

A narrative review of digital health literacy within cystic fibrosis telehealth: are we considering it?

Tamara Vagg^{1,2,3}^, Sarah Twohig¹, Kevin F. Deasy^{1,2,3}^, Hisham I. S. Ibrahim^{1,2,3}^, Barry J. Plant^{1,2,3}^

¹Cork Centre for Cystic Fibrosis (3CF), Adult CF Unit, Ambulatory Care, Cork University Hospital, University College Cork, Cork, Ireland; ²The HRB Funded Clinical Research Facility, University College Cork, Cork, Ireland; ³Department of Medicine, University College Cork, Cork, Ireland *Contributions*: (I) Conception and design: T Vagg, BJ Plant; (II) Administrative support: T Vagg; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: All authors; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Dr. Tamara Vagg, PhD. Cork Centre for Cystic Fibrosis (3CF), Adult CF Unit, Ambulatory Care, Cork University Hospital, University College Cork, Wilton Road, Wilton, Cork T12 DC4A, Ireland; The HRB Funded Clinical Research Facility, University College Cork, Cork, Ireland; Department of Medicine, University College Cork, Cork, Ireland. Email: Tamara.vagg@ucc.ie.

Background and Objective: With the increased adoption of digital health solutions, such as telehealth, there is a need to consider current practices and considerations towards digital health Literacy. The objective of this review is to explore what digital health literacy considerations have been detailed in cystic fibrosis telehealth papers.

Methods: The found papers published from a recent systematic review exploring telehealth within cystic fibrosis care were taken and analysed. These papers were obtained from PubMed, Web of Science, and Scopus databases and included any paper written in English up to May 2021. Data pertaining to Health Literacy, Digital Literacy/Competency, Digital Health Literacy, Training, Readiness Assessments, and Sustained Use were extrapolated using Elicit AI Research Assistant 2024.

Key Content and Findings: From the 26 papers, the data of interest was sparse and mostly unavailable for this review. This may be due to several reasons; however the implication of this mitigation is discussed with reference to the digital divide, health in-equalities, and safety.

Conclusions: This review highlights that a structured approach to assess digital health literacy of care teams and people with cystic fibrosis is critical to the future success of safe telehealth use, and other digital health solutions.

Keywords: Digital health literacy; cystic fibrosis; telehealth; digital competency; health literacy

Received: 27 September 2024; Accepted: 16 January 2025; Published online: 21 March 2025.

doi: 10.21037/mhealth-24-66

View this article at: https://dx.doi.org/10.21037/mhealth-24-66

Introduction

Background

Digital health technologies and solutions are constantly proliferating and evolving to address many gaps in healthcare and to support access to safe quality of care for many patients (1). In addition to this, these digital health solutions can provide opportunities for patients to become more active participants in their own care or care of family members, which is considered to be a key component to effective treatment of some chronic conditions as it can enhance shared decision making (2). However, for this to be fully realised, patients need health literacy skills coupled with digital literacy/competency skills (3). This literacy

[^] ORCID: Tamara Vagg, 0000-0002-6582-2975; Kevin F. Deasy, 0000-0002-1685-249X; Hisham I. S. Ibrahim, 0000-0001-6538-7785; Barry J. Plant, 0000-0002-4611-6768.

Page 2 of 11 mHealth, 2025

combination is commonly being referred to as "Digital Health Literacy", however the components necessary to form this literacy has not been fully finalised, and similar to other challenges with terminology and definitions within this space, is contextual and can change over time.

Health literacy is generally understood to be the ability for an individual to seek out, appraise, and use/communicate health information (4). However, in some areas, health literacy is far more detailed and has a reliance on other literacies such as information, numeracy, and scientific literacy before being fully understood.

Digital Literacy, independent of health literacy, is again where many disciplines and sectors have wrestled with inconsistent definitions or skills. For some, it is regarded as digital skills which are necessary for a specific task, such as participating in education, or to fulfil a working role (5). To address and harmonise this space as well as supporting the digital skills of the general population, the European Commission have released a Digital Competency Framework for Citizens. The latest framework, DigComp 2.2 (6) as released in 2022, aims to support the digital skills required for learning, working and participating in society and has expanded to include more recent technological developments such as artificial intelligence (AI) literacy, data literacy, and remote working. The five main components of the DigComp 2.2 framework include problem solving, Information and data literacy, communication and collaboration, digital content creation, and safety (6).

Digital health literacy, which should represent the unifying of these two literacies into a set of distinct competencies, is still currently being explored by the research community. For many the eHealth Lily literacy model published in 2006 by Norman *et al.* (7) is often described as a digital health literacy model and consists of six components focusing on analytic skills, and context-specific skills. These components include, traditional literacy and numeracy, media literacy, information literacy, health literacy, computer literacy, and science literacy. This eHealth Lily Literacy model also has a survey instrument consisting of eight questions which can be used to assess eHealth literacy amongst patients, with all questions focusing on skills needed for "on the internet" (7).

When comparing the eHealth literacy lily model to the DigComp 2.2 framework, there is an overlap of literacies, but there are also distinct areas not being captured within the eHealth model. For example, safety and wellbeing. Additionally, the eHealth literacy model focuses on what, at-the-time was the largest focal point of the eHealth sector,

online/internet technologies. However, when considering the length and breadth of digital health solutions and technologies available, such as mobile health (mHealth), wearable devices, implantable devices, shared electronic patient records, virtual reality, remote monitoring devices, telehealth, telemedicine, AI powered solutions, and much more, the eHealth literacy model does not capture what is available.

When comparing the three literacy models, all the components of health literacy are encompassed in the eHealth literacy model, and all components of the eHealth literacy model are included (in some parts more generally) within the DigComp 2.2 framework. Showing a natural progression and evolution of this space. To note, the DigComp 2.2 framework does not focus on a specific information domain (such as health, media, or science) and instead includes the same skillset for all domains: information seeking, appraisal, and use/communication. These domain overlaps can be seen in *Figure 1*.

It should also be stated that digital health literacy skills are not unique to patients and the public alone, and these skills are also needed amongst medical and healthcare professionals to support their patients and to implement digital health solutions within their own clinical setting. The need for digital health literacy is ever increasing, and a lack of digital health literacy has been identified in many healthcare areas as a contributor to the digital divide (8), whereby patients/public are unintentionally excluded as they lack the skills, technology, or infrastructure to partake. This is further exacerbated with common misconceptions, such as "digital natives"; generations of individuals who have grown up surrounded by technology and therefore already have the necessary digital skills and knowledge (9). Or even the "grey divide" (10), again the misconception that older adults (>60 years old) are unlikely to engage with technology due to a lack of digital skills, access to devices, or an unwillingness.

Rationale and knowledge gap

As digital health solutions become more ubiquitous with common healthcare practice, there is a need for a standardised approach (11) to screen the readiness (12) of our healthcare teams and patients before implementing a new digital health solution. Likewise, if there is a knowledge gap, training and educational resources should be provided to empower all stakeholders and improve confidence and potential sustained use.

mHealth, 2025 Page 3 of 11

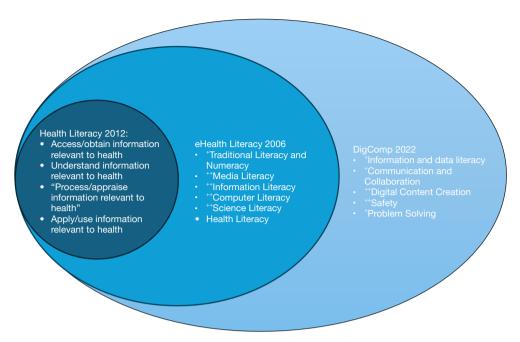


Figure 1 Health literacy is clearly defined and has its own components. eHealth literacy includes health literacy, it builds upon components (+) and adds new components (++). Digital competency is much broader and is about all information seeking behaviours. It builds upon the previous two literacies (+) and adds new components (++).

Objective

The aim of this review is to explore the current digital health literacy considerations being used as part of digital health solutions. To do this, papers identified in a systematic review published in 2023 in the area of telehealth within cystic fibrosis (CF) care will be explored to see if digital health literacy was considered and what resources were provided to support patients and healthcare professionals (13).

Cystic fibrosis is a genetic multi-system chronic condition. Telehealth for the sake of this review follows the definition as set out by the European CF Society (ECFS) telehealth for CF care working group (14); telehealth can provide safe access to care and education by using synchronous communication via communication technology. Within CF, telehealth has been explored for different care delivery solutions for many years. Due to the advent of highly effective modulator therapy (HEMT), the prognosis for many people with CF (PwCF) is changing and life expectancy is increasing. Consequently, other forms of care delivery such as telehealth are being explored in CF centers globally to meet these changing needs. We present this article in accordance with the Narrative Review reporting checklist (available at https://mhealth.amegroups. com/article/view/10.21037/mhealth-24-66/rc).

Methods

To explore digital health literacy considerations within the area of CF telehealth, the papers found from the most recent systematic review (13) in this space was used (*Table 1*). The systematic review published in 2023 analysed all CF telehealth papers that adhered to the aforementioned definition published up to May 2021 and was available in English. This resulted in 39 papers used for analysis to identify best practices or guidelines. These same 39 papers have been taken to analyse digital health literacy considerations. For this analysis, abstracts were excluded (n=13) as it was unlikely they could include such detail due to the limited word count.

For the final 26 papers, the data of interest for this review were, if:

- Health literacy was discussed/considered;
- Digital literacy/competency was discussed/considered;
- Digital health literacy was discussed/considered;
- Training was offered to PwCF or medical/healthcare teams;
- Readiness assessment was performed on PwCF or medical/healthcare teams;
- There were note of any plans to sustain the telehealth service over time with consideration to the above

Page 4 of 11 mHealth, 2025

Table 1 The search strategy modified from recent systematic review published in 2023 (13)

Items	Specification
Date of search	May 2021
Databases and other sources searched	PubMed, Web of Science, and Scopus
Search terms used	"Cystic Fibrosis" and one of the following terms (Virtual Care, Virtual Health, Remote Monitoring, TeleMonitoring, Digital Health, home Monitoring, ehealth, telehealth, telemedicine, wearable devices)
Timeframe	Up to May 2021
Inclusion and exclusion criteria	Must be available in English, all paper types (trials, interventions, reviews etc.)
	Abstracts, not published in English
Selection process	Study selection was conducted by three authors from the original manuscript (T.V., H.I., B.J.P.). For this review, all authors reviewed the table of found papers and agreed to remove abstracts

Table 2 Data variables and definitions used for data extraction within Elicit AI

Variables	Definition/prompt
Health literacy	Report any information on if Health Literacy was mentioned in the paper. Health Literacy is an individual's ability to find health information, appraise it, and use or communicate it
Digital literacy	Give any data on a patient or medical professionals digital literacy skills, technical skills, computer literacy or skills. This can also be described as digital competency
Digital health literacy	Give any data on if a patient or medical professionals Digital Health Literacy was mentioned. This is a combination of Health Literacy and Digital Literacy previously described
Training	Report on any training provided to medical/healthcare teams or patients. Provide details of who the training was for, and what the training was about
Readiness assessment	Give data on if any Readiness Assessments were carried out. This would assess if an individual or an organisation were ready to use the intervention
Sustainability	Give any data on the sustainability of the intervention

literacies or training.

Data extraction of these papers was performed using Elicit AI Research Assistant 2024 (15). The creators of Elicit AI describe its data extraction as always being 80–90% accurate and never 100%. As such correct use of this tool requires human monitoring, cross checking, and reviewing. Elicit AI uses advanced large language models to extract data from PDF documents that are relevant to the data variable and definition provided. The data variables and definitions for this review are described in *Table 2*. This data is then summarized into a structured table that, when clicked on, provides the summary and detailed explanation separated into "claims". Each claim when clicked opens the PDF document and highlights the text used to generate the claim. The language models used as part of Elicit AI

also label some data as "implicit" as it can be inferred from the text but not explicitly stated. This was most seen in the literacy specific variables, for example the "digital literacy/competency" for PwCF and care teams may not have been explicitly stated or discussed in the manuscript, but the results from a usability survey scored highly, indicating that the user was potentially digitally literate or competent to some level. To gauge reliability, all extracted summaries receive a confidence rating from the AI model that is based on the quotes used to generate the summary. This confidence rating is either not reported on each table cell, or reported as "90%+". All results from this process were cross-referenced by an author on this paper (T.V.). If a data extraction value did not receive a 90%+ confidence measure, then manual data extraction was performed.

mHealth, 2025 Page 5 of 11

Results

The results of the data extraction process can be seen in Table 3. Firstly, it is noted that no manuscript explicitly discussed the importance of health literacy or digital literacy/competency. One paper implicitly describes the need for health literacy for PwCF, and 22 papers implicitly describe digital skills as the telehealth intervention was delivered by care teams and received by PwCF. For digital health literacy, two papers explicitly describe how these digital skills are needed by PwCF so that they can safely and confidently access virtual care. Six papers implicitly discuss digital health literacy by exploring how experienced PwCF or care teams are with using digital health technologies as a survey instrument or by describing the current facilities within the care setting. For training, two papers explicitly describe training for PwCF, two explicitly describe training for care teams, and one paper states the importance of training PwCF to better support them in using telehealth. One paper described PwCF being eligible to use the telehealth service if they are clinically stable and have access to technology. No other paper describes readiness or readiness assessments. Finally, no paper discusses the sustainability of these programs with reference to the required literacies, training, or readiness assessments, while 12 papers describe how the telehealth services can or will be used in the future.

Discussion

Firstly, it is noted that the data of interest to this review was greatly lacking from the available papers. This may be due to several indeterminant factors such as the restrictions imposed in scientific publications (for example word count or structure), the study scale of the papers with a greater focus on generating evidence for telehealth within CF care (most were single centre experiences or pilot studies), or the presumption that many care teams and PwCF already have the skills required to complete the outlined telehealth task. This has resulted in a paucity of data describing what skills and knowledge amongst PwCF and care teams alike can drive the success or failure of these telehealth services.

The implications of not considering digital health literacy can have a negative impact on pre-existing health in-equalities. Furthermore, the more advanced the digital health solution, the larger the disparities become between those who are digital health literate verses those who are not (42). Chronically ill groups, such as CF, are the most at

risk of experiencing these disparities (42). These disparities play a significant role within the digital divide (8). As it is reported more and more that access to technologies is becoming less of a challenge for many (43), there is a need to pay careful consideration to digital health literacy to compliment this access, particularly when considering the scale and speed in which these technologies are advancing. Within CF, like many other chronic conditions, burden of care is already considerable, this again could be exacerbated by the addition of digital health solutions that PwCF and care teams do not have the adequate skills to use, or the technical personnel to support its implementation.

Specific to care teams, challenges with digital health solution implementation continues to be acknowledged within research. Such challenges include a lack of interoperability between new systems, increased manual administrative solutions to record data, and lack of technical supports and infrastructures. This is further complicated by a lack of digital literacy skills (44) causing increased burden to care teams. With this increased burden, teams will become sceptical of the use of such systems which can potentially impact on the potential success of the digital health.

For many care teams and PwCF, it may be a case that the digital skills needed to utilise these digital health solutions have already been acquired. That being said, the application of health literacy within a digital context continues to be an area of paramount focus and is written into the "Digital Universal Precautions to promote eHealth" list as described by Smith et al. (45). By incorporating telehealth into clinical practice, parts of healthcare are being moved online. This in turn provides a wide range of information source possibilities, each with their own challenges. For example, social media which has had an impact on mental health self-diagnosis (46,47), increased access to predatory scientific medical journals and websites (48), and even AI tools for information seeking (49). On the contrary to this, focusing solely on digital health literacy and digital health solutions, could have negative impact on the PwCF and care teams alike. For example, the relationship between care teams and PwCF may be negatively impacted, and health information found online may not be used appropriately to co-create care solutions. To overcome this, it is suggested by Palumbo et al. to create tailored digital health solutions (50). Despite these challenges, these literacy considerations, precaution measures, or proactive training attempts were rarely described within the table of research (Table 3). This is not to say that it was not done or considered, but it does appear to be of a lesser importance to the research

Page 6 of 11 mHealth, 2025

Table 3 Summary of data extraction from the 26 papers focusing on health literacy, digital literacy/competency, digital health literacy, training, readiness assessment, and sustainability

Year	Title	Health literacy discussed	Digital literacy/competency discussed	Digital health literacy	Training	Readiness assessment	Sustainability
2020	A Feasibility Study of Urgent Implementation of Cystic Fibrosis Multidisciplinary Telemedicine Clinic in the Face of COVID-19 Pandemic: Single-Center Experience (16)	No	Implicit - discussed access to technology for PwCF. No data for care teams	No	Implicit for care team through iterative cycles. No for PwCF	For PwCF focused on clinical stability and access to technology	Sustainability is discussed. Does not mention literacy
2020	Emerging Alternatives to Conventional Clinic Visits in the Er of COVID-19: Adoption of Telehealth at VCU Adult Cystic Fibrosis Center (17)	ra No	Implicit - discuss technology access being a challenge and potential barrier for PwCF. Explicit statement on the importance and need for IT expertise to provide technical support and troubleshooting	Explicit statement for PwCF having limited computer proficiency with computer and Zoom use could hinder participation in telehealth appointments, and training may be required. No data on care teams	Explicit statement on the importance of training to support some PwCF in using telehealth services. No data on care teams	No	Discussion on future potential improvements that are being explored by the CF centre
2021 (first e-published)	Physiotherapy via telehealth for acute respiratory exacerbations in paediatric cystic fibrosis (18)	No	No	No	No	No	Discusses potential for CF physiotherapy
2017	The use of telehealth (text messaging and video communications) in patients with cystic fibrosis: A pilot study (19)	No	Implicit - as PwCF and care teams were able to complete the task. But recruitment was a challenge as PwCF did not want to commit to video calls. Technical difficulties also noted as a challenge	No	No	No	No
2021	Psychological interventions during COVID pandemic: Telehealth for individuals with cystic fibrosis and caregivers (20	No 0)	Implicit - as PwCF and care teams were able to use the intervention and answer surveys via email	No	No	No	No
2018	Impact of home spirometry on medication adherence among adolescents with cystic fibrosis (21)	g No	Implicit - as PwCF and care teams were able to complete the task	No	Yes - for PwCF on how to use the portable spirometer	No	No
2020	Clinical and microbiological monitoring of Cystic Fibrosis patients, three years of follow-up via Tele-Medicine: an empirical research (22)	No	No	No	No	No	Implicit - this is a follow-up paper 3 years later
2017	Telephone monitoring and home visits significantly improved the quality of life, treatment adherence and lung function in children with cystic fibrosis (23)		No	No	No	No	No
2021	Patient and family perceptions of telehealth as part of the cystic fibrosis care model during COVID-19 (24)	No	Implicit - for PwCF, survey queried if they experienced technical difficulties. No data for care teams	Implicit - for PwCF queried if used telehealth before	No	No	No
2021	Development and evaluation of an internet-based cognitive behavioral therapy intervention for anxiety and depression in adults with cystic fibrosis (eHealth CF-CBT): An international collaboration (25)	in	Implicit - Usability scores post intervention were positive amongst PwCF and care teams	No	CF-CBT training provided to care teams	No	Discusses future plans to make the CF-CBT moedl available in other countries and centres
2008	A feasibility study of home telemedicine for patients with cystic fibrosis awaiting transplantation (26)	No	Implicit - patient satisfaction measures for PwCF was positive. Nothing for care teams	No	No	No	No
2017	Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia (27	No 7)	Implicit - PwCF and care teams were able to conduct tasks	No	Training provided to care teams on how to conduct spirometry	No	States that the service will continue to be used
2012	Safety for home care: The use of internet video calls to double-check interventions (28)	No	Implicit - mention on care teams experiencing technical difficulties with managing multiple technologies was alleviated by introducing new integrated technologies. No data on PwCF	No	Training provided to care teams in both electronic and paper based forms	No	No
2021	ACT with CF: A telehealth and in-person feasibility study to address anxiety and depressive symptoms among people with cystic fibrosis (29)	No	Implicit - Care teams were able to identify HIPAA compliant software. PwCF were able to use the telehealth service	No	Yes - Care teams (MA Students) partook in training to deliver intervention. No data for PwCF	No	Discusses the sustainability of study results (reduction in anxiety at 3 months follow up were not sustained)
2020	Learning to breathe with Tai Chi online - qualitative data from a randomized controlled feasibility study of patients with cystic fibrosis (30)	No	Implicit - discussion around difficulty with screen sizes, access to technology, and technical issues which impacted on experience	No	Training was given to Tai Chi instructors but not PwCF or care teams	No	Discussion with reduction in engagement over time

Table 3 (continued)

mHealth, 2025 Page 7 of 11

Table 3 (continued)

Year	Title	Health literacy discussed	Digital literacy/competency discussed	Digital health literacy	Training	Readiness assessment	Sustainability
2020	The feasibility of online video calling to engage patients with cystic fibrosis in exercise training (31)	n No	Implicit - PwCF and care teams were able to conduct tasks. Results showed that majority of PwCF found the setup of Skype to be easy. It was noted that 25% of calls experienced technical issues	Yes - PwCF were asked if they used telehealth before (4= yes, 3= no) No data for care team	No	No	No
2014	The use of telehealth system in improving adherence to nebulised treatment in children with cystic fibrosis: Benefits and pitfalls (32)	No	No	No	No	No	Discussion on lack of engagement over time
2014	The application of telemedicine in the follow-up of lung transplantation in a patient with cystic fibrosis (33)	No	Implicit - mention on PwCF need to understand and collaborate with telehealth being a deciding factor in the success of intervention. No data on care team	No	No	No	Implicit - as this is a report of current practice
2018	Tele-Exercise as a Promising Tool to Promote Exercise in Children With Cystic Fibrosis (34)	No	Implicit - Most PwCF rated system as usable in usability surveys. No data on care teams	Implicit - Most PwCF were able to use platform without parental guidance and were able to complete necessary tasks like registration. Minimum technical issues reported. No data for care teams	Training provided to PwCF on how to download and setup Vsee telemedicine. A member of the research team was also available for technical support	No	No
2006	Case study: providing evidence-based behavioral and nutrition treatment to a toddler with cystic fibrosis and multiple food allergies via telehealth (35)	Implicit	Implicit - discussed increased access to technology for PwCF. No data for care teams	Implicit - discussed increased access to technology for PwCF. No data for care teams	Nutrition/Dietetic Training for PwCF family. No training discussed for care teams	No	No
2018	Eliciting the Impact of Digital Consulting for Young People Living With Long-Term Conditions (LYNC Study): Cognitive Interviews to Assess the Face and Content Validity of Two Patient-Reported Outcome Measures (36)	No	Implicit - as PwCF and care teams were able to use intervention. PwCF also had difficulty in separating their face-to-face experience from digital experience	No	No	No	Highlights that these technologies are being increasingly implemented
2021	Favorable Clinician Acceptability of Telehealth as Part of the Cystic Fibrosis Care Model during the COVID-19 Pandemic (37)	No	Yes - training, training satisfaction, technical difficulties were queried in survey for care teams. Also highlights in results that for paediatric consultants, digital skills and technology access is a concern for parents of PwCF	Implicit - survey queried if care teams used telehealth before COVID-19. Noted as a potential barrier for some PwCF	Yes for care teams	No	Discusses opinions of telehealth for CF care post COVID-19
2021	Virtual medication tours with a pharmacist as part of a cystic fibrosis telehealth visit (38)	e No	Implicit - PwCF and care teams were able to conduct tasks	No	No	No	Discusses the ability to implement medication tours as part of telehealth visit.
2021	Preserving Multidisciplinary Care Model and Patient Safety During Reopening of Ambulatory Cystic Fibrosis Clinic for Nonurgent Care: A Hybrid Telehealth Model (39)	No	Implicit - discusses care teams access to technology. No data for PwCF	Yes - highlights importance of PwCF having confidence with the safety and efficacy of digital health	No	No	Discusses economic benefits for COVID-19 era and beyond
2020	In the south, if you give us lemons, we will make you lemonade (40)	No	Implicit - for care teams and PwCF as they are using it already	No	No	No	Discusses potential for CF care post COVID-19
2021	Managing Cystic Fibrosis related diabetes via telehealth during COVID-19 pandemic (41)	No	Implicit - for care teams as using several technologies, devices, digital databases, online technologies. For PwCF, implicit as they are using devices	Implicit for both PwCF and care teams as using EMR, CGM, and telehealth	Insulin education provided to PwCF	No	Implicit - currently being used and expanded

ACT, acceptance and commitment therapy; CBT, cognitive behavioural therapy; CF, cystic fibrosis; CGM, continuous glucose monitor; EMR, electronic medical record; PwCF, people with cystic fibrosis; VCU, Virginia Commonwealth University.

Page 8 of 11 mHealth, 2025

goals. Consequently, there is a lack of shared learnings and knowledge amongst the CF community for digital health literacy practices within telehealth care.

Finally, within CF care, each time a new intervention, drug, or therapy are introduced, the CF care teams ensure that the PwCF or their family/caregivers receive adequate education in order to use it safely and effectively. Given the ever-increasing assimilation of digital health technologies into standard care delivery, the same approach is also required to ensure that these technologies are also used safely and effectively. This education piece must consider both health literacy and digital competency combined (digital health literacy). If we continue to introduce the people we care for to an online connected health environment, we must ensure that they have skills required to exercise health literacy within a digital health context.

Limitations

The limitations of this work must be acknowledged when trying to transfer these learning to CF telehealth research or practice. The first limitation is that the papers reviewed were up to May of 2021 as the data analysed was based on our existing published systematic review. There have been a number of new papers exploring telehealth within CF since that time, some as a consequence of the COVID-19 pandemic. As such, there is the potential that some of these papers may have reported their digital health literacy considerations in more detail. Future research should consider exploring this time period (2021 and beyond) further.

Additionally, the papers reviewed in this study predominantly lacked the required data, or only implied some form of digital health literacy. This is noted as a limitation as there is no specific data to draw any definitive conclusions towards what the considerations of digital health literacy within CF telehealth are, only that it is not reported adequately in the reviewed papers.

Conclusions

Digital health solutions are increasingly being implemented into traditional care models. As this convergence of health and technology continues there is need to ensure that patients and care teams alike have adequate digital health literacy skills. This review used the resulting papers from a recent systematic review exploring telehealth within CF. The intention of this review was to scope out what

digital health literacy considerations are being made when implementing or piloting these digital health solutions. Unfortunately only one manuscript explicitly attempted to address this. This has the potential to negatively impact PwCF and care teams by increasing burden, exclusions, health inequalities, and also access to incorrect information. The conclusion of this review is that a strategic approach to assessing and addressing digital health literacy is needed for both PwCF and care teams when implementing digital health solutions. These strategies should consider three key areas, health literacy, the five components of the DigComp 2.2 Framework (problem solving, information & data literacy, communication & collaborations, digital content creation, and safety), and the nuances and necessary skills to the specific telehealth service. Finally, these strategies should also remove misconceptions such as digital natives and the grey divide and focus more on digital inclusion and multi-model training methods. This will help ensure that as many PwCF, families, and care teams can receive digital health literacy training in a way that reflects their current digital competency, access, and confidence with technology.

Acknowledgments

None.

Footnote

Reporting Checklist: The authors have completed the Narrative Review reporting checklist. Available at https://mhealth.amegroups.com/article/view/10.21037/mhealth-24-66/rc

Peer Review File: Available at https://mhealth.amegroups.com/article/view/10.21037/mhealth-24-66/prf

Funding: This work was supported by the Vertex CF-RIA award exploring Digital Health Literacy within Cystic Fibrosis Telehealth (to T.V. and B.J.P.).

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://mhealth.amegroups.com/article/view/10.21037/mhealth-24-66/coif). T.V. and B.J.P. received a Vertex CF-RIA award exploring Digital Health Literacy within Cystic Fibrosis Telehealth. B.J.P. has previously received consultancy fees from Vertex, Insmed and Viatris Pharmaceuticals; and previously received payments from Vertex, Viatris and

mHealth, 2025 Page 9 of 11

Chiesi Pharmaceuticals as a speaker. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the noncommercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: https://creativecommons.org/licenses/by-nc-nd/4.0/.

References

- Meskó B, Drobni Z, Bényei É, et al. Digital health is a cultural transformation of traditional healthcare. Mhealth 2017;3:38.
- Conard S. Best practices in digital health literacy. Int J Cardiol 2019;292:277-9.
- 3. Dunn P, Hazzard E. Technology approaches to digital health literacy. Int J Cardiol 2019;293:294-6.
- Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012;12:80.
- Tinmaz H, Lee YT, Fanea-Ivanovici M, et al. A systematic review on digital literacy. Smart Learning Environments. 2022;9:21.
- Vuorikari R, Kluzer S, Punie Y. DigComp 2.2: The Digital Competence Framework for Citizens - With new examples of knowledge, skills and attitudes. EUR 31006 EN. 2022. Available online: https://publications.jrc.ec.europa.eu/ repository/handle/JRC128415
- Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006;8:e9.
- 8. Hargittai E. The Digital Divide and What to Do About It. In: New Economy Handbook. San Diego, CA, USA: Academic Press; 2003:822-41.
- 9. Helsper EJ, Eynon R. Digital natives: where is the evidence? British Educational Research Journal 2010;36:503-20.

 Quan-Haase A, Williams C, Kicevski M, et al. Dividing the Grey Divide: Deconstructing Myths About Older Adults' Online Activities, Skills, and Attitudes. American Behavioral Scientist 2018;62:1207-28.

- 11. Kemp E, Trigg J, Beatty L, et al. Health literacy, digital health literacy and the implementation of digital health technologies in cancer care: the need for a strategic approach. Health Promot J Austr 2021;32 Suppl 1:104-14.
- 12. Collins SA, Currie LM, Bakken S, et al. Health literacy screening instruments for eHealth applications: a systematic review. J Biomed Inform 2012;45:598-607.
- 13. Vagg T, Shanthikumar S, Ibrahim H, et al. Telehealth in Cystic Fibrosis. A systematic review incorporating a novel scoring system and expert weighting to identify a 'top 10 manuscripts' to inform future best practices implementation. J Cyst Fibros 2023;22:598-606.
- 14. ECFS. Telehealth in Cystic Fibrosis. 2024. Available online: https://www.ecfs.eu/telehealth
- 15. Elicit. Elicit AI Research Assistant. 2024. Available online: https://elicit.com/
- 16. Compton M, Soper M, Reilly B, et al. A Feasibility Study of Urgent Implementation of Cystic Fibrosis Multidisciplinary Telemedicine Clinic in the Face of COVID-19 Pandemic: Single-Center Experience. Telemed J E Health 2020;26:978-84.
- 17. Womack C, Farsin R, Farsad M, et al. Emerging Alternatives to Conventional Clinic Visits in the Era of COVID-19: Adoption of Telehealth at VCU Adult Cystic Fibrosis Center. Int J Gen Med 2020;13:1175-86.
- 18. Benz C, Middleton A, Elliott A, et al. Physiotherapy via telehealth for acute respiratory exacerbations in paediatric cystic fibrosis. J Telemed Telecare 2023;29:552-60.
- Gur M, Nir V, Teleshov A, et al. The use of telehealth (text messaging and video communications) in patients with cystic fibrosis: A pilot study. J Telemed Telecare 2017;23:489-93.
- Graziano S, Boldrini F, Righelli D, et al. Psychological interventions during COVID pandemic: Telehealth for individuals with cystic fibrosis and caregivers. Pediatr Pulmonol 2021;56:1976-84.
- 21. Shakkottai A, Kaciroti N, Kasmikha L, et al. Impact of home spirometry on medication adherence among adolescents with cystic fibrosis. Pediatr Pulmonol 2018;53:431-6.
- 22. De Biase RV, Cristiani L, Paglia C, et al. Clinical and microbiological monitoring of Cystic Fibrosis patients, three years of follow-up via Tele-Medicine: an empirical research. Clin Ter 2020;171:e381-4.

Page 10 of 11 mHealth, 2025

- 23. Chrysochoou EA, Hatziagorou E, Kirvassilis F, et al. Telephone monitoring and home visits significantly improved the quality of life, treatment adherence and lung function in children with cystic fibrosis. Acta Paediatr 2017;106:1882.
- 24. Jaclyn D, Andrew N, Ryan P, et al. Patient and family perceptions of telehealth as part of the cystic fibrosis care model during COVID-19. J Cyst Fibros 2021;20:e23-8.
- 25. Verkleij M, Georgiopoulos AM, Friedman D. Development and evaluation of an internet-based cognitive behavioral therapy intervention for anxiety and depression in adults with cystic fibrosis (eHealth CF-CBT): An international collaboration. Internet Interv 2021;24:100372.
- Wilkinson OM, Duncan-Skingle F, Pryor JA, et al. A
 feasibility study of home telemedicine for patients with
 cystic fibrosis awaiting transplantation. J Telemed Telecare
 2008;14:182-5.
- 27. Wood J, Mulrennan S, Hill K, et al. Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia. J Telemed Telecare 2017;23:673-9.
- 28. Bradford N, Armfield NR, Young J, et al. Safety for home care: the use of internet video calls to double-check interventions. J Telemed Telecare 2012;18:434-7.
- 29. O'Hayer CV, O'Loughlin CM, Nurse CN, et al. ACT with CF: A telehealth and in-person feasibility study to address anxiety and depressive symptoms among people with cystic fibrosis. J Cyst Fibros 2021;20:133-9.
- Ronan P, Mian A, Carr SB, et al. Learning to breathe with Tai Chi online - qualitative data from a randomized controlled feasibility study of patients with cystic fibrosis. Eur J Integr Med 2020;40:101229.
- 31. Tomlinson OW, Shelley J, Trott J, et al. The feasibility of online video calling to engage patients with cystic fibrosis in exercise training. J Telemed Telecare 2020;26:356-64.
- 32. Thornton C, Lamptey O, Chan EY. The use of telehealth system in improving adherence to nebulised treatment in children with cystic fibrosis: Benefits and pitfalls. European Respiratory Journal 2014;44:1965.
- 33. Murgia F, Corona B, Bianciardi F, et al. The application of telemedicine in the follow-up of lung transplantation in a patient with cystic fibrosis. Clin Ter 2014;165:e382-3.
- 34. Chen JJ, Cooper DM, Haddad F, et al. Tele-Exercise as a Promising Tool to Promote Exercise in Children With Cystic Fibrosis. Front Public Health 2018;6:269.
- 35. Piazza-Waggoner C, Ferguson KS, Daines C, et al. Case study: providing evidence-based behavioral and

- nutrition treatment to a toddler with cystic fibrosis and multiple food allergies via telehealth. Pediatr Pulmonol 2006;41:1001-4.
- 36. Sturt J, Dliwayo TR, Forjaz V, et al. Eliciting the Impact of Digital Consulting for Young People Living With Long-Term Conditions (LYNC Study): Cognitive Interviews to Assess the Face and Content Validity of Two Patient-Reported Outcome Measures. J Med Internet Res 2018;20:e268.
- 37. Perkins RC, Davis J, NeSmith A, et al. Favorable Clinician Acceptability of Telehealth as Part of the Cystic Fibrosis Care Model during the COVID-19 Pandemic. Ann Am Thorac Soc 2021;18:1588-92.
- 38. Warda N, Rotolo SM. Virtual medication tours with a pharmacist as part of a cystic fibrosis telehealth visit. J Am Pharm Assoc (2003) 2021;61:e119-25.
- 39. List R, Compton M, Soper M, et al. Preserving Multidisciplinary Care Model and Patient Safety During Reopening of Ambulatory Cystic Fibrosis Clinic for Nonurgent Care: A Hybrid Telehealth Model. Telemed J E Health 2021;27:193-9.
- 40. Garcia B, Christon L, Gray S, et al. In the south, if you give us lemons, we will make you lemonade. J Cyst Fibros 2020;19:842-3.
- 41. Hasan S, Cecilia Lansang M, Salman Khan M, et al. Managing Cystic Fibrosis related diabetes via telehealth during COVID-19 pandemic. J Clin Transl Endocrinol 2021;23:100253.
- 42. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. J Med Internet Res 2012;14:e19.
- Vollbrecht H, Arora V, Otero S, et al. Evaluating the Need to Address Digital Literacy Among Hospitalized Patients: Cross-Sectional Observational Study. J Med Internet Res 2020;22:e17519.
- 44. Pfob A, Sidey-Gibbons C, Schuessler M, et al. Contrast of Digital and Health Literacy Between IT and Health Care Specialists Highlights the Importance of Multidisciplinary Teams for Digital Health-A Pilot Study. JCO Clin Cancer Inform 2021;5:734-45.
- 45. Smith B, Magnani JW. New technologies, new disparities: The intersection of electronic health and digital health literacy. Int J Cardiol 2019;292:280-2.
- 46. Hasan F, Foster MM, Cho H. Normalizing Anxiety on Social Media Increases Self-Diagnosis of Anxiety: The Mediating Effect of Identification (But Not Stigma). J Health Commun 2023;28:563-72.
- 47. Rutter LA, Howard J, Lakhan P, et al. "I Haven't Been

mHealth, 2025 Page 11 of 11

- Diagnosed, but I Should Be"-Insight Into Self-diagnoses of Common Mental Health Disorders: Cross-sectional Study. JMIR Form Res 2023;7:e39206.
- 48. Wallace WA. The Challenges from Predatory Journals and Fake Medical News. In: Integrity of Scientific Research: Fraud, Misconduct and Fake News in the Academic, Medical and Social Environment. Springer; 2022:515-21.

doi: 10.21037/mhealth-24-66

Cite this article as: Vagg T, Twohig S, Deasy KF, Ibrahim HIS, Plant BJ. A narrative review of digital health literacy within cystic fibrosis telehealth: are we considering it? mHealth 2025;11:20.

- 49. Ayers JW, Poliak A, Dredze M, et al. Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum. JAMA Intern Med 2023;183:589-96.
- 50. Palumbo R, Nicola C, Adinolfi P. Addressing health literacy in the digital domain: insights from a literature review. Kybernetes 2022;51:82-97.