Appendix

Change package: to request access to the CFLN TH ILab, please contact the authors at: da9zj@virginia.edu

Agenda /pre-visit planning: to request access to a different AS PVP template please contact authors at: da9zj@virginia.edu

QI definitions

A key driver diagram (KDD) is a visual communication display tool that helps a team focus on testing interventions likely to achieve the aim of the project, while creating a common theory of improvement. A KDD includes a global aim in the top left corner to center the aspirational efforts of the improvement project, and a SMART aim below it. A SMART aim is Specific Aim, Measurable, Actionable, Realistic, and Timebound. To the right of the aims are the key drivers, which define the necessary conditions of successful improvement. Finally, a list of interventions to be tested in a Plan-Do-Study-Act format lie to the far right of the diagram. Interventions may be categorized as those in active testing, those ready for potential future testing, and those that have already been adopted or abandoned as a result of PDSA testing. Interventions are linked to the key drivers they influence with uni-directional arrows.

Appendix Figure 1. sFMEA Telehealth Simplified Failure Mode Effects Analysis; Adapted from Cincinnati Children's Hospital Medical Center A simplified FMEA is a process improvement tool to identify potential risks of failure in a process and identify process improvement strategies. Each process step is listed in a single textbox along the center of the diagram. In the textboxes below the process step, outlined in red, risks to successful completion of each step are named. The textboxes above the process steps, outlined in green, name the interventions identified to mitigate risk of process failure.

Appendix Figure 2a Factors which support IDC Interdisciplinary Care, PVP Previsit Planning, VV Virtual Visits, IT Information Technology

Appendix Figure 2b Factors which support Agenda Setting: PVP Pre-visit Planning, PEP Partnership Enhancement Program

Parent testimonial: In addition to the everyday challenges of balancing work, life, and child care when scheduling any medical appointments, there are many other factors parents, primary caregivers, and family members always consider when planning in-person pediatric CF clinic visits specifically, including meal planning and toilet access. Because of the quarterly schedule for CF care, these visits often last well over an hour, sometimes two, allowing providers in many

disciplines time to meet with the child. But of course young children with CF often need many snacks and meals throughout the day, which means packing accordingly, giving enzymes and feeding in the clinic setting while meeting with providers. Using bathrooms and keeping children entertained and focused for such long appointments can also be challenging

One great promise of virtual visits, then, is that many of these challenges are mitigated by being at home for appointments, or at least somewhere more conducive to caring for a young child and his or her needs. As the pandemic continued and telehealth became more of the default rather than the standard method for CF care, one drawback emerged of course. While tracking nutrition, height, weight, and eventually spirometry data for eligible patients was relatively easy to sustain, there is simply no substitute for having a doctor put a real ear to a real body.

As a response to both the advantages of telehealth and the irreplaceable need for some degree of in-person care, many centers now employ a mixed approach to quarterly care, in which some visits are still conducted virtually and some are in-person. The key to making the hybrid model successful is to make sure that families still feel that they can make the right decisions for themselves, whether that means seeing some providers in person and others virtually, perhaps less often

People with CF testimony

There exists both positive and negative aspects of telehealth virtual visits for the cystic fibrosis community. They added significant convenience in regard to ease of incorporating into daily routine and reduced time requirement for travel, and less time off from work or school. There are also some barriers involving ease of telehealth access and increased burden of participation for some patients and families, specifically those with technology literacy challenges. In my opinion, this, along with some outlined examples from my own telehealth experience below, highlights the potential result in a degree of avoidance of tele-appointments on the part of some patients.

In addition, clinical team's attention to shifting telehealth requirements, causing a new work environment and new technology, added challenges. For example, because of these changing work environments and shifting responsibilities, there may have been a lack of attention to following up with a patient if before a scheduled clinic appointment, the patient could not be successfully contacted. If a patient pre-visit agenda was sent through the health portal, but no acknowledgement of receipt was provided to the clinic from the patient, follow up should be made to assure the patient did receive the message and should serve as a reminder to the

scheduled appointment. To achieve greater success in assuring the patients attendance for the clinic telehealth appointment, multiple follow ups should be conducted if unsuccessfully contacted. If the patient didn't see the health portal message in time, and they were not receiving any other correspondence ahead of the scheduled meeting, this reduces the likelihood of participating in the clinic appointment.

Before telehealth appointments, typically a date for a future appointment would be set during the previous clinic visit. The burden that remained on the patient and family was to remember to attend the following appointment and coordinate their schedule by prioritizing commitments to make time. When covid began and all-in person appointments shifted to virtual, this added new responsibilities to patients. Due to HIPPA regulations, correspondence with patients had to be done through the health portals. If a patient wasn't accustomed to accessing and communicating with their team through this avenue, it created a potential barrier to participating and a decrease in willingness to adopt new clinic processes.

Being the nature of telehealth, routine testing cannot be performed during such visits like spirometer tests, blood draws, sputum cultures, and general physical examination. Because the results of these tests are a marker of health status and are an indication of a completed appointment, the lack of these performed tests could have resulted in less incentive to participate virtually. Outside of conversation between the care team and the patient and family on health status, no other concrete markers of health status could be obtained. The use of home spirometers across many clinics aided to bridge this, but the different environment perhaps resulting in less sense of pressure from the home setting, could contribute to a decreased sense of responsibility or performance requirements, resulting in less adherence to such a home test and less adherence to routine appointments overall.

At my center, blood and sputum samples collection could be conducted in person in the lab at the clinic, but a separate nursing appointment had to be scheduled by the patient directly for this to take place due to the organization and distribution of various roles within the CF clinic and the larger clinic building that houses the CF clinic. This extra step placed onus on the patient to remember to make a separate phone call and go into the clinic at an appointed time. For those patients who found telehealth coordination burdensome and shied from the responsibility of scheduling separate appointments, this could have been a deterrent.

The advent of telehealth clinic appointments did aid significantly to the convenience factor of routine appointments for many. It allowed for reduced time consumption, less transportation burdens, and less scheduling conflicts with other responsibilities. Nonetheless, attention needs to be given to the difference in nature between the level of care that can be provided by a telehealth appointment and by an in-person visit. For those who demonstrated responsibility for their care before covid, possessed technology literacy, and maintained communication with their care teams would have been more likely to continue with routine appointments. For those patients who may have been lax with their care before covid, the changes in responsibilities for scheduled appointments, and the lack of concrete appointment outcomes like completed test results could have contributed to a sense of wasted time for patients perpetuating a lack of

adherence to routine visits. Perhaps for those individuals, a shift back to in - person care to reestablish these cornerstones of care that they were familiar with, would resolidify their feelings toward the value of routine appointments and enable them to maintain routine care in the future.

Appendix Figure 3. UVA Adult CF clinic agenda setting example: