

**Cystic Fibrosis Virtual Patient Advocacy**

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**Abstract**

Cystic Fibrosis is a rare life-limiting genetic disorder that affects 30,000 people in the United States. The CF population has seen an increase in their life expectancy as new research, therapies and technology has improved their quality of life. Knowledge of these resources is important for empowering patients and caregivers to engage in and coordinate their own care and wellness. The Cystic Fibrosis Foundation's Central Eastern Carolinas chapter is interested in connecting the population to the available resources. Virtual methods of connection become important in a community which requires social distancing due to disease process and increased risk of infection. Virtual communication is even more vital, as Coronavirus disease (COVID-19) limits interactions with others. A virtual patient advocate (VPA) and quick response (QR) code are the identified methods of providing awareness and education while helping establish a relationship with local resources through local CFF chapters.

*Keywords:* advocacy, virtual, resources, awareness, Cystic Fibrosis

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## Section I. Introduction

### Background

According to the Cystic Fibrosis Foundation (CFF) website, Cystic Fibrosis (CF) is a progressive autosomal recessive genetic disease that affects the lungs, pancreas, and other organs, and is due to a mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene. The CFTR protein becomes dysfunctional and keeps chloride from moving to the cell surface and attracting water, resulting in thick, sticky mucus. Thick, sticky mucus, causes chronic infections and progressive organ damage, affecting the quality of life and causing premature death in this population (Cystic Fibrosis Foundation, n.d., CF Genetics: The Basics section).

The Cystic Fibrosis Foundation (CFF) is considered the “world’s leader in the search for a cure for CF”, raising more funds for CF research than any other organization as a “donor-funded, 501(c) (3) nonprofit, fully accredited by the Better Business Bureau’s (BBB) Wise Giving Alliance Program” (Cystic Fibrosis Foundation, n.d., About Us section). The CF Foundation was started in 1955, by a group of parents who felt there was a need for action, because at the time, there were no available treatments, and little was known about the rare condition their children suffered from. Their goal was to advance the understanding of the disease, create treatments and specialized care, and ultimately find a cure for the disease which now affects more than 70,000 people worldwide and 30,000 people in the United States (Cystic Fibrosis Foundation, n.d, About Cystic Fibrosis section). “The mission of the CFF is to cure CF and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care” (Cystic Fibrosis Foundation, n.d., Our Mission section, para. 1).

Although there is not a cure, the CF population has seen an increase in their life expectancy as new research, therapies and technology has improved their quality of life. In 1982, newborn screening methods were implemented as a nationwide program to identify CF and determine those that would benefit from early interventions. Prior to newborn screening efforts, patients were diagnosed later in life when symptoms began to be a problem and they presented for care.

Cystic Fibrosis is the most common, life-limiting recessive genetic disorder in Caucasians (National Organization of Rare Diseases, 2017). The disease occurs in one out of every 2,500 white newborns but is less common in other ethnic groups, affecting only 1 of every 17,000 African Americans and 1 of every 31,000 Asian Americans (U.S. National Library of Medicine, 2020). CF can now be diagnosed with the newborn screening test and confirmed with a sweat test. Approximately 10% of people affected with CF were diagnosed after 18 years of age (National Organization of Rare Diseases, 2017). This is a rare genetic mutation that affects a disproportionate group of people.

### **Organizational Needs Statement**

The Central Eastern Carolinas Chapter of the CF Foundation has an immediate need to go virtual in all aspects, including outreach, advocacy and fundraising (Figure 1). The CF population has always needed to remain six-foot apart as a part of their disease process, as they are at an increased risk of sharing dangerous bacteria between each other (Cystic Fibrosis Foundation, n.d., 7 Ways to Guard Against Germs in Health Care Settings section). With the recent Coronavirus Disease 19 (COVID-19) situation, it is important now more than ever, for the CF community to be connected virtually as they are considered high-risk during the pandemic (Figure 1). Implementing a Virtual Patient Advocate (VPA) avatar for the CF community and

creating a Quick Response (QR) code to distribute to care centers, hospitals, pediatricians, and primary care providers will provide quick access and connection to the local CF chapter. This project will streamline the process and connect patients to resources whether at diagnosis or upon transfer into the area from another care center. The CFF staff expressed a need to identify all CF patients early in diagnosis to assure they are connected to needed resources that can significantly improve their quality of life when having access to resources (Figure 1).

Healthy People 2020 leading health indicators related to this project include access to health services, educational and community-based programs and health communication and health information technology (Office of Disease Prevention and Health Promotion, 2020). Providing virtual patient advocacy, for a high-risk population like CF, that must social distance six-feet from others with CF in general and especially during a COVID-19 pandemic helps to meet all arms of the Triple Aim, incorporating many of the Doctor of Nursing Practice (DNP) Competencies and Essentials (Table 1). This includes “improving individual experience of care, improving the health of populations and reducing the per capita costs of care for populations by increasing access to care virtually, reducing the incidence of exposure to viral and bacterial infections, and decreasing the cost of care that results due infections requiring medications, treatments, and hospitalizations” (Merkley & Barton, 2016, para. 2). No metrics currently exist for the proposed project, yet pertinent data can be obtained from the CF patient registry.

### **Problem Statement**

The CF Patient Registry is made up of information collected during care center visits from individuals with cystic fibrosis who have consented to share that data for research purposes (Cystic Fibrosis Foundation, n.d., Patient Registry section). Utilizing the CF Patient Registry to disseminate information regarding chapter resources would limit this information to those who

are already established with a care center and have access to local resources. A major portion of the target population may not be reached, (Appendix A) as the identified need is to reach patients who are not already connected to a local care center or a local CF chapter. Patients moving into the area, not established with a care center, would not necessarily be identified by the registry. The Central Eastern Carolinas Chapter identified a need to increase outreach, advocacy and fundraising events virtually during the COVID-19 pandemic as well as in preparation for the future. They reported having adult patients that have never connected with a CF chapter and therefore have never been exposed to the resources that the CFF has to offer. Newborns are being born with CF during quarantine and patients transferring into the area are not able to connect as usual with the CF Foundation because the normal process of referrals has been interrupted. Numerous opportunities for awareness and fundraising have been missed as care centers have been closed and staff are working from home, and advocacy and fundraising events have been postponed (CFF project partner, personal communication, June 15, 2020). (Appendix A).

### **Purpose Statement**

Virtual patient advocacy begins by assuring that CF patients are connected to a CF Foundation Chapter. As seen in Appendix A, providing a generated QR code that connects patients to the local chapter, to resources, to upcoming events and introducing them to a personal Virtual Patient Advocate (VPA) will streamline the process by which patients, either newly diagnosed in the newborn setting or private office, or those transferring into the area, can quickly connect with resources and staff at a CF Chapter. North Carolina has two CFF chapter offices, one in Raleigh and one in Charlotte, comprising the Central Eastern Carolina's Chapter of the CFF. The QR code and hyperlink were made available for patients to scan at all entry points into



the system allowing access to resources and the VPA. This is invaluable to virtually connecting the CF community and staff. The VPA was designed to provide an avenue for patients and caregivers to be informed, involved and interactive by communicating with staff when needed. It is a way for families to research CF topics 24 hours a day, 7 days a week when it is convenient for them, and in a manner that is less intimidating, than speaking directly with hospital or foundation staff. A VPA can be designed to look like and communicate with patients of various backgrounds, ethnicities, and gender that put the patient and caregiver more at ease. Connecting patients, caregivers and staff virtually will be invaluable in improving the quality of life and experience of those who are diagnosed with CF.

## **Section II. Evidence**

### **Literature Review**

A literature review to determine current methods of patient outreach and advocacy was done to assess the usefulness of a virtual intervention aimed at increasing patient literacy via advocate interaction. In addition, current methods of practice were assessed to determine if and where gaps occur in connecting patients to these needed resources. A literature search log and literature matrix were utilized to compile and organize the various articles and research findings related to the search criteria. Searched databases included PubMed and ProQuest. Search words included patient outreach, advocacy, virtual advocacy, connecting patients to resources, virtual patient advocate, resources, virtual resources and access to care. Literature included those in the English language dated between the year 2015 and 2020. An initial 1,907 articles matching the key word search was then filtered to 35 articles utilizing filter criteria of articles published less than five years ago and full text articles. This was further narrowed when inclusive of higher level of evidence parameters were set to include randomized controlled trial (RCT) articles. The introductions and conclusions of the 35 articles were assessed to determine overall theme and usefulness regarding the problem and solution of the proposed plan.

As the healthcare system has changed, the focus has shifted to patient-centered care. Daily innovations in delivery have improved access to care. Current literature identifies a need to provide hybrid care that is both in-person and online (Kent & Yellowlees, 2015). Virtual care is not meant to replace the patient-provider relationship but supplement it.

### ***Current State of Knowledge***

Current literature does not address patient advocacy and outreach specific to the cystic fibrosis community. For chronic conditions or disease processes which affect larger portions of

the general population, more attention is received. Healthcare is becoming more patient-centered and technology-supported. There is a trend towards virtual means of outreach and education, inclusive of telehealth services. Patient advocacy groups and foundations, like the Cystic Fibrosis Foundation, have led advances in research and management of rare diseases.

***Current Approaches to Solving Population Problem(s)***

There is a need to develop practice tools that can be used to assess health risks and facilitate the initiation of interventions that will address these risks. Advances in technology have caused a shift in the way healthcare is delivered, as facilities and organizations are looking for virtual ways to connect with patients. Providers and organizations implementing advocacy tools such as the VPA creates avenues for patients to advocate for themselves and be involved in their care.

The Shared Decision-Making Model was presented in a study where patients were prescreened for health risks and given access to a health communication tool (Jack, 2017). Information was available to patients in an educational format to improve outcomes related to specific health diagnoses and topics. The tool was a virtual patient advocate known as “GABBY”, and patients were to utilize the technology for 6 months in hopes of improving outcomes through education preconception (Jack, 2017).

The Community Navigator Support System is a method that allows patients to be connected virtually to a “community navigator” (Lloyd-Evans et al., 2017). The navigator works with them individually to increase involvement in social activities to reduce feelings of loneliness (Lloyd-Evans et al., 2017). The navigator serves as a patient advocate and gives a sense of connection to the outside world.

Psychoeducation is another avenue identified in which the patient learns through play (Thomas et al., 2019). A gaming system design demonstrates the potential to assist patients in advocating for their needs and priorities through an interactive game (Thomas et al., 2019). The game focuses on “teaching advanced self-advocacy skills, including communication, decision-making, and social connectivity, to improve their quality of life with cancer” (Thomas et al., 2019, para. 1). The premise is to engage learners in a way that is fun but educational.

A virtual patient advocate (VPA) that is easily accessible by all Cystic Fibrosis patients and caregivers, is an ideal solution to fulfill the need of connecting patients to resources and the local CFF chapter. The VPA will provide needed information, in a non-intimidating environment. Patients and caregivers are often afraid to ask questions of the provider and staff for various reasons and the VPA would serve as an avenue to access information without the fear of judgement.

The VPA was chosen over an online user in a community-style forum, as it is preferred for patients to receive information and education from a professional source and not a layperson. Although a community navigator would be a more reputable source of information dissemination than the online community, it would require staffing resources, an expense that is not often feasible. A gaming system can be interactive and fun, but this may not be a fit for everyone, so a more professional delivery system is preferred.

### ***Evidence to Support the Intervention***

The Cystic Fibrosis Foundation Central Eastern Carolinas Chapter expressed a need for increased patient outreach and advocacy through a virtual delivery mode. BioMerieux, a world leader in the field of in vitro diagnostics, details in their science and medicine-oriented publication, BioMerieux Connection (2020), that guidelines for Cystic Fibrosis patients include

the “six-foot rule” which recommends that people with CF should stay six feet away from individuals who are sick and any individual who has CF, to avoid cross-infection. The current global pandemic created an increased need to self-distance and access resources virtually for this population. The Central Eastern Carolinas Chapter staff noted that there are adult patients that have never connected with a CFF chapter and the resources it has to offer (CFF project partner, personal communication, June 16, 2020). They identified a need to connect with patients who have never reached out, possibly due to a lack of knowledge, and those diagnosed elsewhere but transferring into the Central Eastern Carolinas Chapter region. They identified this gap in patient connections to local resources and were looking for a solution to improve outreach and connection within the local CF community. The goal of the project was to virtually increase patient outreach and advocacy.

### **Evidence-Based Practice Framework**

#### ***Identification of the Framework***

Havelock’s Theory of Change (1973) model is a modified version of Lewin’s 1951 model of change. The model simplified in Appendix A involves six phases, beginning with building a relationship (Havelock, 1973). The first step involves predetermining a need for change in the system. Knowing that patients often prefer to chat with providers without the necessity of an appointment, patients may perceive that eliciting information from a subject matter expert such as a non-profit dedicated to a chronic health condition is advantageous. Diagnosing the problem is the next step identified in the model (Havelock, 1973). Determining whether a change is needed or desired is the goal. Partnering with the CFF, the need for virtual patient outreach and advocacy was identified.

Assessing possible solutions to the identified issue is accomplished in the third step of the model, acquiring resources for change (Havelock, 1973). Reviewing the literature was necessary to determine evidence-based practice (EBP) methods that would lead to change. Selecting a pathway for the solution from EBP methods gathered in the literature search is the fourth step in Havelock's model and includes implementation (Havelock, 1973). The literature review resulted in the VPA avatar method of disseminating information to patients, meeting the needs of both the patients and the CFF Carolinas Chapter.

The next step involves promoting the implementation that was initiated in the previous step (Havelock, 1973). Patients were provided with a QR code to connect with the Central Eastern Carolinas Chapter and a hyperlink to access the VPA. The QR code and VPA details were to be distributed to area care centers, pediatricians and primary care providers with instructions on use and distribution.

The final stage of Havelock's model involves monitoring the affected system to ensure the change is successful and maintained (Havelock, 1973). A survey was distributed to patients, in various facilities, to follow up and determine whether the patient received information regarding the QR code and VPA avatar availability, and then if the program was accessed by the patient. The post-survey assessed if the patient or caregiver accessed the program and if so, how useful the information was. The plan was to partner with the CFF to assure that the VPA program is updated with current data and continue to have a relationship with area facilities to continue to promote the project.

### **Ethical Consideration & Protection of Human Subjects**

To ensure that patients of all ages, ethnicities, and socioeconomic groups would be reached within this population, multiple access points into the system were targeted. The sites

included a CF care center providing care to diagnosed CF patients, a local health department providing care to patients that would otherwise not have access, and a large pediatric primary provider group. The VPA system can be equitably designed to cater to various ethnicities, ages, and gender. The future of the VPA system will give the patient or caregiver a choice between different VPA providers, of various ethnicities, ages, and gender, to communicate with, maximizing the relationship and fostering communication between the patient and VPA provider.

Ethical considerations included informed consent and voluntary participation in utilization of the proposed intervention. Metrics to determine the usefulness of the program were voluntarily collected via surveys during follow up care visits. To address the issue of patients not having access to the required technology necessary in utilizing the QR code and VPA, information could be provided in a written format or accessed in the facility on provided electronic devices during the visit.

To prepare for the formal approval process, Collaborative Institutional Training Initiative (CITI) modules were reviewed detailing both the process and the requirements necessary to conduct human research. The CITI modules helped establish the necessary steps in assuring proper research procedures and determine that all aspects of the process are considered for ethical and safety concerns. No potential harm was identified in providing a QR code and connection to the VPA system, nor when assessing the utilization of these resources by patients. There was no foreseeable harm to any of the target population when taking advantage of provided resources.

### **Section III. Project Design**

#### **Project Site and Population**

The Cystic Fibrosis Foundation (CFF) is a nonprofit organization based in Bethesda, Maryland. The Central Eastern Carolinas Chapter of the CFF has an office based in Raleigh and is committed to serving the CF population in the surrounding areas including Durham, Raleigh, Winston Salem, Greenville and Wilmington. Patients from birth through the adult population and their caregivers were included in the project design.

#### ***Description of the Setting***

The Central Eastern Carolinas Chapter was the home for the project from development through evaluation, but multiple facilities were utilized during implementation and evaluation. A CF care center, a local health department, and a private pediatric provider practice were all involved in the project to promote and disseminate information that assisted in connecting patients and caregivers with CFF Central Eastern Carolina Chapter Resources (Appendix A).

#### ***Description of the Population***

Currently there are 30,000 people living with CF in the US, and more than 70,000 worldwide (Cystic Fibrosis Foundation, n.d. About Cystic Fibrosis section). North Carolina is home to around 1,070 patients living with Cystic Fibrosis (Cystic Fibrosis Foundation, n.d. About Cystic Fibrosis Foundation section). The population that was targeted in the project included newly diagnosed patients, generally identified weeks after birth when newborn screening and a confirmation sweat test was positive. It also included patients newly or previously diagnosed, living with CF and being treated at a local CF care center, health department, and pediatric primary care office. Patients previously diagnosed elsewhere and transferring into the area were also included.



**Project Team**

The Central Eastern Carolinas CF Chapter site champion and nursing staff at the various access points, assisted with the development of resource compilation and evaluation via surveys, in determining patient use of the provided resources. East Carolina University College of Nursing Faculty, Dr. Tomika Williams, and the CF Central Eastern Carolinas Chapter Site Champion were updated periodically via email and google documentation on project details and progression as survey data was collected.

**Project Goals and Outcome Measures**

The goal of the project was to increase awareness virtually and improve access to the resources available to the local CF population. This will lead to an improved quality of care and quality of life in individuals affected by this rare genetic life-limiting disease. Outreach, advocacy and fundraising are aspects that the Central Eastern Carolinas Chapter of CFF identified as needs within the CF population. Assessing CF patient and caregiver needs and awareness of available resources via survey assisted in identifying what information should be included in the future through this platform, in addition to what information the project partner feels is available and should be advertised as a means of advocacy in present day.

***Description of the Methods and Measurement***

Appendix A details how surveys, project information, and QR codes for distribution were provided in an informational session to staff at the identified sites. A pre-survey, assessing the CF patient's awareness of the Central Eastern Carolinas Chapter of CFF and resources available, was obtained at all access points into the system provided by staff who had been educated on the process. Nursing staff collected the completed surveys. Bi-weekly data was extracted from those completed, in addition to reinforcement of the project process with staff members. CF

patients and caregivers were made aware of the existence of the Central Eastern Carolinas CFF Chapter and the resources available to the CF population via education information sheets and the VPA avatar link distributed by the nursing staff. This was provided at all access points into the system, whether at diagnosis or during care visits post diagnosis. Nursing staff were educated, at the three access point locations, on project details and their role in identifying and disseminating information to CF patients. Patients were given the QR code which would connect them to the Central Eastern Carolinas Chapter website and a hyperlink to connect to the virtual patient advocate (VPA) avatar. A follow-up post-survey was obtained on patients at their eight-ten week follow up clinic visit. Metrics were obtained and compiled into an excel spreadsheet from those patients provided with the QR code and hyperlink. The information as noted in Appendix A, assisted in determining access, usefulness, and sustainability of the QR code and VPA system.

### ***Discussion of the Data Collection Process***

Surveys, both pre-process and post-process, were collected on a bi-weekly basis from the various sites. They were used to assess the number of patients with CF encountered and the number of CF patients who were provided the survey and project information. Project information included the pre-survey, the QR code and hyperlink to VPA with instructions on use, and the post-survey. Staff were provided a tote with project materials and a folder for collection of completed surveys. Information collected was reviewed bi-weekly. Information compiled from the surveys and the metrics obtained were input in an excel spreadsheet, stored on my personal computer with no identifiable patient information, and available to the project partner site champion and faculty for review via a google document. The data provided the site champion at the organization with important information about how they can improve their

visibility and connection with the CF population. Data analysis included all survey material obtained to help determine usefulness of the program and how to increase use of the product. It improves access to the various resources available to the CF population and ultimately should lead to better outcomes and quality of life in those affected by this life-shortening disease.

Information regarding utilization of the process and resources allowed the organization valuable information with which to build upon for future efforts and an avenue with which to connect this population to needed resources.

### **Implementation Plan**

A QR code connected to the CFF Central Eastern Carolinas Chapter website and a hyperlink for the CF VPA avatar was provided to staff and later patients and caregivers at area access points into the identified entry areas of the healthcare system. Over a 12-week period, staff at project sites were educated on and provided with needed materials to disseminate to patients and caregivers. Patients presenting to the various access points were identified and provided with a pre-project survey that assessed their knowledge of the CFF and available resources. A QR code and information regarding the VPA resource were given to patients and caregivers during their visit. At a follow up appointment, generally 8-10 weeks later, patients were given a post-project survey. This would determine if the patient or caregiver was in fact provided with the materials, whether they accessed the resources via QR code, if they connected with the Central Eastern Carolinas Chapter of the CFF and if they utilized and found the available resources helpful. Metrics were obtained over the 12-week implementation period from the surveys to determine the sustainability of the project process.

**Timeline**

The Doctor of Nursing Practice (DNP) project topic was developed, beginning in the Summer of 2020, after the CFF Central Eastern Carolinas Chapter was approached to determine a practice problem (Figure 2). A relationship was formed at this time with the project partner and a need for virtual outreach, advocacy and fundraising was determined to be their desire. After an initial literature review, the DNP project paper was initiated, and a project goal was determined. The QR code and VPA avatar program was envisioned, and work began in Summer of 2020 to connect and partner with a computer science program for assistance with program design. Faculty within the UNC Computer Science program and program head at Shadow Health were contacted in hopes of partnering to design a VPA. Conversations with Shadow Health's Nursing director led to a partnership with a computer science student at the University of Florida (UF). This partnership resulted in an introduction to their Virtual Interviewer Platform.

Fall of 2020, brought additional collaboration with ECU faculty, CFF Central Eastern Carolinas Chapter site champion, and UF student to develop the project and tools to bring the project to life. Section 2 and 3 of the DNP project paper were composed and work began on tools to begin implementation. A QR code was designed, a narrative for the VPA was written, and survey tools and educational information were developed during Fall of 2020 for the Institutional Review Board (IRB) to review. Spring of 2021 involved education of staff, distribution of materials and evaluation of use via surveys. Sustainability was addressed with the project partner site champion and faculty to assure that the CF population continues to benefit from implementation of this practice project.

## Section IV. Results and Findings

### Results

Appendix B demonstrates the findings of the project. The virtual interviewer platform and QR code became a valuable tool in providing virtual advocacy with the CF community and the local CFF chapter. Three new family contacts were made with the Central Eastern Carolinas Chapter of the CFF after being provided program information. CF care center staff and the CFF site champion voiced their excitement for the advocacy platform and request to continue use and build on the program after the implementation period.

The CF Care Center currently provides care to 317 patients (CF Care Center Nurse, personal communication, May 17, 2021). During the 2020 year, visits were done primarily by virtual means, and at this point in 2021, the care center is only at 40% in person capacity (CF Care Center Nurse, personal communication, May 17, 2021). Prior to implementation, the predicted range of patient volume for the care center site was five to ten patients weekly. Due to COVID-19 process changes and transition to virtual visits, survey completion volume during implementation ranged from only one to two patients weekly. A total of 15 patients provided pre-survey data through the care center site.

The primary care and health department settings were chosen to capture patients at different access points in the health care system. Overall, there was no CF patient flow through these sites over the 12-week implementation period. Predicted patient volume was expected to be rare, like the incidence of disease.

No post-survey data points were obtained from either of the three sites as patient return appointments were extended beyond the routine eight to ten week follow up or being performed virtually. Although there was a lower volume of patients and caregivers available to survey and

for whom to provide resources, information was obtained from 15 families. The data obtained was useful and provided insight in connecting this population with the local CFF Chapter and resources.

### **Discussion of Major Findings**

A total of 27 patients/caregivers across the three implementation sites were given the resource information during the 12 weeks. The pre-survey was completed by 15 patients/caregivers. At the CF care center site, three patients did not complete the survey in the clinic and took it home. The three patients did not return to the clinic with the completed survey during implementation. At the primary care office site, seven patients were mailed project information, but none responded. A follow-up survey and reminder of project resources were sent on a second occasion via mail, and again, no patients or caregivers responded during implementation. No patients presented to the health department site during implementation. Health department staff reported having only one positive screening consultation in the past six months (Health Department Nurse Practitioner, personal communication, February 21, 2021).

Of all respondents who completed the pre-survey, 93% were caregivers of someone under the age of 20; 67% were mothers of the patient. Only 7% of respondents were adult patients with CF, who were responding as themselves. As noted in Figure 1, 33% of respondents had never attempted contact with the CFF, but 87% were interested in contacting the local CF Chapter via a Virtual Patient Advocate avatar. Text was the preferred method of contact, when the VPA could not answer their questions, in 53% of patients. When additional information was needed beyond the capabilities of the VPA, 40% of respondents requested being reached by phone, and another 33% preferred email correspondence. A live chat feature was considered a desirable method of communicating with the CFF in 47% of respondents. Although 93% of respondents were

familiar with the CFF, only 60% had connected with the Central Eastern Carolinas Chapter (Figure 1). There were 33.3% who had connected with other chapters of the CFF but not the Central Eastern Carolinas Chapter. Internet searches, to gain knowledge about CF, had been used by 87% of respondents, and only 33% reported utilizing the local CFF chapter for information. An overwhelming 73.3% of respondents had questions they needed answers to after normal business hours when a provider or CFF representative was unavailable (Figure 1). Each respondent reported having access to a smartphone with internet access, versus 67% with internet access using a personal computer. As initially thought, awareness is the key, and providing virtual access to available resources will increase knowledge of resources and likelihood of usability, connecting patients and caregivers with the CFF. A literature review of the topic did not yield any results and therefore no comparison was able to be made regarding the usefulness of the program.

## **Section V. Interpretation and Implications**

### **Costs and Resource Management**

The virtual interviewer platform design is a cost-effective strategy to provide virtual advocacy for CF patients and caregivers. The platform was developed in conjunction with a doctoral student pursuing a degree in computer science at no cost but did involve time and effort of both the developer and script writer. Time was spent with both the CFF Central Eastern Carolinas site champion and CF Care center site facilitator to determine information to be included on the platform.

The Cystic Fibrosis Virtual Patient Advocate resources were created to disseminate to patients and caregivers at various sites. Education information sheets, quick reference cards, and survey copies were created. Using my laptop, a Google doc survey form was created that would be used to assess prior knowledge of and use of CFF resources. Original plans involved laptops being provided to patients in the clinic to increase the likelihood of survey completion (Appendix A). The electronic version was chosen to provide real-time feedback to the program coordinator and to provide data points as patients presented to a clinic and completed the survey. The resources would be given, and then a post-survey would be provided for completion on the return visit. Typically, patients return in 8-10 weeks for routine follow up.

Due to COVID-19 pandemic restrictions, a paper copy was adopted (Appendix C) so that patients were not utilizing the same device and staff were not responsible for cleaning electronic devices between patients. As noted in Appendix D, portable file totes were purchased along with file folders, disposable pens, and paper surveys and provided to staff to organize materials. Later, additional resources were purchased to account for the lack of patient appointments in the primary care setting during the implementation period. Envelopes, stamps, and additional letters



were utilized to distribute information to seven identified CF families in the primary care practice setting (Appendix D). Additional time was spent preparing these items for mailing along with primary care office staff addressing the envelopes to maintain patient privacy.

If the organization was conducting the project without the benefit of student labor and expertise, the project cost would have been around \$50,000 (Appendix D). Additional time and resources would be necessary to take this to a more significant scale. Although many aspects of the CFF VPA script would be across the board for all chapters, many topics would need to be specific to the location or local area to ensure optimal value for patients and caregivers. Additional funds would be necessary to have education information sheets and quick reference cards provided throughout North Carolina.

As with any project, there is room for improvement on repeat implementation. The first consideration or improvement to consider would be to collaborate with a software applications developer to expand the platform to include the ability to be utilized from a smartphone or device other than a personal computer (PC). The original thought was for quick access using a smartphone to scan the QR code and access both the VPA and the CFF chapter website. Unfortunately, the current platform as developed functioned solely on a PC.

The second change I would make if replicating would be expansion of the resource to the CF care center adult clinic and utilization of a listserv for efficient and early distribution of the resource. This would ensure that information reached more patients and caregivers in a timely manner. This would combat the issue that presented itself when in-person patient volume decreased in clinics due to COVID-19. Continuing to advertise the program with site staff to assist in capturing those patients who are newly diagnosed and not yet added to a listserv or those with CF who are new to the geographic area and have not yet connected with the local CFF

chapter is essential. Other resources, including posters placed in patient care areas of clinics, would be an additional way to spread awareness and could include the QR code and link.

### **Implications of the Findings**

The Cystic Fibrosis Central Eastern Carolinas Chapter benefited from the implementation of the VPA and QR code dissemination. Three new families contacted representatives of the chapter after receiving the resources. Although post-survey data was not abundant, numerous responses on the pre-survey indicated caregivers and patients were unaware of the local chapter resources. The responses indicated that they would be interested in connecting with the local chapter and in potentially utilizing a VPA if they had access to the technology. They reported having questions for which they needed answers in the past that they did not feel were important enough to ask a provider or nursing staff member or that occurred after normal business hours.

Awareness is critical, and making patients, caregivers, and site staff aware of the resources available is beneficial for all involved. CF chapters statewide and nationwide can adopt the premise behind the implemented program to connect area CF patients and caregivers to their chapter and resources. The quality of life for the CF population can be improved through connections made via the VPA, awareness of the resources and the information provided through the resources.

### ***Implications for Patients***

A diagnosis of a rare disorder, like Cystic Fibrosis, can leave a family feeling isolated. CF patients and caregivers may benefit by connecting with others that have CF or those who are educated and familiar with the disease process and available resources. The VPA avatar allows the patient and caregiver a personal advocate they can connect with when exploring CF topics. Connecting the CF community will increase the quality of life of those involved. The QR code

is paramount in quickly accessing and being connected to available resources. Providing more accessibility to a central location that provides information on diverse, relevant topics will allow the patient and caregiver to focus in on their needs without the burden of time-consuming web searches. The VPA is categorized and allows the patient a central location to peruse and determine individual needs or interests. Unlike a search feature that requires the consumer to know search terms or key words, the VPA platform provides topics that assist the patient or caregiver in determining unique learning needs. For example, users may not be aware that college scholarships specific to a CF diagnosis exists and, therefore, are not prepared to search for them. Connecting with and establishing a relationship with the local CFF chapter with knowledgeable representatives who can help provide an avenue to become involved in all aspects of living with a rare disease process is invaluable.

### ***Implications for Nursing Practice***

The nursing profession, in general, has a desire to connect their patients with resources that will improve their quality of life. Promoting an advocacy program will allow nurses an avenue to educate the CF population. The surveys provided information for nursing staff on patients' and caregivers' needs and questions. The CF care center facilitator noted that she has been caring for CF families for years and had coordinated a parent education group for CF families. She was surprised that the topics she thought would be important were not necessarily the topics identified by parents (CF Care Center Nurse, personal communication, October 8, 2020). Polling families to determine their needs helps both the CF community and the nurses that care for them.

***Impact for Healthcare System(s)***

Outreach into the primary care and health department settings captures patients and caregivers that were not already connected to a CF care center or a local CF chapter. Providing awareness and resources through education increases access to the healthcare system. The CF population will have an improved quality of life with the connections made. The interactions between patients, caregivers, and providers will benefit all involved in CF care, including the formal healthcare system.

**Sustainability**

The virtual interviewer platform can be easily updated with current events and new resources. The standard VPA link and QR code can quickly connect patients to the new updated information. The project platform allows for disseminating current information in a virtual manner that connects the CF community to resources in one central location. Making changes to the platform is easy and can be done by one individual that works in conjunction with the local CFF chapter. The individual that maintains the site can be a volunteer with access to current information provided by CF staff. The program is sustainable and has the potential for improvement and expansion in the future. Ultimately, expansion to be added to the CFF's platform nationally would benefit a more significant number of patients and caregivers.

**Dissemination Plan**

Plans to disseminate the project process, resultant data, and ideas for sustainability begin with formal presentation during the ECU College of Nursing DNP Project presentation for students and faculty at ECU in July 2021. Additionally, the outcomes will be presented to the CFF Central Eastern Carolinas Chapter. Although no patient data was collected during

implementation at the other implementation sites included in the project, they will be included in follow-up project dissemination meetings.

The project report will be submitted to *The ScholarShip*, East Carolina University's Institutional Repository. The *ScholarShip* is a digital archive for the scholarly output of the East Carolina University community (East Carolina University, n.d.). Future searches for project details will be possible on databases and commercial search engines like Google via *The ScholarShip* search and Uniform Resource Locator (URL) provided. Publication in several journals will be considered.

## **Section VI. Conclusion**

### **Limitations and Facilitators**

As detailed in Appendix E, through Plan-Do-Study-Act (PDSA) cycles, the COVID-19 pandemic led to significant deviations throughout the project process. The pandemic created the inability of patients to utilize electronic devices, as the hospital implemented safety protocols to protect patients from the spread of the virus. A change from in-person visits to virtual visits were additional changes in patient care and services as an intervention to limit viral exposure. Patient volume decreased in the clinic as a result. The initial project plan included patients seen in the clinic over the 12-week implementation period where nursing staff could provide electronic surveys, education materials and educate the patients on the project resources. Access to sites, site partners, and patients was limited as staff began working from home; clinics were closed as a response to the pandemic. The resulting project included paper versions of surveys, a decreased volume of data, and extended length of access to data from site partners.

Virtual methods of correspondence and access to technology facilitated the creation of the new project process. Communication with site partners and the staff were maintained via virtual means, email, and phone conferences. Google forms were utilized to share updates on data with site partners. Although deviations in the process caused alterations in the project, technology facilitated the continuation of the project.

### **Recommendations for Others**

Awareness and education are keys to optimal patient care and patient outcomes. Increasing the number of patients and caregivers reached would be the initial recommendation for persons attempting to replicate this project. Increasing the number of sites for implementation would improve the volume of patients reached. There are currently 70 Cystic

Fibrosis Foundation chapters and branch offices across the country (Cystic Fibrosis Foundation, n.d. Find a Local Chapter section). The project process provided educational materials to in-person patient encounters. COVID-19 resulted in a limited number of patients encountered and inability to utilize electronic surveys in the clinic setting. Electronic versions of surveys would be beneficial when implementing this project at re-implementation to improve timeliness of data collection and utilization. Future recommendations would include emailing materials to all known CF patients in participating clinical sites, to families of newly diagnosed patients, or patients transferring their care to new providers as a result of being new to the geographic area. Utilizing a listserv for current patients will capture those that may not present for in-person appointments routinely.

### **Recommendations Further Study**

Virtual patient advocacy is a valuable tool that is designed to ensure patients are connected to needed resources. The following steps to connect the CF community would be best managed through virtual methods and include expanding the project to the other North Carolina Chapters and then nationwide. On a local level, providing education materials to other health departments, practice sites, and CF care centers will improve the likelihood of capturing more patients. “I think your project can make a real impact...it will be super helpful” (CF Care Center Nurse, May 21, 2021). Implementing a virtual advocate in western NC would be recommended before expanding to other states.

For real-time conversations between patients, caregivers, CFF, or CF Specialty Clinic staff, a live chat box feature was initially envisioned to connect CF patients and caregivers. The live chat box feature requires additional personnel to monitor the chat lines and provide evidence-based responses. Additional funding would be needed to become a reality.

The VPA avatar platform could be expanded to other disease processes. Many organizations and communities could benefit from a virtual advocate that will educate and be aware of resources. Medical conditions can be overwhelming and time-consuming; knowing what you need to know and where to look for answers can be even more overwhelming. Providing a central location for resource awareness is beneficial as numerous hours can be spent searching for knowledge.

### **Final Thoughts**

Patient advocates are an essential aspect of patient care and improving quality of life. The cystic fibrosis population has an increased need to access care and services virtually as their risks of complications from exposure to viruses and bacteria are greater than the risks of the general population. Social distancing and virtual care are ways to maintain safety within the population. Advocacy is necessary to ensure CF patients are aware of available resources and connect them to the CF community. Providing virtual advocacy increases the likelihood patients and caregivers will be aware of and connect to the appropriate available resources.



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## Appendix A

Table 1

*AANC DNP Essentials*

<b>AANC DNP Essentials</b>	
<b>Essentials</b>	<b>Competency / Description</b>
Essential I  <i>Scientific Underpinning for Practice</i>	<p><b>Competency</b> – Analyzes and uses information to develop practice</p> <p><b>Competency</b> -Integrates knowledge from humanities and science into context of nursing</p> <p><b>Competency</b> -Translates research to improve practice</p> <p><b>Competency</b> -Integrates research, theory, and practice to develop new approaches toward improved practice and outcomes</p>
Essential II  <i>Organizational &amp; Systems Leadership for Quality Improvement &amp; Systems Thinking</i>	<p><b>Competency</b> –Develops and evaluates practice based on science and integrates policy and humanities</p> <p><b>Competency</b> –Assumes and ensures accountability for quality care and patient safety</p> <p><b>Competency</b> -Demonstrates critical and reflective thinking</p> <p><b>Competency</b> -Advocates for improved quality, access, and cost of health care; monitors costs and budgets</p>

	<p><b>Competency</b> -Develops and implements innovations incorporating principles of change</p> <p><b>Competency</b> - Effectively communicates practice knowledge in writing and orally to improve quality</p> <p><b>Competency</b> - Develops and evaluates strategies to manage ethical dilemmas in patient care and within health care delivery systems</p>
<p>Essential III</p> <p><i>Clinical Scholarship &amp; Analytical Methods for Evidence-Based Practice</i></p>	<p><b>Competency</b> - Critically analyzes literature to determine best practices</p> <p><b>Competency</b> - Implements evaluation processes to measure process and patient outcomes</p> <p><b>Competency</b> - Designs and implements quality improvement strategies to promote safety, efficiency, and equitable quality care for patients</p> <p><b>Competency</b> - Applies knowledge to develop practice guidelines</p> <p><b>Competency</b> - Uses informatics to identify, analyze, and predict best practice and patient outcomes</p> <p><b>Competency</b> - Collaborate in research and disseminate findings</p>
<p>Essential IV</p> <p><i>Information Systems – Technology &amp; Patient Care Technology for the Improvement &amp; Transformation of Health Care</i></p>	<p><b>Competency</b> - Design/select and utilize software to analyze practice and consumer information systems that can improve the delivery &amp; quality of care</p> <p><b>Competency</b> - Analyze and operationalize patient care technologies</p> <p><b>Competency</b> - Evaluate technology regarding ethics, efficiency and accuracy</p>

	<p><b>Competency</b> - Evaluates systems of care using health information technologies</p>
<p>Essential V</p> <p><i>Health Care Policy of Advocacy in Health Care</i></p>	<p><b>Competency</b>- Analyzes health policy from the perspective of patients, nursing and other stakeholders</p> <p><b>Competency</b> – Provides leadership in developing and implementing health policy</p> <p><b>Competency</b> –Influence’s policymakers, formally and informally, in local and global settings</p> <p><b>Competency</b> – Educates stakeholders regarding policy</p> <p><b>Competency</b> – Advocates for nursing within the policy arena</p> <p><b>Competency</b>- Participates in policy agendas that assist with finance, regulation and health care delivery</p> <p><b>Competency</b> – Advocates for equitable and ethical health care</p>
<p>Essential VI</p> <p><i>Interprofessional Collaboration for Improving Patient &amp; Population Health Outcomes</i></p>	<p><b>Competency</b>- Uses effective collaboration and communication to develop and implement practice, policy, standards of care, and scholarship</p> <p><b>Competency</b> – Provide leadership to interprofessional care teams</p> <p><b>Competency</b> – Consult intraprofessionally and interprofessionally to develop systems of care in complex settings</p>

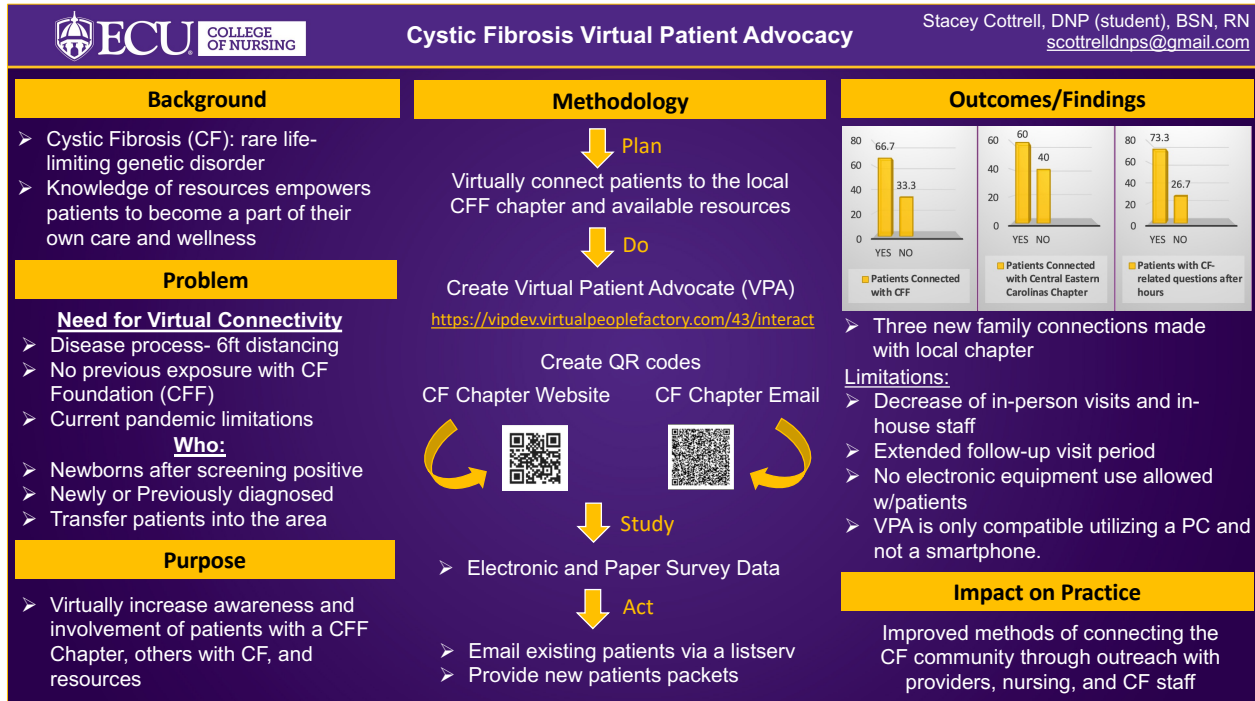
<p>Essential VII</p> <p><b><i>Clinical Prevention &amp; Population Health for Improving the Nation's Health</i></b></p>	<p><b>Competency-</b> Integrates epidemiology, biostatistics, and data to facilitate individual and population health care delivery</p> <p><b>Competency –</b> Synthesizes information &amp; cultural competency to develop &amp; use health promotion/disease prevention strategies to address gaps in care</p> <p><b>Competency –</b> Evaluates and implements change strategies of models of health care delivery to improve quality and address diversity</p>
<p>Essential VIII</p> <p><b><i>Advanced Nursing Practice</i></b></p>	<p><b>Competency-</b> Melds diversity &amp; cultural sensitivity to conduct systematic assessment of health parameters in varied settings</p> <p><b>Competency –</b> Design, implement &amp; evaluate nursing interventions to promote quality</p> <p><b>Competency –</b> Develop &amp; maintain patient relationships</p> <p><b>Competency –</b>Demonstrate advanced clinical judgment and systematic thoughts to improve patient outcomes</p> <p><b>Competency –</b> Mentor and support fellow nurses</p> <p><b>Competency-</b> Provide support for individuals and systems experiencing change and transitions</p> <p><b>Competency –</b>Use systems analysis to evaluate practice efficiency, care delivery, fiscal responsibility, ethical responsibility, and quality outcomes measures</p>

*Note: American Nurses Credentialing Center (ANCC) Doctor of Nursing Practice (DNP) Essential Competencies.*

Appendix B

Figure 1

Cystic Fibrosis Virtual Patient Advocacy DNP Poster

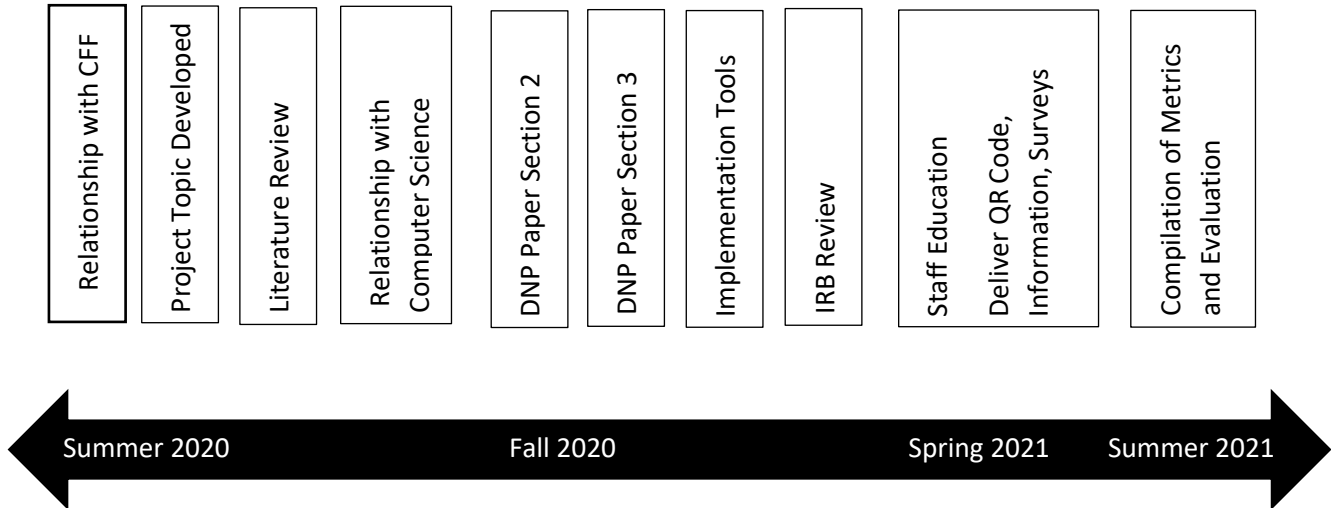




Appendix C

Figure 2

Project Timeline



**Appendix D**  
**FORM 8274A**  
**Project Implementation Worksheet & Tools**

Student's Name \_\_\_\_\_ Stacey Cottrell \_\_\_\_\_

Project Site Champion \_\_\_\_\_ CFF Project Partner \_\_\_\_\_

Project Name \_\_\_\_\_ Cystic Fibrosis Virtual Patient Advocacy \_\_\_\_\_

What data will you be collecting?

- Number of CF patients/caregivers who have utilized the CFF Central Eastern Carolina's Chapter CFF
- Prior knowledge of CFF and use of CFF resources
- Number of CF patients/caregivers given VPA link and QR codes
- How many CF patients/caregivers utilized the Virtual Patient Advocate (VPA) and ease of use with perceived patient/caregiver benefit
- How many CF patients/caregivers utilized QR Code to access CFF Central/Eastern Carolina's Chapter site and ease of use.
- How many CF patients/caregivers utilized QR Code to connect with CFF Central Eastern Carolina's Chapter via direct email, establishing a relationship between the patient/caregiver and local resources and usefulness of this feature.

Where will you get the data?

- From staff at each access point (Care Center, Health Department, and Primary Care Provider) where implementation is to occur and will be obtained directly from patients/caregivers.
- From patients pre survey and post surveys
- From Central/Eastern Carolina CFF chapter staff- number of email contacts made

How often will you be at the project site?

- Weekly, beginning with implementation and education of staff followed by weekly collection of surveys and data.
- As needed for evaluation of process and follow through with staff.

How often will you meet with your site champion?

- Weekly- by phone/email to discuss progress and additional needs and site maintenance

What tools will you use to track implementation and data (PDSA, Excel tracking form, etc.)?

- Google Docs Survey
- Google Docs Timeline
- Excel tracking form via Google Doc

Why did you select this tool or method? Succinctly and thoroughly tell faculty why this seemed like the optimal tool/method.

- Google Docs is a program that is familiar and making a timeline utilizing google spreadsheets will be a quick and easy way to add and provide quick updates among the team members.

What is the implementation methodology or change theory that you are using to guide you through the implementation phase of the project?

- Havelock's (1973) model is a modified version of Lewin's 1951 model of change. It involves six phases that begin with building a relationship with a project partner and ending with monitoring the process to determine if change was successful and able to be maintained (Havelock, 1973).

Why did you select this tracking tool/method? Succinctly and thoroughly tell faculty why this seemed like the optimal tool/method.

- Havelock's (1973) model is a modified version of Lewin's 1951 model of change and seemed as it would follow along the pathway to achieve the desired goal based on knowledge of intent of DNP project. The PDSA cycle will assure that the six steps are accomplished and reassessed and redesigned as needed

6 steps:

1. Establishing a relationship and predetermining a need for change in the system
2. Diagnosing the problem
3. Assessing possible solutions to the identified issue
4. Selecting a pathway for the solution from Evidenced-Based methods
5. Promoting the implementation
6. Monitoring the affected system to ensure the change is successful and maintained

How will you communicate changes and project status to each member of your project team – academic and team members with the project site?

- Email correspondence
- Face-to-face visits
- Phone communication

Complete the following dates and map these on a timeline (Google "timeline" and construct your timeline using Word, PowerPoint, or Excel)

Date Implementation began or will begin \_\_\_\_\_ 02/10/2021 \_\_\_\_\_

Date (after 1/19/2021) for meeting with site champion to discuss your chosen tools and timeline.  
\_\_\_\_\_ 01/28/2021 \_\_\_\_\_



**Appendix E**  
**FORM 8274.C**  
**DNP Project Implementation Report**

**Project Progress**

The Cystic Fibrosis Virtual Patient Advocate project overall went as expected. The initial project implementation plan had to be deviated from slightly as COVID-19 affected some aspects of the original plan. Original planning included electronic design for survey completion, while in the clinic setting, to increase likelihood of completion. Patients with a potential CF diagnosis or an established CF diagnosis would complete the survey while in the presence of office staff on a provided electronic device and an information packet would be given for resource utilization. A follow up survey would be obtained at 8-10 week return visits on the same electronic device in clinic. Unfortunately, the site had process changes due to COVID-19 and would not allow electronic device use, between patients, therefore paper and pen method had to be adopted. This affected collection timing of survey data. Patient volume seen in the CF care center was also affected by COVID-19, as patient visits were switched to a virtual method and follow up appointments were extended beyond their usual timing, resulting in inability to obtain post-survey data. The pediatric provider site reported only having seven established patients diagnosed with CF and none were scheduled for a visit during the implementation period (Private Pediatric Provider Nurse, personal communication, February 18, 2021). The health department had no patients present during implementation with a positive screening or diagnosis of CF. The site partner stated that their overall volume is low in general as she has only had one positive CF screening sweat test in the past 6 months that came through clinic.

Plan-Do-Study-Act (PDSA) as seen in Appendix E, is a four-stage problem solving model used for improving a process or carrying out a change (Institute for Healthcare

Improvement, 2021). Using the PDSA worksheet, I determined modifications would be needed to account for the inability to use the electronic devices for VPA use and data collection and the decrease in patient volume in clinics. Paper versions of surveys were developed and distributed to replace electronics and resource packets were created and mailed with the assistance of pediatric primary care provider staff. CF care center staff emailed resources to a Patient Advisory Board group for utilization.

In retrospect, I would have planned to disseminate information to all CF care center patients as a group, electronically through a list serv method. This could have been done in combination with in-person visits to capture optimal data and increase visibility and awareness of the project resources. I believe having done this would allow more data to have been obtained and would have ensured all CF patients established within the center who had access to email would have been given the opportunity to have the information and complete a survey.

The premise behind the project overall for the project site champion was to increase awareness and connection to the local CF chapter and available resources, so I am excited to note that connections were made even though post survey collection was not possible. Three families received the information and contacted the local chapter. The site champion verbalized her excitement in having three new family connections (CFF project partner, personal communication, March 31, 2021).

### **Project Champion Meetings**

I met virtually with my project champion bi-weekly throughout the implementation period. I did not meet face-to-face with the project champion due to COVID-19 restrictions and staff working from home and not working from the organization. I had 21 total meetings with the project champion and three implementation sites. CF Care Center, Pediatric Provider Clinic,

and local Health Department were additional sites where the project was implemented. I met with only one staff member each at the CF Care Center and Pediatric Provider clinic, the CF care center nurse and Pediatric Provider office manager. I contacted two staff members at the health department, the family practice provider and the staff nurse.

### **Project Sustainability**

The plan is to continue the project past this semester as awareness and education on available resources is vital to the growth and connections of this community. Improved awareness and access to services will lead to improved quality of life for those with CF. The platform used can successfully be used in other chronic disease processes.

### **Organizational Changes**

An educated staff member, that is dedicated to maintaining updated information in the Virtual Patient Advocate (VPA) Platform, would be necessary to continue the project past the implementation semester. The staff member would need to be well versed in all things CF and be able to continue to ensure that QR codes for access to the VPA, CFF local chapter website, and the automatic email inquiry are also maintained when changes are made to any of the site uniform resource locator's (URL's). Distribution of these resource cards and information sheets need to be made available to the point of entry sites where patients will potentially enter the health care system. Staff education needs to be easily accessible to ensure continuity of compliance when there is staff turnover potential.

### **Project Benefits**

First, I feel I benefited from the project. I have a better understanding of the process involved in creating change in practice. There are a lot of moving pieces that must come together to have effective outcomes and a successful project. The best laid plans must be altered

when there are numerous people involved in the project and tasks are dependent on various team members who all have varying schedules, priorities, and buy-in with the project. Meeting deadlines can often be tricky when there are numerous members responsible for data collection.

Although there was not an abundance of data to support the benefit for the organization and patients surveyed, I believe both the organization and patients both benefited from the project. Patients that were initially surveyed voiced their excitement regarding the project resources both on paper and verbally to the site staff on distribution (CF Care Center nurse, personal communication, March 17, 2021). The site champion at the local CFF chapter, reported several CF parents communicating new family connections as a result of contact with and resources given with project distribution (CFF project partner, personal communication, March 31, 2021). Patients and caregivers gained benefit through awareness of local chapter and resources and the site gained benefit through new family connections.

### **Organization Recommendations**

I believe this platform is a way to offer valuable information, in one easily accessible location to resources available to a particular population. The project was designed for the Cystic Fibrosis population, but it could be replicated in other chronic disease settings. Although platforms exist for various disease processes, I feel there is not one place for all “available” resources, instead it is a fragmented system. It is almost necessary to know where to look and what to look for in order to find available resources. As the mother of a child with CF, the possibilities are overwhelming and each time I look, I find a new resource or outlet that could benefit the CF community. Awareness is the key and providing a resource platform for all things CF and distributing it to the CF population at diagnosis or transfer of care into the system is the best way to keep patients informed. This can be a platform utilized by other organizations and



chronic disease management groups as a “one stop shop” for all things related to the condition. I visualize it as the control center of resources. If you don’t know something exist to look for, you can’t look for it.

Although I tried to capture patients in different points of entry into the system, a CF care center, a private provider office, and a local health department, my recommendation for others who replicate the project would be to distribute the information not just to those in a clinic setting, but to distribute electronically to all via a list serv. I was dependent on patients presenting to clinic for appointments whether as a newly diagnosed patient or as an established patient being seen for follow up visits, but due to COVID-19 and the decrease in in person patient volume and process changes, I missed a large portion of the population during the defined implementation period.

I would also recommend utilizing electronic means of collecting data as originally planned. Paper forms were more tedious and involved manual input into a tracking tool and there was not an instant form of feedback as I would have preferred.

## **Conclusion**

Plan-Do-Study-Act (PDSA) is a four-stage problem solving model used for improving a process or carrying out a change (Institute for Healthcare Improvement, 2021). This implementation period required weekly PDSA use as it was a dynamic process. It seemed deviations from the original plan were a constant and necessary to overcome the challenges faced as a result of the global pandemic. Useful data was obtained from surveys and communication with patients, caregivers, and site representatives. Continued distribution of project resources is imperative to increasing connections between the CF community and the local chapter and available resources.

**Appendix F**  
**FORM 8274.B**  
**Project Management Report**

Name \_\_\_\_\_ Stacey Cottrell \_\_\_\_\_

Were you able to collect the data you thought you'd collect? Yes No  
 If no, why not? \_\_\_\_\_

Did you meet with your site champion on the date(s) you had planned to meet? Yes No

If not, why not? Winter Weather concerns, alteration in clinic schedule due to COVID-19 and post COVID- 19 shot #2 reaction, fever, body aches, chills requiring testing and absence from clinical sites.

Succinctly identify & discuss barriers to your implementation.

The first barrier to implementation involved miscommunication between my-self and the program developer regarding the Virtual Patient Advocate Avatar program accessibility. It was not made clear that the program was not compatible with mobile devices. The virtual interviewer platform design was only compatible with laptops and PC's. COVID-19 has also been a barrier that has prevented full implementation that was envisioned. Opportunities to meet with staff face to face is limited. Additional barriers presented themselves including not being able to use electronic devices as planned with patients to complete surveys and obtain real time data in the clinic setting. Data must be obtained by paper and obtained from staff, allowing time to compile data manually, changing the timeline of meetings.

Did you update/revise your tools (PDSA, data collection tools, etc.)? Yes No If No, why not?  
 \_\_\_\_\_

What date(s) were you at your project site during this implementation interval (face-to-face or virtually)?

2/5/2021 CF Care Center virtually, 2/5/2021, 2/10/2021, 2/15/2021 Health Department virtually, CF Care Center 02/8/2021 face to face, 02/12/2021 Health Department 02/12/2021 face to face, Pediatrics Provider 02/19/2021 face to face, CF Care Center 02/25/2021 face to face, Pediatric Provider 03/01/2021 virtually, 03/02/2021 Health Department face to face, 03/02/2021 Pediatric Provider face to face

Succinctly identify 1-3 things you've learned during this implementation interval.

During this implementation interval I learned that you must be flexible. Regardless of the amount of planning and forethought put into the process, things will occur that are outside your predetermined notions, and you must be adaptable.

***Statement of Collaboration***

We have collaborated on the revision of the Operational Tool, Tracking Tool, and agree that this project is on target with the timeline. As needed, provide additional comments on the following page.

Student Signature \_\_\_\_\_ Stacey Cottrell \_\_\_\_\_ Date \_\_\_\_\_ 03/05/2021 \_\_\_\_\_

Site Champion Signature \_\_\_\_\_  \_\_\_\_\_ Date \_\_\_\_\_ 03/05/2021 \_\_\_\_\_

**Comments**

This project that has great potential for expanding in the future to increase awareness and utilization of CFF chapter resources to the CF population.

## Appendix G

### Budget (Organization)

- **Personnel:**

Stacey Cottrell, Project Coordinator

Project Site Champion at CFF

Project Site Facilitator at CF Care Center

Project Site Facilitator at Pediatric Provider Clinic

Project Site Facilitators at Health Department

- **Equipment:**

\$250 x 3 (\$750) laptops for survey submissions and VPA avatar access in clinic setting

- **Supplies:**

\$200 Business cards for QR codes/ hyperlink for distribution

\$200 Patient information sheets for distribution

\$100 Patient Surveys Backup Paper Copies

\$5 Pens

\$150 Totes

\$20 File Folders

\$15 Stamps

\$10 Envelopes

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\$700.00

- **Other Expenses:**

\$49,300.00 staff labor

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Total: \$50,000

## Appendix H

### PDSA Cycle #1

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Create an initial electronic survey, QR codes for CFF local chapter website and email, and a VPA avatar. Discuss information with CF care center, local health department, and pediatric primary care site.



Due to COVID-19 and change in processes, hospital CF care center would not allow electronic surveys and requested paper survey copies be distributed with use of disposable pens instead.



Electronic survey process for patients was abandoned and a paper survey process was adopted, created and budgeted for.

### PDSA Cycle #2

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit. Education materials for websites, emails, and the VPA avatar platform was given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial paper survey and patient information sheet created. Survey, information sheet and QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits.



Due to COVID-19 pandemic and limitations on in-person interactions resulting in decreased patient volume, weekly collection of surveys was not feasible or worthwhile.



Abandoned weekly survey collections and adopted a bi-weekly check in for survey collection.

### PDSA Cycle #3

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit. Education materials for websites, emails, and the VPA avatar platform was given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits.



Eight surveys were collected from hospital CF care center, zero surveys were collected from health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits. As a result of COVID-19, less survey volume and fewer connections made than originally predicted. Realized CF patient population at pediatric primary care office had no scheduled visits during implementation period, and therefore only new diagnosed or newly evaluated patients would be encountered.



Adapted by asking pediatric primary care provider to mail a copy of the information sheet with a newly created letter explaining the project along with survey, QR codes, and VPA avatar link to current CF patients of the practice to capture this population within the implementation period.

#### PDSA Cycle #4

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



A survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit and current patients who did not have a scheduled appointment during implementation period at 3 different entry point in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits and provided pediatric primary care practice manager with packets inclusive of all materials and newly created introduction letter with addition of pre-addressed, stamped envelopes for mailing and return of survey. Surveys were collected bi-weekly to obtain and compile data.





Observed lower volume of patient encounters due to fewer in-person visits. As a result of COVID-19, less survey volume and fewer connections made than originally predicted.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators to assess needs for additional materials. Communicated with project site champion to assess contacts made with CFF Central Eastern Carolinas Chapter as a result of the project. Updated VPA avatar platform with new events as needed.

### PDSA Cycle #5

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit and current patients who did not have a scheduled appointment during implementation period at 3 different entry point in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during

clinic visits and electronic versions available for encounters that aren't in-person. Surveys were collected bi-weekly to obtain and compile data.



Two surveys were collected from the hospital CF care center, zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits. As a result of COVID-19, less survey volume and fewer connections made than originally predicted.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #6

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit and current patients who did not have a scheduled appointment during implementation period at 3 different entry point in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits and electronic versions for those patient encounters not in-person. Surveys were collected bi-weekly to obtain and compile data.



One survey was collected from the hospital CF care center, zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits. Hospital CF care center staff requested to send electronic versions of materials to Patient Advisory Board group.



Adopted an additional method of survey collection and resource distribution, to include electronic submission by email. Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #7

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?

- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits, provided via mail to pediatric primary care practice patients, and electronically to a CF Patient Advisory Board. Surveys were collected bi-weekly to obtain and compile data.



Zero surveys were collected from the hospital CF care center, zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #8

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?

- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits, provided via mail to pediatric primary care practice patients, and electronically to a CF Patient Advisory Board. Surveys were collected bi-weekly to obtain and compile data.



Zero surveys were collected from the hospital CF care center, zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #9

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits, provided via mail to pediatric primary care practice patients, and electronically to a CF Patient Advisory Board. Surveys were collected bi-weekly to obtain and compile data.



One survey was collected from the hospital CF care center, zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #10

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina’s Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry

points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform will be given, in addition to a pre-survey.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



Initial survey, patient information sheet, pre-survey, QR codes for CFF local chapter website and email, and a VPA avatar provided to site staff to provide to patients during clinic visits, provided via mail to pediatric primary care practice patients, and electronically to a CF Patient Advisory Board. Surveys were collected bi-weekly to obtain and compile data.



Four surveys were collected from the hospital CF care center via electronic submissions from CF Patient Advisory Board, zero surveys were collected from the health department and pediatric primary care practice. Implementation period near completion.



Ensure CF Patient Advisory Board and the Pediatric Primary Care have Post Survey via mail for electronic dissemination. Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #11

**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey. A post-survey was created to be made available to site facilitators to distribute to patients in-person, by mail, or electronically.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



A pre-survey and post-survey were distributed to site facilitators to distribute to patients in-person, by mail, or electronically. Surveys were collected bi-weekly to obtain and compile data.



Zero surveys were collected from the hospital CF care center and zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress.

### PDSA Cycle #12



**Objective:** To virtually connect Cystic Fibrosis patients and caregivers to the Central Eastern Carolina's Chapter of the Cystic Fibrosis Foundation and available resources.



An initial survey was given to identified, diagnosed CF patients and caregivers when presenting for a clinic visit, current patients who did not have a scheduled appointment during implementation period and a CF Patient Advisory Board group, through 3 different entry points in the healthcare system. Education materials for websites, emails, and the VPA avatar platform were given, in addition to a pre-survey. A post-survey was created to be made available to site facilitators to distribute to patients in-person, by mail, or electronically.

- Are current patients and caregivers already aware of and connected to the local CFF Chapter? Are they aware of and utilizing available resources?
- Are there newly screened and diagnosed patients, that due to COVID-19, unable to access providers and nursing staff in-person? Due to the change in process, were they not made aware of the local CFF Chapter and available resources?
- Capture patients and caregivers presenting to clinic visits at 3 different entry points in the healthcare system. A hospital CF care center, a local pediatric primary care office, and a local health department that services an adult and pediatric population.



A pre-survey and post-survey were distributed to site facilitators to distribute to patients in-person, by mail, or electronically. Surveys were collected bi-weekly to obtain and compile data.



Zero surveys were collected from the hospital CF care center and zero surveys were collected from the health department and pediatric primary care practice. Observed lower volume of patient encounters due to fewer in-person visits.



Continued to monitor flow of survey data and patient volume, communicating with site facilitators and project site champion to assess progress. Created visuals and reports for site dissemination of project.