TeCC (Telemedicine, Coronavirus, Cystic-fibrosis) Study

Cork Experience

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 I have received honoraria and speaker fees from Novartis, Gilead, Chiesi and Vertex Pharmaceuticals

• Nobody has ever given me a smartphone or iWatch !!!

Virtual Monitoring not new



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Using digital technology increasing in CF



igure 1 Publications relating to the use of digital technology in cystic fibrosis over the last 20 years.

Calthorpe, R.J., Smith, S., Gathercole, K. and Smyth, A.R., 2020. Using digital technology for home monitoring, adherence and self-management in cystic fibrosis: a state-of-the-art review. *Thorax*, *75*(1), pp.72-77.

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Its not a new as you think...

	A the area	Veeu	
litie	Authors	Year	Journal
Compliance measures for home monitoring in cystic fibrosis.	Stanley M. et al.	1984	Annual international conference of the IEEE engineering in medicine and biology - proceedings
Home monitoring in cystic fibrosis: a model program.	S. M. Finkelstein, et al.	1985	IEEE/engineering in medicine and biology society annual conference
Feasibility and compliance studies of a home measurement monitoring program for cystic fibrosis	S M finkelstein, et al.	1986	Journal of chronic disease
A home-based pulmonary function monitor for cystic fibrosis.	E K Shultz et al.	1988	Journal of medical instrumentation
Implementation of a home-based program for early detection of clinical deterioration in cystic fibrosis.	L J Brown-Ewing et al.	1988	Journal of medical instrumentation
Monitor: an expert system that validates and interprets time- dependent partial data based on a cystic fibrosis home monitoring program.	J R Slagle, et al.	1989	IEEE transactions on biomedical engineering
The impact of home monitoring and daily diary recording on patient status in cystic fibrosis.	S M finkelstein et al.	1992	Pediatric pulmonology



Its not a new as you think...





Recent significant activity...

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Focus	Title	Authors	Year	Journal
Pharmacy:	Virtual medication tours with a pharmacist as part of a cystic fibrosis telehealth visit.	Nicole Warda BS, Shannon M. Rotolo PharmD	2021	Journal of the American Pharmacists Association
Psychology/Mental Health	Act via telehealth: acceptance-based behavioral therapy for anxiety and depression among individuals with cystic fibrosis	C Virginia O'Hayer 1 , Caitlin M O'Loughlin 2 , Chelsi N Nurse 3 , Patrick J Smith 4 , Michael J Stephen 5	2017	Journal of Cystic Fibrosis
Dietetics/Nutrition	Web-based intervention for nutritional management in cystic fibrosis: development, usability, and pilot trial	Lori J. Stark, PhD, Lisa Opipari-Arrigan, PhD, Stephanie S. Filigno, PhD, Stacey L. Simon, PhD, Amanda Leonard, MPH, RD/LD, Peter J. Mogayzel, MD, PhD, Joseph Rausch, PhD, Cynthia Zion, BS, Scott W. Powers, PhD	2016	Journal of Pediatric Psychology
Physiotherapy (CyFiT & Fizzyo)	Cyfit telehealth: protocol for a randomised controlled trial of an online outpatient physiotherapy service for children with cystic fibrosis.	Lang, Ray Lei, Christine Wilson, Kellie Stockton, Trevor Russell, and Leanne Marie Johnston	2019	BMC Pulmonary Medicine
	Protocol for project fizzyo, an analytic longitudinal observational cohort study of physiotherapy for children and young people with cystic fibrosis, with interrupted time-series design.	Raywood, E., Douglas, H., Kapoor, K., Filipow, N., Murray, N., O'Connor, R., Stott, L., Saul, G., Kuzhagaliyev, T., Davies, G. and Liakhovich, O.	2020	BMJ Open
Exercise (Steps Ahead & Tai Chi)	Steps ahead: optimising physical activity in adults with cystic fibrosis: study protocol for a pilot randomised trial using wearable technology, goal setting and text message feedback.	Curran, M., Tierney, A.C., Collins, L., Kennedy, L., McDonnell, C., Jurascheck, A.J., Sheikhi, A., Walsh, C., Button, B., Galvin, R. and Casserly, B	2020	HRB Open Research
	Learning to breathe with tai chi online-qualitative data from a randomized controlled feasibility study of patients with cystic fibrosis	Ronan, P., Mian, A., Carr, S.B., Madge, S.L., Lorenc, A. and Robinson, N.	2021	European journal of integrative medicine
Pulmo. Exacerbation Detection (eICE & Project Breathe)	Home monitoring of patients with cystic fibrosis to identify and treat acute pulmonary exacerbations. Eice study results.	Noah Lechtzin, Nicole Mayer-Hamblett, Natalie E. West, Sarah Allgood, Ellen Wilhelm, Umer Khan, Moira L. Aitken, Bonnie W. Ramsey, Michael P. Boyle , Peter J. Morazyel Jr., Ronald L. Gibson, David Orenstein, Carlos Milla, John P. Clancy, Veena Antony, and Christopher H. Goss; <u>https://royalpapworth.nhs.uk/our-hospital/latest-</u>	2016	American Journal of Respiratory and Critical Care Medicine
	Project breathe at royal papworth hospital	news/cloud-based-health-monitoring-cystic-fibrosis- covid-19		
Medication Adherence (CFHealthHub)	professional support to increase adherence to nebulizer treatments in adults with cystic fibrosis: qualitative interview study	Drabble, Sarah J., Alicia O'Cathain, Alexander J. Scott, Madelynne A. Arden, Samuel Keating, Marlene Hutchings, Chin Maguire, and Martin Wildman	2020	Journal of Medical Internet Research
Virtual Clinics (there are many due to Covid)	Tecc (telemedicine, cystic fibrosis, corona-virus) study in a previous telemedicine-naive centre; clinical challenges, outcomes, and user experience in the first six months of a global pandemic.	David Morrissy, Tamara Vagg, Mairead McCarthy, James Dorgan, Claire Fleming, Ciara Howlett, Joseph A Eustace, Barry J. Plant	2021	ECFS Poster

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Do we want it?

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DIGITAL RESPIRATORY MEDICINE - REALISM v FUTURISM A digital health summit of the ERS Keynote speaker Professor Martin Cowie. (head of the ESC Digital Health Committee).

"Be part of the conversation,

the future is not something passive that we are moving towards,

it is something we can co-create"

"Often people who were the most resistant,

become the most involved and enthusiastic

once they can see the benefit"

Covid- March 2020

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- In the USA, 154% increase in the number of telehealth clinics in the last week of March 2020 compared to March 2019
- Koonin LM, Hoots B, Tsang CA, et al. Trends in the use of telehealth during the emergence of the COVID-19 pandemic: United States, January–March 2020. Morb Mortal Wkly Rep 2020; 69:1595.
- Images taken from: https://www.sportireland.ie/news/coronavirus-covid-19 https://www.pfizer.ie/covid-19-updates https://www.sportireland.ie/news/coronavirus-covid-19 https://www.irishtimes.com/news/ireland/irish-news/covid-19-updates 19-a-further-56-deaths-and-574-new-cases-recorded-by-nphet-this-evening-1.4493950

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Tecc (telemedicine, cystic fibrosis, corona-virus) STUDY

PREVIOUS TELEMEDICINE-NAIVE CENTRE

Delleve

• COVID PACK



Figure 1: Covid Pack equipment + image of telemedicine software

Assess what patients and staff thought about it....

Troubleshooting

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TeCC Study: Participants

Response Rate	
Number of patients who attended a Virtual Clinic	95
Number of Patients who consented to participate	80
Response rate (%)	84.2

Demographics	
Age	Mean (31.2), Std Dev (9.13), Range (18-68)
Sex (%Male)	61.3 (n=49)
Genotype (% DelF508/DelF508)	60 (n=48)
CFTR Modulator (5)	66.25 (n=53)
Transplant Status % (Lung/Liver)	7.5 (n=6)

- 80 patients and 11 staff members agreed to partake in study
- 6 patients (3m/3f) and 5 staff members (nurse, clinician x2, dietician, physio) were interviewed



- Patients and staff regarded the system as highly usable
- (System Usability Score): *Highest possible score = 100*

	80 Patients	11 Staff Members
Mean SUS Score	82.33	83.86
Global Percentile Rank %	88	97
Global Classification (Percentile)	А	А
Adjective (Raw SUS)	Excellent	Excellent



Tecc (telemedicine, cystic fibrosis, corona-virus) Study
<u>PATIENTS & STAFF like it!</u>
User experience results

TUQ (Telehealth Usability Score) .: The system received **a score of >6 out of 7** from both patients and staff in the *Scale 1(disagree)-7(agree), Highest possible value is 7*

	80 Patients		11 Staff	
Variable	Median	Range	Median	Range
Usefulness (3Qs)	6.33	1.33-7	7	3.33-7
Ease of Use & Learnability (3Qs)	6.66	2-7	7	4.66-7
Interface Quality (4Qs)	6.5	2.5-7	6	4-7
Interaction Quality (4Qs)	6.75	2.5-7	6	4-7
Reliability (3Qs)	5.16	1-7	5	2.33-7
Satisfaction and Future Use (4Qs)	6.75	2-7	6.25	5-7
TUQ Total Score (mean of all 21 qs medians)	6.40		6.19	



TeCC: IT Familiarity is important

Both staff and patients use technology daily and would have high IT familiarity

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• 1=Daily Use -2 = Seldom Use -3 = Never Use

	80 Patients	11 Staff Members
IT Familiarity Score Average of all Qs Medians	1.125	1



TeCC: Qualitative Survey designed by MDT

Select Questions and Patient Responses

What did you like least about using the Remote Clinic / TeleMedicineSystem?	What did you like most about the Remote/Clinic/TeleMedicineSystem?	
Only got the link through text, maybe if I got an email so I could access the call easier on my laptop through email.	Not having to travel	
Some technical difficulties (connection, audio, logging in)	Pretty easy to use	
Personal Connection	Just that it enabled clinics to happen, otherwise given the pandemic they would not have if the system was not available, and I would not be able to talk to my doctors and nurses easily	
Couldn't explain some problems to doctor as I would at clinic	Not having to travel and not being in a hospital environment risking getting infection and the communication was 99% the same as in person, great idea and should be the most of clinic appts apart from when you need to be in person for tests or to be seen physically every 6 months etc	
Nothing		
The music in the background		
No physical check up		







Semi-structured interviews. Following the deductive thematic analysis, and similar to the custom qualitative survey, several expected themes emerged (such as the benefits to reduced travel and implementation during a pandemic). However six novel and key themes also emerged

- 1. Technical Issues the need for support:
- 2. Pre-Established Relationships the impact this has on telehealth success
- 3. Telehealth formality and its impact of sharing of health concerns, and the social experience
- 4. Telehealth informality and its impact on clinic control
- 5. Harnessing wait times to improve experience
- 6. Telehealth and the future A hybrid approach

Interview Data: Affordances of Telehealth vs Traditional communication portals

Feature	Phone	TeleMedicine	Physical Clinic
Physical Examination	no	no	yes
Eyeballing a patient	no	yes	yes
Ability to see secretions	no	yes	yes
To see home setup +monitor home devices	no	yes	no
Collect samples	no	no	yes
Quick + easy access to communicate with MDT	yes	yes	no
Ability to assess emotional health and look for other cues	no	Yes (some disagreement)	yes
Relaxed/informal environment	no	Yes (some disagreement) (similar to home visits)	no
Informal chat to support rapport	no	Yes but not as good as physical clinic	yes
Personal Connection	no	Yes but not as good as physical clinic	yes
Long wait times	no	Mixed but mostly no (shorter than clinic)	yes
Patient Engagement	no	Yes (but if technical issues patient will dis- engage)	yes
Call backs (could not complete clinic) [incomplete assessment]	yes	yes	No (everything completed in clinic)

TeCC Study: Conclusion

• In a previously telemedicine naïve clinic, the first 6 month data are positive for the remote clinic as a first default during the pandemic.

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- Preliminary data are positive for the usability and acceptance by all stakeholders, but it is not a replacement for physical clinics.
- High acceptance rates of the custom remote clinic may be reflective of
 - 1. the local MDT input into the design of the remote clinic,
 - 2. the necessity for an alternative safe approach during the pandemic
 - 3. patient and staff IT familiarity scores
- Future Directions A Hybrid Model. Our data would support the integration of Telemedicine in CF Care during the Covid Pandemic, and it's continued use after the pandemic via a Hybrid Model.

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REVIEW



Telehealth and virtual health monitoring in cystic fibrosis

Tamara Vagg^{a,b,c}, Shivanthan Shanthikumar^{d,e,f}, David Morrissy^{a,b,c}, Wendy W. Chapman⁹, Barry J. Plant^{a,b,c}, and Sarath Ranganathan^{d,e,f}

Purpose of review

At many institutions, the Covid-19 pandemic made it necessary to rapidly change the way services are provided to patients, including those with cystic fibrosis (CF). The purpose of this review is to explore the past, present and future of telehealth and virtual monitoring in CF and to highlight certain challenges/ considerations in developing such services.

Recent findings

The Covid-19 pandemic has proven that telehealth and virtual monitoring are a feasible means for safely providing services to CF patients when traditional care is not possible. However, both telehealth and virtual monitoring can also provide further support in the future in a post-covid era through a hybrid-model incorporating traditional care, remote data collection and sophisticated platforms to manage and share data with CF teams.

Summary

We provide a detailed overview of telehealth and virtual monitoring including examples of how paediatric and adult CF services adapted to the need for rapid change. Such services have proven popular with people with CF meaning that co-design with stakeholders will likely improve systems further. In the future, telehealth and virtual monitoring will become more sophisticated by harnessing increasingly powerful technologies such as artificial intelligence, connected monitoring devices and wearables. In this review, we harmonise definitions and terminologies before highlighting considerations and limitations for the future of telehealth and virtual monitoring in CF.

Keywords

cystic fibrosis, digital health, telehealth, telemedicine, virtual monitoring

Current element of CF care	Potential implementation of virtual monitoring and telehealth	Potential benefits for all stakeholders	Limitations	Potential future adaptations
Multidisciplinary Clinic Visit •CF Physician •Dietetics •Physiotherapy •Nursing •Pharma •Psychology	Telehealth Consult [34] [31]	Less travel and interruption to daily life, less cross infection risk, high patient and family acceptability	No physical examination; barriers to those with low access to technology, unknown if telehealth consults result in equivalent, superior or inferior outcomes. There may be different impact on outcomes for different members of MDT (<i>i.e</i> some may find it more useful than others)	Mix of in-person and telehealth consult, use of devices such as digital stethoscopes to replicate physical examination of chest
Multidisciplinary Discussion	Teleconferencing Platform (Zoom, Microsoft Teams <i>etc.</i>)	More flexibility for staff, safer during a pandemic	Additional requirement and cost for portable encrypted hardware for staff, such as laptop with microphone and webcam. Interface with booking systems and hospital medical records; need access to radiology and ability to request pathology and drugs	Potential for "Work From Home" setups where staff are supplied with a laptop that connects to a docking station with external monitor, mouse, and keyboard for easy transition between home and hospital working
Spirometry	Home Spirometry [33]	Less travel for families, increased frequency of assessment	Quality of assessment (infrequent calibration of equipment, unsupervised vs. supervised testing by lung function scientist). Inability to assess lung volumes, lung clearance index and cardiopulmonary exercise tests	Frequent testing with artificial intelligence enabled result analysis to detect the earliest signs of a pulmonary exacerbation; Digitally enabled models of care that support diverse types of communication between provider team and patients/carers
Sputum microbiology	Collection of Samples at Home [34] [37]	More convenient for some people with CF, potentially allow for more frequent assessment	Testing of samples in laboratories unfamiliar with culturing CF samples, collection of samples from non-expectorating people with CF, safety of transporting biospecimens, delay in results being sent or available to CF team	Novel diagnostic methods such as point of care testing may remove need for samples to be transported to laboratories with CF-specific expertise, improved connectivity and integration of services to allow efficient transfer of results to CF team
Anthropometric Measurement	Weight and Height Assessment at Home [34]	More convenient for some people with CF, potentially allow for more frequent assessment	Accuracy of assessment, access to equipment for those that cannot afford it	Automated, standards-based integration of data in electronic medical record systems
Airway Clearance Review with Physiotherapist/ Respiratory Therapist	Telehealth Consult [48]	Less travel and interruption to daily life, less cross infection risk	Less information gained from manual assessment, harder to trouble shoot equipment and technique. Inadequacy of assessment of exercise tolerance	Mix of in-person and telehealth consult, the use of 'Smart' airway clearance devices that provide feedback on technique
Investigations (blood tests, radiology)	Perform locally rather than at CF centre	Less travel and interruption to daily life, less cross infection risk	Tests may not be optimized for performance in people with CF (<i>i.e.</i> chest CT protocol), delay in transfer of results to CF team	Identification of which tests are suitable to be performed locally, improved connectivity to allow results to be easily accessed by CF team
Inpatient Admissions	Hospital in the Home	Less travel and interruption to daily life, less cross infection risk, improved well-being and mental health, less family and sibling disruption	Not suitable for all patients, not available in all settings	Digitally enabled models of care that support diverse types of communication between provider team and patients/carers
Patient and family education	Telehealth Education or Education Feedback Loops Into Virtual Monitoring	Programmes of education at important times, such as at diagnosis, school entry, transition and so on are easy to deliver. Link feedback with education for example during virtual monitoring of therapies such as airway Clearance	Reduced non-verbal communication may impact quality of education and understanding	Techniques to improve online communications embedded into to software and platforms
Cross – Infection/Infection Control	Home based care	Eliminates cross infection risk. May be especially beneficial in centres experiencing clonal spread of multi drug resistant organisms	Limits social interaction with MDT	Use media to enhance, not just social but medical connectivity to replace the "in person" relationships with care team and other members of CF Community; enhance peer-to-peer networks and support
Sweat Test	Specific Wearable Device for Sweat Testing ("Sweat Sticker") [49]	More convenient for some people; ability for home based CFTR function monitoring in specific situations	Limited assessment/Real word evidence	May allow sweat testing to be used to assess real world response to CFTR modulators, with identification of patients with elevated sweat chloride despite being on modulators which may represent drug-drug interaction reducing modulator efficacy, non- adherence, and insufficient fat intake with modulators etc.
Clinical Trials	Remote Trial Methods (Home visits, electronic consent, telehealth assessments, home delivery of study drug, <i>etc.</i>) [50]	Less travel and interruption to daily life, less cross infection risk, less barriers to participation in clinical trials	Reduced in-person assessment may result in delayed identification of serious adverse events	Holistic trial outcome measures that are assessed outside of hospital; Increased rigorous assessment of new models of care based on virtual monitoring





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