

## Poster Session Abstracts

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## OPTIMIZING NEWBORN SCREENING FOR CYSTIC FIBROSIS IN ALABAMA: A QI PROJECT

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**Background:** Newborn screening (NBS) for CF was implemented in Alabama in 2008. We identified program barriers on the level of families, primary care pediatricians (PMD), and communication practices. This QI project addressed these barriers to decrease time to sweat testing, improve the knowledge and experience of PMDs, and increase the satisfaction of families undergoing screening.

**Methods:** We used PDSA cycles to test and implement change ideas. 1. **PMDs.** An educational tool for PMDs was developed and included a script, likelihood of diagnosis, and what families would expect of their visit at the NBS clinic. The tool was faxed to PMDs after initial discussion with the NBS coordinator. Additionally, on-site 30-minute educational sessions were implemented, with a pre/post survey to assess knowledge and satisfaction. 2. **Families.** Prior to the appointment, the NBS coordinator contacted families to answer questions and offer support. A genetic counselor was added to the team to answer questions. A post-visit survey assessed knowledge, anxiety, and satisfaction among families.

**Results:** We received 171 referrals on NBS-positive babies: 18 CF, 10 CRMS, 143 carriers. Mean days to sweat test decreased from 16 to 15 days (range 1-59, median 14). 1. **PMDs.** The educational tool was delivered to 83% of 171 PMDs. On-site educational sessions were provided at 5 pediatric practices and 1 AAP regional meeting. Of 51 PMDs surveyed, 61% reported to have referred a patient to the NBS clinic; of them, 81% reported satisfaction with their patient's experience and none reported dissatisfaction. At baseline, only 39% of PMDs correctly identified the median predicted survival for people with CF in the US, 29% the carrier rate for Caucasians, and 27% for African Americans. After the educational session, correct answers increased to 96%, 80%, and 88%, respectively ( $p < 0.001$  for all). Similarly, at pre-test, only 35% correctly identified the NBS method for CF screening in Alabama, compared to 94% at post-test ( $p < 0.001$ ). The proportion of PMDs who knew that there is only one accredited CF center in the state increased from 61% to 99% ( $p < 0.001$ ). The mean total number of correct responses increased from 1.9 to 4.5 ( $p < 0.001$ ). 2. **Families.** Of all referred families ( $N = 171$ ), 63% could be reached prior to their appointment. Of 44 surveyed families, 66% were White, 30% Black; 32% had high-school education or less, 30% were college graduates. In the survey, 84% reported receiving a call from the NBS coordinator; the call was rated 4.9 (SD 0.4) on a 1-5 scale (1=worst, 5=best). The overall experience in the NBS clinic was rated 4.9 (SD 0.3). Positive NBS test induced anxiety (4.1 on 1-5 scale, where 1=No anxiety to 5=Extreme anxiety). One-third (32%) remained anxious about their baby's health even after a normal sweat test, 23% worried about their baby's health due to being a carrier, and 23% responded that carrier status affected their decision to have more children.

**Conclusion:** This QI project decreased time from referral to sweat testing, improved the knowledge of NBS among PMDs, and enhanced the family experience. Given the success of the intervention, we will continue educational sessions with PMD practices via web-conferencing and work to improve family education during NBS clinic visit.

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## A VIRTUAL CLINIC AND REMOTE MONITORING IN CHILDREN WITH CYSTIC FIBROSIS

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**Background:** Children with cystic fibrosis and their parents spend a lot of time in hospitals. Today novel gadgets exist to allow CF patients to conduct health examinations at home that are normally performed in hospitals. This patient's health information can be shared digitally with their health provider and be the basis for a teleconference meeting with the CF clinic. The aim of this study was to investigate if children 6–17 years old can perform spirometry at home and to evaluate the experience of the virtual meetings of all participants.

**Method:** All children aged 6–17 at Gothenburg's pediatric CF center were informed about the project that included two virtual meetings with their CF clinic. The participants were all equipped with a mobile spirometer (Air Next, Nuvoair) and a digital scale. Prior (same day or three days before) to the virtual visit the patient should have performed a spirometry, weighed themselves and sent a pre-visit report through the CF-app Genia. The spirometry results are accessible for the clinical team through a caregiver portal and the pre-visit reports were accessible through the Swedish CF-registry portal. A digital questionnaire was sent to all participants after they have completed the survey.

**Results:** A total of 13 patients (age 6–17 years old) and their parents were included in the survey. During a period of six weeks 26 virtual visits were performed. A correct spirometry according to ERS/ATS criteria was performed by 12/13 children. All participants managed to create and share a pre-visit report before the virtual meetings. The questionnaire was completed by 11 children and 13 parents. The children and their parents valued the virtual meeting as "very good" and "good" and all participants were positive to continue with virtual meetings. The virtual meeting was valued as "better" or "equal" compared to a physical meeting by 23/24 of the participants (children and parents). To attend a physical visit at the hospital the participant normally had to travel on average 120 km and take ½–1 day off from work and school.

**Conclusion:** This study indicates that it is possible for children to perform spirometry and other health-related measurements at home. Children with CF and their parents were positive to continue with virtual visits. In June 2020 Gothenburg pediatric CF center started a prospective multicenter study including 70 children aged 5–17 in Sweden to compare the outcome of CF disease (respiratory, nutritional and quality of life) before and after introducing virtual visits.

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## ACCELERATED IMPLEMENTATION OF A VIRTUAL VISIT PROGRAM AT A COMMUNITY HOSPITAL CF PROGRAM DURING THE COVID-19 PANDEMIC

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**Background:** Our 80 adult CF patients travel from up to 300 miles and we sought to improve the experience of care by instituting a virtual visit (VV) program. Planning was initiated pre-COVID-19 pandemic (preC19). Implementation of our VV program was expedited during the COVID-19 (C19) pandemic. The VV program may allow patients to be seen even more frequently than in clinic, with comparable experience of care and potentially less unengaged time during visits. Ease of scheduling and lack of need to be physically in CF clinic may provide increased convenience to providers.

**Methods:** Our CF team and patient representatives participated in the quality improvement initiative. Operationally, GoToMeeting (HIPAA compliant) was selected after testing multiple VV platforms. Staff underwent VV platform training, and VV equipment was selected. Inter-team communication centered around a team "quarterback" and using texting through our EHR. Number of total sick visits, follow-up visits and regular quarterly virtual visits (3/19/20 - 5/26/20) were collected and compared to a similar time period preC19 when all visits were in clinic (1/7/20 - 3/2/20). The patients' total in-clinic time (TT), engaged (ET) and unengaged time (UT) during in-clinic visits ( $n = 43$ ) are compared to VV times ( $n = 39$ ). The TT, ET and UT was measured for 6 virtual visit clinic days in total. Times collected started at virtual check-in to the clinic and finished with virtual check-out. An Excel spreadsheet was used to collect all data. Patient and provider satisfaction were assessed through a SurveyMonkey.

**Results:** The total number of routine in clinic visits were 36, follow-up visits 10 and sick visits 3 during the preC19 time period. The total number of routine VV were 31, follow-up visits 18 (+1 in clinic) and sick visits 7 during the C19 time period. The median baseline in clinic UT was 21, ET 115 and TT 141 minutes. After initiating our VV program, our median UT decreased to 9, ET decreased to 69 and TT decreased to 75 minutes. Patient satisfaction survey (17 patients) revealed 94% believe it has had a positive effect on the patient-physician relationship. The Provider satisfaction survey (9 providers) revealed all CF team members believe VVs increase access to care. Provider concerns included technological issues