standard beverage is not well tolerated by some patients;
- For health care teams, it may be difficult to set up an effective diabetes screening system. Material costs and time are not negligible.

We hope to increase patients' acceptance of the test and ultimately patients' adherence to this screening test. CGM system will also provide many real-time blood glucose data which will allow us to better understand glycemic excursions in CF.

Challenges

- We would like to recruit other centers to participate in a validation study.
- A larger number of patients is considered and on a longer period.
- Pediatric population will be considered.

Ideal Next Steps

- We would like to recruit other centers to participate in a validation study.
- A larger number of patients is considered and on a longer period.
- Pediatric population will be considered.

Image 1: Abbott Flash Libre Continuous Glucose Monitoring System

This CGM device is painless and can be installed easily by patients themselves.

It reads glucose value every 15 minutes for 14 days.

References

1. Shewell K et al. *Respir Health*. 2015; 10: 1-10.
2. Brodeur V et al. *Can J Diabetes*. 2016; 40(1): 66-70.

Author Disclosures
The authors have nothing to disclose.

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4

Improving education and support for CF patients using (a) virtual online support groups and (b) targeted frequent exacerbation care (education, mental health care, symptom diaries & home spirometry)

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¹ Adult CF Program, University of Virginia Health System, Charlottesville, Virginia

Objective

- Establish a first-in-kind virtual support group for CF patients using telemedicine platform
- Improve care for patients with frequent exacerbations, particularly in the transition from hospital to home

Audience

We have designed online support groups to target the needs of 3 separate adult patient populations:

- Stable patients
- Patients with frequent exacerbations
- Young adult patients who use exercise as ACT

Patients with frequent exacerbations requiring IV antibiotics 3 or more times per year are the target for our education / discharge interventions.

Deliverables

New and novel online platform for CF education and support

- Ability for CF patients to engage with each other in a safe and supportive online environment
- Sessions designed and targeted at unique issues important for each patient population
- Moderated by their healthcare team

A new frequent exacerbation plan of care that includes:

- Education on IV therapy, inhaled therapies, airway clearance
- Mental health assessments
- Home spirometry and symptom diaries
- Frequent contact with health care team

Impact

- Establish online discussion groups as a viable method of education, support, and engagement for CF patients (and families)
- Allow CF patients to safely share their ideas and/or concerns
- Improve and standardize exacerbation care with the goal of decreasing rates of exacerbation for at-risk population

Support Group Design

- 6 sessions for each patient group
- 5-10 patients per group, by invitation only
- Use of the BlueJeans video conferencing platform which is mobile-device friendly
- Support from UVA Telemedicine program
- Inclusion of a patient "moderator" to encourage open dialogue, inclusion, & engagement
- Multiple team members serving as facilitators
- Post-completion survey to assess effectiveness, areas for improvement

Strengths

- Strong motivational telemedicine program with history of using similar platform for patient care
- Diverse team member engagement, perspectives
- Team members trained in motivational interviewing, effective group facilitating, QI
- Established exacerbation protocol with significant % of patients returning to baseline FEV1 (below)

Challenges

- Patient discomfort with the unknown re: online support group
- Busy adult patient population with job and family demands
- Technological hurdles, availability of University telemedicine support staff
- Access to home spirometers, insurance barriers
- Time to implement these processes
- New staff onboarding, training

Next Steps

- Recruit the next round of support group participants
- Use of video conferencing platform for diverse aspects of CF education, care
- Improve access to home spirometry to enable earlier intervention during exacerbations
- Continue to monitor outcomes of exacerbation interventions, improve educational program

Key Components of the Protocol:

- In-hospital (or in-clinic) education re: managing IV therapy, augmentation of CF specific therapies during illness
- Home symptom diary
- Home spirometer (Spiro PD) to monitor FEV1 at least 2x weekly
- Follow up phone call at least once weekly for the duration of therapy
- Short term (2-3 week) follow-up visit in clinic
- Mental health screening during and post-exacerbation with interventions (counseling, pharmacologic) as indicated
- Patient experience of care surveys for inpatient and outpatient management

Stable Patient Group Planned Curriculum:

Session	Topic	Facilitator
1	Introduction, Personality Colors	Physician
2	Co-Production of Care	CF Parent, QI Leader
3	Lifestyle / Behavior Change Process	Nutritionist
4	Time Management	Physician
5	Mental Health Care	Social Worker
6	CF Therapies	Physician

Frequent Exacerbation Protocol

Goals of this intervention:

- Decrease rate of exacerbations in select patients,
- Improve patient experience, and
- Improve co-production and patient involvement in care through symptom tracking and home spirometry

Discharge
Patients are being trained to decrease and have no formal involvement with providers when they return to the hospital.

Acknowledgments
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I progetti vincitori:

MOBILE Device Utilisation Lifting Adherence and Treatment Engagement in Cystic Fibrosis (MODULATE-CF) 5

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 1. Prince Charles Hospital Adult CF Centre, Queensland, Australia; 2. University of Queensland, Queensland, Australia; 3. Supporters of 65 Roses Inc, Queensland, Australia

The Problem

As survival in CF has improved, treatment complexity has increased and patients ability to complete prescribed treatments has decreased, with estimates that CF patients complete less than half of their prescribed physical and medication therapies.
 Regular engagement with a specialist CF centre result in better outcomes, however, patients living in remote locations, do not have easy access to specialist care^{1,2}. This challenge is most keenly felt in Australia where patients may reside 1000s of kilometres from a specialist CF Centre.

Objective

1. Develop, determine the uptake and evaluate the impact of a CF specific educational website and parallel health tracking web application, upon CF patient knowledge and adherence to maintenance therapies.
2. Develop a web based education portal that will improve knowledge and confidence in delivering CF care by non-CF specialist HCPs in regional Queensland hospitals distant from specialist CF centre.

Audience

Initial Target audiences

- Adults under the care Prince Charles Hospital Adult CF Centre – Positive results will lead to rollout to adult and paediatric centres nationally and internationally
- Health care professional who do not have specialist knowledge of delivering CF Care

Impact

This project has brought together the combined knowledge and experience of university based specialists in delivering online health, an Adult CF Centre with an international reputation for producing research outcomes and a pro-active patient advocacy group, with a focus on improving the lives of patients living in regional areas. The collaboration aims to deliver powerful online resources to improve the delivery of healthcare to patients by CF living distant to specialist care and increase patient adherence with treatment, through improvement in knowledge and empowering self-ownership of their disease management. It is envisaged that the use of the tools developed will result in improved health outcome, especially in the most isolated and vulnerable patient groups.

Study Design

Patient and Healthcare professionals questionnaires inform the development of educational and health tracking websites

Challenges

Local, institutional ethics and governance issues resulted in unanticipated delays in project commencement. However, these issues are now resolved and it is anticipated the project progression will gather momentum in coming months

Ideal Next Steps

Final educational and health tracking web application development and consumer feedback from patients living in regional centres, before providing access to patients willing to submit their usage data for research purposes

Acknowledgements

The MODULATE-CF Collaborator group comprise a dedicated group of health professionals with a high level of expertise in their fields and who are crucial to the development of quality educational materials and critical to the success of this project

School of Online Health:
Development of website, health professional educational tools and Health tracking web application

The University of Queensland

Prince Charles Hospital Adult CF Centre:
Patient and health care practitioner recruitment, questionnaire development and deployment. Study oversight.

Supporters of 65 Roses Inc:
Patient engagement in regional Queensland to develop resources that are suitable for patients living distant to specialist care

Deliverables

2017	March 2017	September 2017	November 2017	May 2017	June
Study Concept, Design, Funding	Ethics and Institutional Governance Approval	Subject Recruitment and Pre-Rollout Questionnaires	Website Design and deployment	Post-Rollout Questionnaires and Usage Analysis	Determination of clinical utility and future support

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Self-monitoring healthcare devices addressed to pre and post-transplant CF patients 6

Marco Magri, Governing Council, Lega Italiana Fibrosi Cistica Onlus - Rome, Italy

Objective

- Evaluate if self-monitoring can be useful for early diagnosis of major adverse events that complicate the course of lung transplantation
- Assess the impact of telemonitoring on patients' quality of life, pre and post-transplant hospitalisation, onset of chronic rejection
- Detect multiple vital parameters of the patient at home in the pre-transplantation phase
- Avoid the risk of infections for immunosuppressed CF patients when attending hospitals for medical checks
- Make patients play an active role in the management of their own health

Audience

- 60 CF patients
 - 20 followed by Lombardia Regional Transplant Center
 - 40 followed by other Italian Regional Transplant Center

Parameters Evaluated

- FEV1 and FVC (forced vital capacity)
- Discomfort assessment according to MRC (Medical Research Council)
- SpO2 during programmed maximum physical activity
- Axillary body temperature
- Body weight
- Glycaemia: mean and median of daily blood glucose
- Quality of life (self-assessment with St. George's Respiratory Questionnaire SGRQ)

Project Status and Challenges

- The project started in Ospedale Maggiore Policlinico - Milan on 01/09/2017 after the approval of the Ethics Committee. By now the project has 10 patients enrolled and 1 physiotherapist enrolled to read and analyze the data
- Other National Transplant Centers have been contacted to join the project and involve CF patients: Florence, Palermo and Padova
- The difficulty was starting the project due to the lack of qualified staff who could read and analyze the data. Once equipped with the staff, the project finally started in Ospedale Maggiore Policlinico - Milan

Impact

- After a year from the enrollment in the project, reports will be produced, based on which the benefits expected will emerge

Next Steps

- Increase the number of patients enrolled
- Involve in the project other National Transplant Centers

Devices

NONIN WristOx 3150
Spirometer Thor Othom
Home Medical Assistant
Patients interface

LIFC
Lega Italiana
Fibrosi Cistica

Fondazione IRCCS Ospedale Maggiore Policlinico
Regione Lombardia

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Marco Magri, Consiglio direttivo LIFC, V Forum FC Napoli

I progetti vincitori:

Cystic Fibrosis Trust **ADULT ROYAL CYSTIC FIBROSIS HOSPITAL CENTRE LONDON** **cysticfibrosis.org.uk** **7**

Delivering High Quality End of Life Care to People with Cystic Fibrosis

Su Mudge¹, Fiona Colthart², Nick Medhurst¹
¹ Royal Brompton Hospital, London, United Kingdom; ² Cystic Fibrosis Trust, London, United Kingdom

Objective
 Despite increases of improvement in the prognosis for people living with cystic fibrosis (CF), it is a condition that continues to cut lives short. In 2010, out of 16,461 registered on the UK CF Registry, 148 people with CF died in the UK, with a median age of just 31 years. Deaths in CF remain hard to predict and although sudden death is rare it can be shocking, not just for bereaved loved ones but also for CF healthcare professionals.

Our goal is to improve the experience of care at the end of life for people with cystic fibrosis. Recognising the benefit of preparing for care at the end of someone's life and their death, our project aims to ensure that people with CF and their caregivers have the opportunity, skills, resources and confidence to make informed choices about treatment and care and aware of their options at the end of life.

Audience
 Our project has three audiences: people with CF, their loved and CF healthcare professionals.

The vital role that specialist teams play in facilitating discussions about end-of-life care is self-evident. However, in CF a lack of tailored training, recognised documentation and confusion in the roles of the ACP and palliative care professionals can be significant barriers to delivering optimum advance care planning and end-of-life care.

Deliverables

Advanced Care Plan

1. An online standardised, CF-specific Advance Care Plan (ACP) template for everyone with CF and all CF clinical teams
2. Guidance notes for completing the ACP, providing structure and documentation for conversations
3. Delivered by a multi-professional group of experts covering:
 - End-of-life care
 - Palliative care, symptom control and pain management
 - Transplantation
 - Advance care planning

Training Programmes

1. An accredited, multi-module online training programme aiming to bridge gaps in training and provide CF-specific strategies for education and service development – relevant to all specialists working in CF, regardless of experience and profession
2. Freely accessible via the Cystic Fibrosis Trust website and the dedicated CF portal
3. Delivered by a multi-professional group of experts covering:
 - End-of-life care
 - Palliative care, symptom control and pain management
 - Transplantation
 - Advance care planning

Feedback from users of the ACP so far has included:

- "It's brilliant having it done by someone who has performed the same tasks as I do."
- "It's brilliant having it done by someone who has performed the same tasks as I do."
- "The form is really easy to use and it was helpful to have it done by someone who has performed the same tasks as I do."
- "The form is really easy to use and it was helpful to have it done by someone who has performed the same tasks as I do."

The work has led RBHT to create:

- Dedicated space for the ACP on Electronic Patient Records, available to all staff
- Dedicated open meetings every two months to discuss end-of-life issues
- Training for professionals using the ACP, including communication skills
- Six monthly follow-up discussions with patients

Impact
 The impact of both the ACP and the training programme will be broad based – transforming care teams across the country with the documentation and training to support it. The success of the online training programme will provide an opportunity to further extend the impact, including the Cystic Fibrosis Trust's practice guidance by end-of-life planning (<http://www.cysticfibrosis.org.uk/files/with-cystic-fibrosis-advance-care-plan-for-end-of-life>).

Ideal Next Steps
 We plan significant promotion of the ACP materials to the end of 2017 and beyond – formalising care teams across the country with the documentation and training to support it. The success of the online training programme will provide an opportunity to further extend the impact, including the Cystic Fibrosis Trust's practice guidance by end-of-life planning (<http://www.cysticfibrosis.org.uk/files/with-cystic-fibrosis-advance-care-plan-for-end-of-life>).

Author Disclosures
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 Nick Medhurst: None. There are no direct or indirect financial interests.

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 Elizabeth Hester for improving the writing, alongside the Royal Brompton Hospital, the CF Trust and the wider project and the experts who supported the work of the ACP document. Special thanks to the Cystic Fibrosis Trust, Cystic Fibrosis Trust website and the Cystic Fibrosis Trust, Cystic Fibrosis Trust website and the Cystic Fibrosis Trust.

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#WILLPOWERDONORS. Social Awareness Campaign against Sedentary Lifestyle **8**

Juan Antonio Da Silva Irago, vice president of Spanish Federation of Cystic Fibrosis, Valencia, Spain.

Objective
 To improve the quality of life of children and young people affected by Cystic Fibrosis through the awareness of the significance of physical exercise and healthy habits in the struggle against sedentary lifestyle.

Recommendations to maintain and improve health indicate that children should accumulate a minimum of 60 minutes of moderate or vigorous physical activity per day. According to a scientific study carried out by Spanish researchers in 2014, only 34% of healthy children meet the minimum recommendations for physical activity while children affected by Cystic Fibrosis who meet these recommendations only reach 2%.

Impact

- The campaign was launched on the 5th October and many CF patients have joint and sent their sport videos with the hashtag #Willpowerdonors.
- Only two media outlets have published the news so far.
- The campaign has a broad acceptance in the social profiles of the Spanish Federation of Cystic Fibrosis since the spot of the campaign has been shared on Facebook 600 times and has been viewed 120000 times in a week.

Challenges

- The start of the campaign was delayed since the project exceeded by far the work efforts anticipated by the organizers.
- The campaign reached less interest on media than expected. The organizers consider that this is due to the fact that mass media are focused on other relevant issues in the country, especially political campaigns and events which have overloaded media and social networks.

Deliverables

- The premise from which our campaign #Willpowerdonors: People with Cystic Fibrosis undergo a daily routine that could rival the training routine of elite athletes: daily respiratory physiotherapy, diets, sprays, medication, hospital visits... And now also physical exercise, is included in treatment. CF patients should be seen as the driving force because of the daily efforts. Often CF patients have the will power that healthy people lack.
- We shot a spot: <https://youtu.be/H4DqeF3YLNQ>, that has been shared on social networks. And a campaign website: www.donantesdeganas.com.
- We shot a spot: <https://youtu.be/H4DqeF3YLNQ>, that has been shared on social networks. And a campaign website: www.donantesdeganas.com.
- Creation of social profiles of the campaign and dissemination in social networks involving infant and young CF patients, publishing their sport videos and stories of improvement.
- We are currently publicizing the campaign through mass median trying to raise awareness and interest.

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#DONANTESDEGANAS

Audience

- Children and youth with Cystic Fibrosis
- Population with sedentary lifestyle

Ideal Next Steps

- Our goal to extend the campaign and join more people with CF.
- We would like to expand it so that healthy people (not affected by CF) could also join the campaign by sending their videos, explaining how they have managed to gain will power.
- A good idea would be to export this campaign to other Cystic Fibrosis associations from different countries, adapting it to their language and environment.

Marco Magri, Consiglio direttivo LIFC, V Forum FC Napoli

I progetti vincitori:

CF Circle of Care / PREMs and PROMs to Evaluate Online Support

John Wilson, MD PhD, Janet Wei-Phyllis, RN BSN MBA, Suzanne Concanan, Denise Clark, RN, Leanne Habesh, Chris Ryan, Karin Koozeck, Alfred Health, Melbourne, Australia; 2 Cystic Fibrosis Victoria, Melbourne, Australia

Objective

- Establish a CF advisory group using telemedicine
- Facilitate technical use of video-conferencing for the group
- Introduce USB spirometers for home use
- Develop a nurse co-ordinator role for home monitoring

Audience

- Adult CF patients capable of using telemedicine
- Advantage provided for those in rural areas or unable to attend clinic

Deliverables

- Introduce home spirometry for video consultations ✓
- Develop feedback measures for patient outcomes and experience ✓
- Road-test instruments for evaluation of video consults and meetings ✓

Impact

- Improve patient satisfaction
- Reduce risk of cross infection
- Improve access to care, reduce patient costs and monitor more effectively
- Reduce burden on clinic facility

Challenges

- Gaining acceptance of technology by patients and staff
- Integration of telehealth into workflow
- Integrating spirometry results into the EHR
- Convincing staff of validity of patient recordings

Ideal Next Steps

- Introduce remote model of care to enable well patients to be monitored at home and have investigations done locally
- Enable annual / bi-annual reviews at the CF centre to reduce patient resource demand and cross infection risk
- Evaluate outcome and experience measures of change in model

Patient reported outcome measure PROM

The outcome measure has been successfully used both in a) studies and b) clinical care, taking less than 30sec to complete.

Patient reported experience measure PREM

We conducted a survey of needs and satisfaction to determine the major domains of patient experience in all areas of care, including home, telemedicine, ED, wards and clinics (Figure 2).

Figure 1: The AwScore® correlates well with the CFQ-R™ and is easy to administer on paper of using online survey tools.

Figure 3: The home spirometer, used in video consultations.

Figure 4: The home spirometer, results used in patient's record.

Summary

Major challenges in CF today include access to care, optimization of digital technology, infection control and development of novel patient interface strategies. In previous work we reported on the use of telemedicine and home-monitoring programs(1-3). The use of PROMs has been reported to focus care and improve patient satisfaction(4). We have developed a CF specific Patient Reported Outcome Measure that has greater utility than more detailed instruments(5, 6). This project will use these measures to qualify outcomes and experiences of CF patients using telemedicine and remote spirometry for clinical care.

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BENCHMARKING IN CZECH CF CENTRES Preparation Stage

Jindřich Jirák¹; Simona Záborská²; Anna Arellanesová³

Klub nemocných cystickou fibrózou, z.s. (Czech Cystic Fibrosis Association - CCFA), Prague, Czech Republic

Objective

- CF Association (CCFA) in Czech Republic
- No feasibility of quality of care across all CFC
- Minimal interval of state healthcare system

Number of patients

	Children	Adults	Total
No. CF patients	304	318	622

Note: largest CFC in Prague - MOTOL (54% patients)

Project targets

- Set up process of evaluation and comparison of care quality
- Improve level of care for our CF patients

Audience

- CF patients and their families (influence quality of their lives)
- Health professionals and care takers in the Czech CFC
- Other CF patient organizations – to be shared (Middle and Eastern Europe)

Deliverables

Process description – methodology taken over from Dutch CF patient organization (NCFs) and tailor made to Czech environment

Issues

- On Site Audits in CFC – check sheet, physical check
- Patient SW questionnaire – set of questions, trigger, SW, data analysis
- Czech CF Register– KPIs, analyze correlation with our data

Deliverables (Output):

- CF Evaluation – interpretation of collected data, report
- Benchmark all Czech CFC – comparison, feedback

Project Schedule

2018

Month	Activity	Status
4	Kick-off	Completed
5	Cooperation foreign CFC	Completed
6	CZ CF Register application	In Progress
7	Benchmark methodology	In Progress
8	SW Questionnaire	In Progress
9	Regular progress meetings, involved experts from various fields	In Progress
10	Regular progress meetings, involved experts from various fields	In Progress
11	Regular progress meetings, involved experts from various fields	In Progress
12	Regular progress meetings, involved experts from various fields	In Progress
1	Trial	Planned
2	Trial	Planned
3	Project Assessment	Planned

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Author Disclosures

Jirák J, Záborská S, Arellanesová A. Patient response to the introduction of telemedicine and home spirometry. *Cystic Fibrosis*. 2013;21(2):121-127.

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Marco Magri, Consiglio direttivo LIFC, V Forum FC Napoli

I progetti vincitori:

11

RESPIRATORY THERAPY PROGRAM AT HOME

IN RURAL GALICIA

JUAN ANTONIO DA SILVA RAGO - PRESIDENT OF GALICIAN ASSOCIATION OF CYSTIC FIBROSIS - GALICIA - SPAIN

GENERAL OBJECTIVES

- Minimise the complications caused by the illness.
- Improve the quality of life of the people with Cystic Fibrosis.
- Increase their functional capacities.
- Assist the people within the rural community with Cystic Fibrosis with their main difficulties of access to the services.

AUDIENCE

The program is intended for all people with Cystic Fibrosis in the rural community of Galicia, once the program had started and having given it the necessary publicity, people who did not know the association contacted us to access the program consequently because of that the number of beneficiaries increases progressively. Before we started the program we attended 150 people and at this moment we are approaching 200 people growing gradually over time.

IMPACT

Conducting physiotherapy sessions at home in the rural community reaching each and every place where they require it.



3 internationally validated questionnaires were used to obtain the results associated with quality of life.

- the SF-36
- ST George's respiratory questionnaire
- The revised Cystic Fibrosis questionnaire

OBJECTIVE

SPECIFIC OBJECTIVES

- Inform, assess and teach the parents and the person affected the theory of the respiratory physiotherapy enabling its correct execution.
- Raise awareness of the importance of the treatment and of its preventative effectiveness with regards to future infections in bronchial cavity of the secretions caused by Cystic Fibrosis, helping to understand it, accept it and so achieving that it will be carried out regularly.
- Adapt the implementation of different techniques of physiotherapy according to the personal necessities and pathological development of each individual.
- Generate the habit to carry out daily the physiotherapy treatment in the patients with Cystic Fibrosis.

DELIVERABLES

At this moment the two physiotherapists who attend Galicia are performing sessions of physiotherapy to people with Cystic Fibrosis at least once a week, the results achieved are very satisfactory since there were people who did not perform their physiotherapy daily and thanks to the program it is getting control and adherence.

CHALLENGES

The main problem we encountered was hiring one of the physiotherapists as there are no physiotherapists with experience and sufficient training in respiratory physiotherapy.

IDEAL NEXT STEPS

In the future we would focus on encouraging sports and physical activity in people with Cystic Fibrosis by creating a training plan that would be carried out by the physiotherapist.

NUMBER SESSION/USER



2015: 7 (only 5 months)
2017: 20 (only 5 months)

NUMBER OF SESSIONS



2016: 157
2017: 480 (only 5 months)

At first, a reduction in the complications of the disease and an increase of adherence to treatment are perceived.

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CF 4 Kids

A Game to Develop Coping Skills in Children Living With Cystic Fibrosis

PAULINE FLORES - MEd, PhD, MEd, PhD, PhD
Cystic Fibrosis Research Institute, University of Colorado Colorado Springs, Colorado, USA

Objective

Parents of young children with CF have limited time and resources to support their children with CF. There is a lack of support for these children, who are often seen as the "invisible" children.

The CF 4 Kids game is designed to help children with CF understand and cope with their illness. The game is designed to be played with a parent or caregiver. The game is designed to be played with a parent or caregiver. The game is designed to be played with a parent or caregiver.

Audience

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

Deliverables

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

Impact

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

Stage Two

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

Challenges

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

Ideal Next Steps

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

The Game

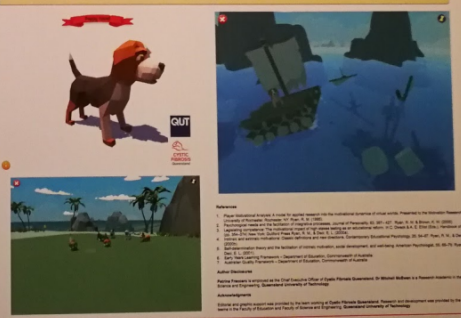
Player Choices, Gameplay Achievements, Social Features

Psychological Needs

Autonomy, Competence, Relatedness, Self-Determination Theory

EYLF Objectives

Wellbeing and Resilience, Sense of Identity, Sense of Empathy, Sense of Connection



Challenges

The CF 4 Kids game is designed to be played with children living with CF between 4 and 10 years old. The game is designed to be played with children living with CF between 4 and 10 years old.

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I progetti vincitori:

Anticipatory Guidance Tools to Facilitate Successful Transitions in Care

13

Laik Buzza, MD, Sophie Stanger, BA, Jamie Miller, LISW, Susan Moore, LISW, Stephanie Filgro, PhD, Nikki Orskov, MA, Ginger Browning, RRT, Elizabeth Heric, MPH, Thomas Boat, MD, Lisa Mullen, MHA, Inga Baudzyte, Joanne Welland, CNP
Cincinnati Children's Hospital Medical Center, Cincinnati, OH, United States

Objective

- Develop anticipatory guidance tools to prepare caregivers and their children to successfully transition by addressing developmental milestones related to CF care
- Empower patients to learn essential self-management skills
- Help patients to become more active participants in the transition process throughout the life course and to teach caregivers how to help their children achieve this goal

Audience

- Children from birth to 21 years and their caregivers
- Healthcare providers helping to teach caregivers and patients

Impact

- Most caregivers liked having this additional CF specific guidance that they cannot obtain from their pediatrician
- Tools sparked conversations on topics that may not have been brought up otherwise and provided an opportunity to provide additional educational materials
- Facilitates co-production between various providers, caregivers, and patients
- Empowers families to bring up topics and/or concerns that may not be routinely addressed in a typical CF clinic visit
- Provides clinical team insight into what topics matter to the families

Deliverables

Challenges

- Establishing team buy-in on the importance of these topics as we ask teams to spend more time in clinic reviewing information
- Developing materials that is general enough to apply to most families and specific enough to be useful
- Keeping our education materials at an appropriate reading level
- Multiple competing initiatives
- Identifying most appropriate provider and time to introduce the tools
- Impact on clinic flow
- Balancing the priority of the caregivers vs. providers
- Ensuring supporting resources are readily available to address each topic/issue

Ideal Next Steps

- Address the challenges identified with Anticipatory Guidance
- Continue refining the knowledge scenarios
- Create assessments to allow healthcare providers to have a conversation with patients using the Knowledge Scenarios
- Develop a process to track areas that need further education and which topics are well known to the caregivers and patients

Acknowledgments

Tools created are the result of a multidisciplinary team effort with input from our entire CF team including Jackie Taylor, RD, Kathy Santos, RD, Theresa O'Hara, RN, Monica Chapman, RN, Gae Davina, RN, Denise Lambert, RN, Kara Foster, Kelly Byers, PhD, John P. Garay, MD, Christopher Strassus, MD and finally the caregivers who participated in our focus group.

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Exercise Grant Collaboration

14

Objective

Provide grants for athletic activities between 4 organizations with organically developing missions - Supporting active lifestyles for people with CF through direct aid, and overcoming cost barriers to exercise. Through this collaboration, we become the

Audience

The cystic fibrosis community, including people with CF, their families and support systems. The collaboration has the ability to provide grants across the nation.

Deliverables

- Data Tracking Demographics | FEV1 scores | travel/expense applications | activity type | duration | response rates
- *Communication
- *Collaborative Sponsorships

Data

58 grants awarded
23 states represented
Age range 2-57 years (Average age 22.5)
Average FEV1 67.625%

Challenges

Meeting the needs of the adult CF population | Financial limitations of our organizations | How to track usage rates

Exercise

Improves lung function, mental health, and community engagement.

Physical Activity

is an essential tool in managing and fighting CF.

Lincoln | 2 | MFCF

Lincoln is a very active little boy and loves to run and play. We would love to add swimming to his routine. Swimming will be beneficial to our son's lung function and overall safety.

Kamea | 6 | CFLF

Kamea participated in a swim with me at CFLF and wanted gymnastics offered her. She is a strong and fit determined little girl who never complains about what she has to do. Kamea has built strength and has an active passion for all her treatments and requires close to her's not safe to her gymnastics program.

Jessika | 23 | CDBF

CDBF recently began supporting the amount of miles during a sport hike. found self-confidence, passion, and friendships in snowboarding and roller derby have significantly helped my health, and neither would be possible without this amazing support.

Mark | 22 | Coach Ed

Mark has always been my wife's best friend. He has been a stress reliever and my best friend ever since we met. With Coach Ed's help, I was able to get up on my feet after a long day and his presence was the only thing that kept me going.

Activities: Swimming lessons, Surfing lessons, Sports team/league, Fitness classes, Rock climbing lessons, Yoga classes, Dance classes, Gym membership, Summer camp, Horseback riding, Martial arts classes, Skateboard/park.

Stato dell'arte del progetto LIFC

Attualmente sono stati individuati circa 10 pazienti seguiti dal Centro Trapianti della Lombardia.

La maggiore difficoltà che abbiamo incontrato è trovare personale qualificato per monitorare i dati. Attualmente è stato impiegato un fisioterapista a Milano.

Passi successivi

Identificare nuovi pazienti e nuovo personale qualificato.

Dopo un anno dall'avvio del progetto (settembre 2017) si potranno analizzare i risultati ottenuti attraverso la realizzazione di report.

Vertex Innovation Forum - Milton Park 20/11

La LIFC è stata invitata a partecipare al meeting che si legge nel titolo.

Sono stato al meeting che si è svolto presso i laboratori di Ricerca della Vertex in Europa a Milton Park - Abingdon, Oxfordshire (UK)

L'obiettivo del meeting è stato il confronto fra diversi e qualificati player del settore al fine di identificare nuove strategie e prodotti per la cura delle Fibrosi Cistica.

Alcune foto di Milton Park



Marco Magrì, Consiglio direttivo LIFC, V Forum FC Napoli

Alcune foto di Milton Park



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Grazie a tutti per l'attenzione.....e

Avanti e veloci !



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