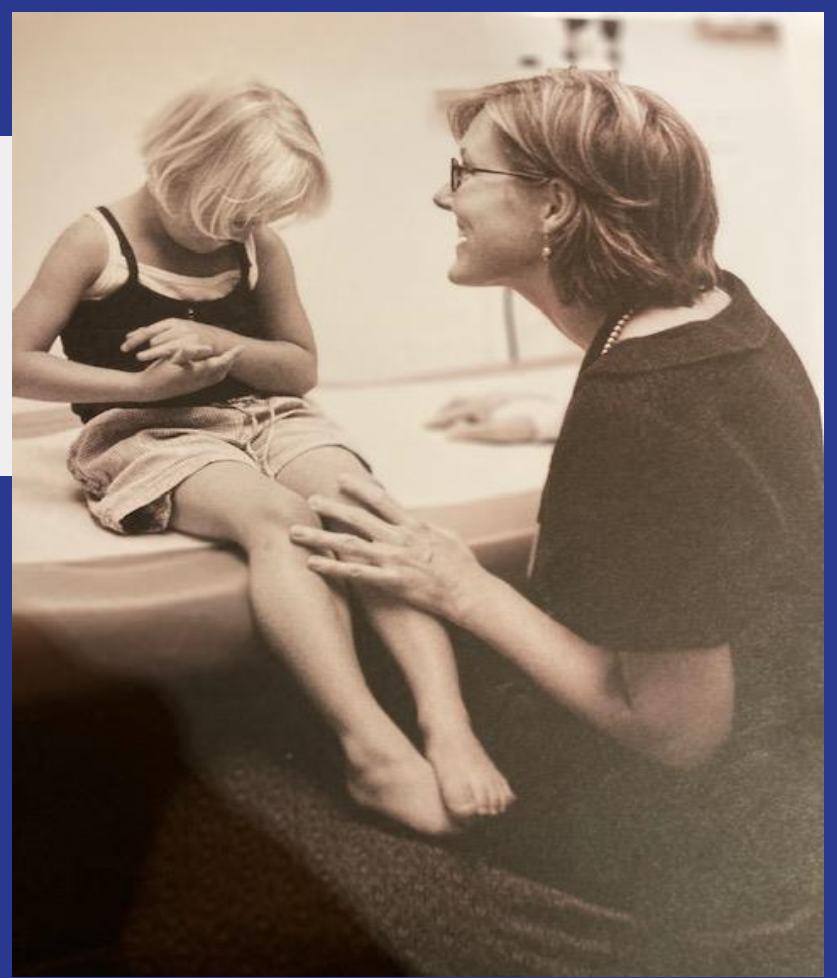


UVA Pediatric Cystic Fibrosis Team

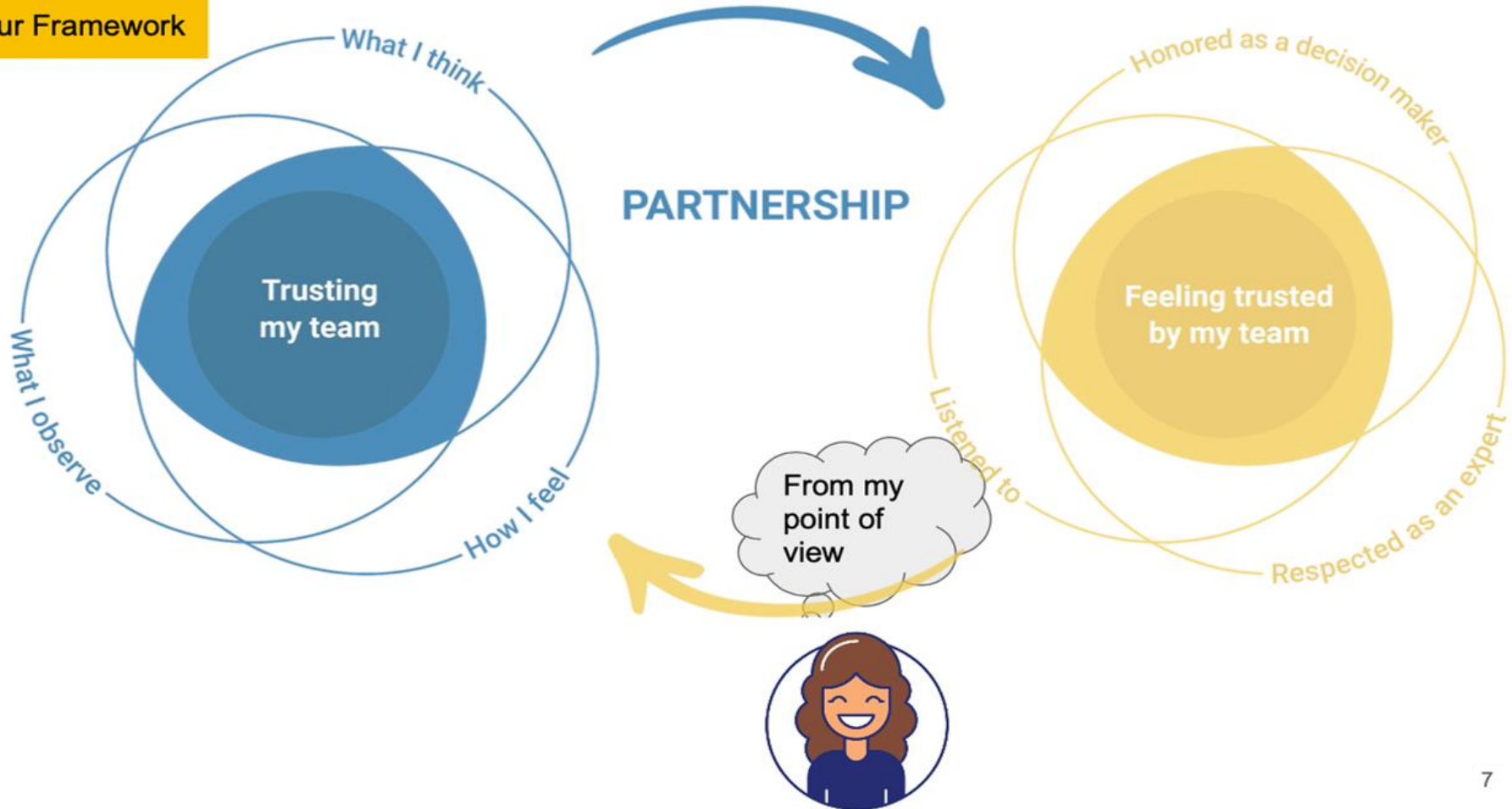
Team-based Care Synthesis Course

February 10, 2022

*A nurse's path starts
with a patient's story...*



Our Framework





**ENGAGE
STAKEHOLDERS &
PROMOTE DIALOGUE**

Create an open forum
for sharing ideas.

**ESTABLISH OBJECTIVE
MEASURES & TEST
BEHAVIORAL
INTERVENTIONS**

Define benchmarks first,
then prove long-term
efficacy by researching
over time and across
experiences.



EMBED INTO CF CARE

Develop tools and
training to educate about
new CF care solutions.
Then, discuss opportunities
for continued innovation
and improvement.



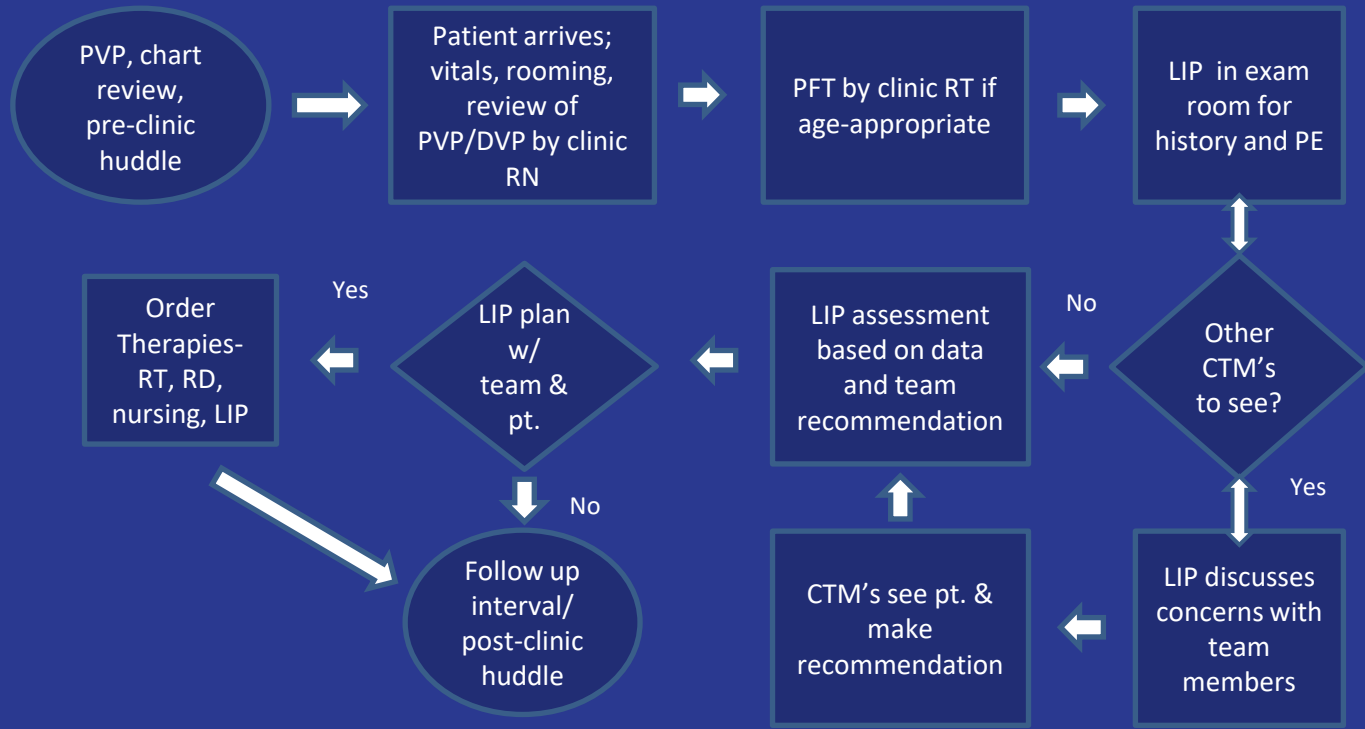
Different Perspectives...

Medication
albuterol (PROVENTIL) (2.5 MG/3ML) 0.083% nebulizer solution
Cholecalciferol 25 MCG (1000 UT) CHEW
dornase alpha (PULMOZYME) 1 MG/ML nebulizer solution
Multiple Vitamins-Minerals (DEKAS PLUS) CHEW
pancrelipase, lip-prot-amyl, (CREON) 12000 units CPEP
polyethylene glycol (MIRALAX) 17 g packet
sodium chloride, Inhalant, (HYPER-SAL) 7 % NEBU

1	Typical Day when working:
2	6:10 am - Wake up
3	6:20 am - Boil Water for Sinus Rinse, Make Tea or other beverage, Gather Nebulizers and Inhaled Medications
4	6:30 am - 6:40 am - Inhale Albuterol (bronchodilator) via Nebulizer while strapped into The VEST (high frequency chest com
5	6:40 am - 7:00 am - Inhale 7% Hypertonic Saline via Nebulizer while still doing The VEST
6	7:00 am - 7:10 am - Inhale Pulmozyme via Nebulizer while still doing The VEST
7	7:10 am - 7:30 am - Complete VEST treatment and Inhale Tobi antibiotic via Nebulizer
8	7:30 am - 7:45 am - Prepare and do 8 oz hypertonic saline sinus rinse w/ baby shampoo in each nostril
9	7:45 am - 8:15 am - Shower, Get Dressed and Ready for Work
10	8:15 am - 8:25 am - Make tea, pack breakfast (sometimes lunch as well) and snacks/drinks for the day
11	8:25 am - 8:30 am - Inhale Advair steroid, Inhale Spiriva, Squirt Nasonex in each nostril
12	8:30 am - 9:00 am - Commute to work
13	9:00 am - Arrive at work. (I am often late due to coughing fits while trying to shower or get dressed, or if I fall asleep during
14	9:15 am - Eat breakfast at desk. Requires taking pancreatic enzymes, insulin (and checking blood sugar two hours after), i
15	12:00 pm - Eat lunch at desk. Requires taking pancreatic enzymes, insulin (and checking blood sugar two hours after), as
16	3:00 pm - Eat afternoon snack. Requires taking pancreatic enzymes, and insulin if high carb.
17	5:00 pm - If arthritis is flaring up, take tylenol or percocet to allow me to do effective airway clearance (exercise and chest p
18	6:30 pm - Leave work, and drive to my mom's house for airway clearance - exercise and chest physical therapy. (This is off
19	6:45 pm - 7:45 pm - Exercise: walking, aerobics, pilates, yoga, or strength training with light weights - depending on my tol
20	recent hemoptysis episode, sometimes cannot tolerate high impact aerobics), always with frequent stops to cou
21	7:45 pm - 8:30 pm - My mom performs manual chest physical therapy while I huff cough and use other clearance technique
22	8:30 pm - Drive back home
23	9:00 pm - Eat dinner prepared by my husband, or take out. Requires taking pancreatic enzymes, insulin (and checking blo
24	9:20 pm - Rest (read, watch tv, email, computer) - need to take a break between dinner and evening treatment in order to nc
25	9:40 pm - Clean all nebulizers and sinus rinse bottles (requires dis-assembling all nebulizer parts, washing in hot soapy wat
26	10:00 pm - Gather Nebulizers and Inhaled Medications
27	10:00 pm - 10:10 pm - Inhale Albuterol (bronchodilator) via Nebulizer while strapped into The VEST (high frequency chest cc
28	10:10 pm - 10:30 pm - Inhale 7% Hypertonic Saline via Nebulizer while still doing The VEST
29	10:30 pm - 10:40 pm - Inhale Pulmozyme via Nebulizer while still doing The VEST
30	10:40 pm - 11:00 pm - Complete VEST treatment while huff coughing or other airway clearance techniques
31	11:00 pm - 11:20 pm - Inhale Tobi antibiotic via Nebulizer
32	11:20 pm - 11:30 pm - Inhale Advair steroid, Squirt Nasonex in each nostril
33	11:30 pm - Light snack before bed, take bedtime pills
34	12:00 pm - Go to bed.

UVA Routine CF Follow up Visit Process Map

Continuous Quality Improvement



Communication is key!



- HIPPA Certified Webex workroom
- Real time clinic tracking tool



Anonymous Platypus					CARE TEAM MEMBERS											CLINICAL NEEDS			AGENDA SETTING		POST-VISIT DATA - PLEASE COMPLETE				Webex Sent				
Appt. Time	Patient/Check IN	Intake	Consent Y/N	PFT	FEV1 Baseline ACTUAL	FIEB Threshold (10% decline)	FROH	GOTT	Endo RN	MAISON	MED STONT (RES)	Lauren	Martina	Libby	Cory	Allison	Kevin	Joe	Needs/Requests	OGTT Qual/Ten	My Chart	PVP/DVP	Visit Length	Survey Link in Chat?	Exacer-bation (n/a, mild/mod/severe)	Multi D (1=Y, 0=N)	Follow Up	Webex Sent	
9:30		9:43	9:43	95%	85%	10:10						11:40	11:36	11:29		11:23	Not Here		Labs/xray/trika discussion/eye exam in prep. Not in PortCF	n/a	Pending	PVP/dvp	2:17	Hybrid	n	1	3 month in person	Team	
9:30	9:26 rm 2	9:54	10:07	101%		11:42			13:45		15:15	9:35	L-10:32	10:30		16:00	11:04		coming prepared for admission if needed. Bringing vest & neb - not working. Needs help w/spirometer	Overdue in clinic today	Need	PVP/dvp	5:47	Hybrid	y-resolv		1	Dx CFRLD. Endo admission from clinic. flu 6 wk post discharge	Team
11:30	8:46 rm 3	9:30	10:25	95%		12:40		14:55		16:00	9:45	10:56	11:29	X	15:12	11:22			Rec, transportation - arranged. Xray, LFTs, Vitamin Labs, Hypoint Phase 17	Oct 2020 IGT	Active	PVP	2:57	Hybrid	n-had n	1	3 mo in person/cab needed	Team	
11:30	10:04 rm 6	10:13	10:51	76%	68%	12:48				10:30		12:30	12:08	11:54	11:23	11:38			Needs Ciron Refill, Can more than one spirometer pair to the same phone?	July 2020	Active	PVP	1:40	Hybrid	y-mild		1	flu 2 weeks	Team
13:00	10:49 rm 5	12:50	13:10	80%		14:25					13:45	14:41	13:40	X		13:40	X				Active	PVP	3:45	1 per fa	n	1	3 mo -- could be telehealth	Team	
14:00	10:37 rm 7	11:10	13:49	??	83%	14:55		12:05	11:20		12:00	X	13:40	X		13:25	12:53		Needs albuterol & HTS refills, Seeing Endo.	CYRD	Active	PVP							

Clinic RN: review PVP, add DVP, vitals, rooming, check for vaccines, labs, port flush



Clinic RT/CF RT- PFT, sputum collection, in clinic treatment/ review home regimen, counsel re: home spirometry, CF registry, exercise regimen



CF RD: healthy eating behaviors, enzyme dosing, vitamins, supplements, bone health, CF specific programs



Sustaining B's Care

CF NP: health history and PE, coordination of care, referrals, diagnose and treat, initial and ongoing CF education, coordinate transitions of care, precept nursing students, participate in CF research



CF SW: mental health screening, counseling re: mental health issues, financial assistance, CF specific programs, setting up therapy/finding best fit, care transition



CF RN: coordination of appointments/other specialties, in btw visit issues, home health liaison, interface with schools, ongoing patient and family education, facilitate transition



CF pharmacy tech: tracking rx and filling, PA's, patient assistance, CF specific programs, and rx issues



CF pharmacist: monitoring drug dosing, adherence and interactions, side effects, modulator eligibility and safety, overview of patient's drug plan



