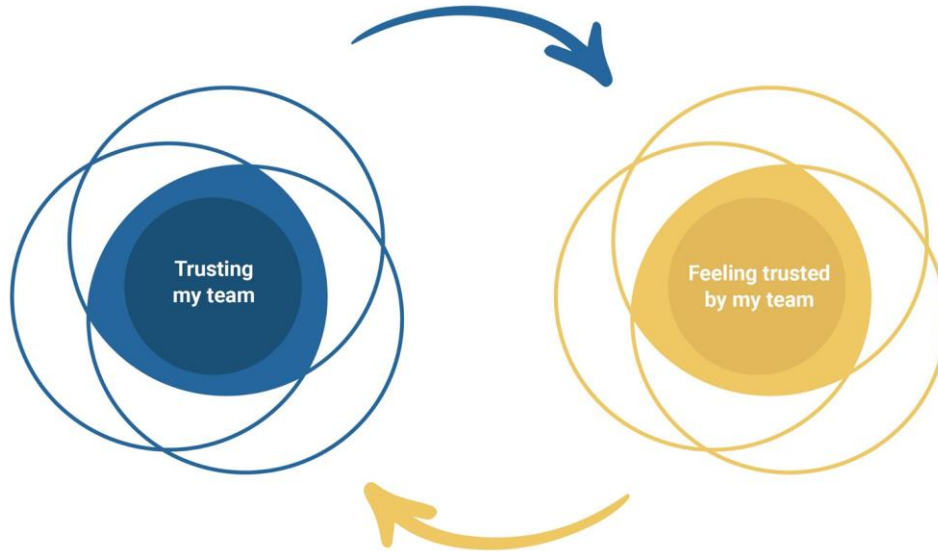


“It is hard trusting someone with your life expectancy.”



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Rachel Grob and Audrey Tluczek

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Methods

Our Purpose

Learning about trust in the health care setting from narratives of people with Cystic Fibrosis and their families.

Methods

- Patient and Family Experience of Care survey.
- 124 respondents used “trust” in 6 open ended questions
- No questions asked about trust.

Please tell me in your own words what do you **like best** about the CF center.

Do you have **suggestions for the CF center** to improve the care and services?

Please tell me what have you learned or found to be **helpful in managing your CF**.

Methods

- Developed a codebook
 - Literature review
 - Team's expertise
 - Some codes emerged
- 2 independent coders
 - Reconciled disagreement
 - Clarifying code definitions
- Reviewed findings with team
- Member checking with 10 people
 - 6 parents and 4 adults

Parent or Adult with CF	CF Provider, CF team, or other
Who or what is the reference of trust/distrust	
Trust Self	Trust other
Emergent	CF Provider
Instinct	CF Team
Present	CFF or Guidelines
Trust Child	Other
Parent Trusting Child Present	Ambivalent trust
Parent Trusting Child Emergent	Present
Self Trust established	Disrupted trust
Present	CF Provider
No self trust	CF Team
Not Present	Hospital
	System
	Unknown/unclear
Feeling trust because	
Listened to	
Respected	
Included	
Provider trusts child	
Not feeling trusted	
Ambivalent Feeling Trusted	
Elements of trust/distrust	
Competency negative	Benevolence positive
Competency positive	Benevolence negative
Desire to Comply	Benevolence positive
Reliability	Competence positive
Vulnerability	Competence negative
Grateful	Honesty positive
Openness	Honesty negative
	Reliability positive
	Reliability negative
	Open negative
	Open positive
	Nonjudgmental positive
Actions	
Advocating	Communication
Asking for Assistance	Communication trans
Comparing	Relational
Following Orders	Provider Attributes/Values
Learning/Seeking Info/Asking Questions	Working with Family/Person w/CF
Prioritization	Care Coordination
Find balance	
Treatment care	
Taking Charge of Own Care	
Working with Provider	

Narratives are a powerful way for people to express the vulnerability of living with a chronic illness.

Please tell me what do you find to be the hardest thing in managing your CF.

“ I have to trust that my child's health care team is being aggressive without any point of reference. How do I know I'm getting satisfactory care? I don't. And if my child becomes symptomatic, then it's too late and damage is already done. One is stuck between a rock and a hard place because one doesn't know if the care is exceptional or deplorable. It's ridiculous.

(Parent of a child Age 2 - 5)

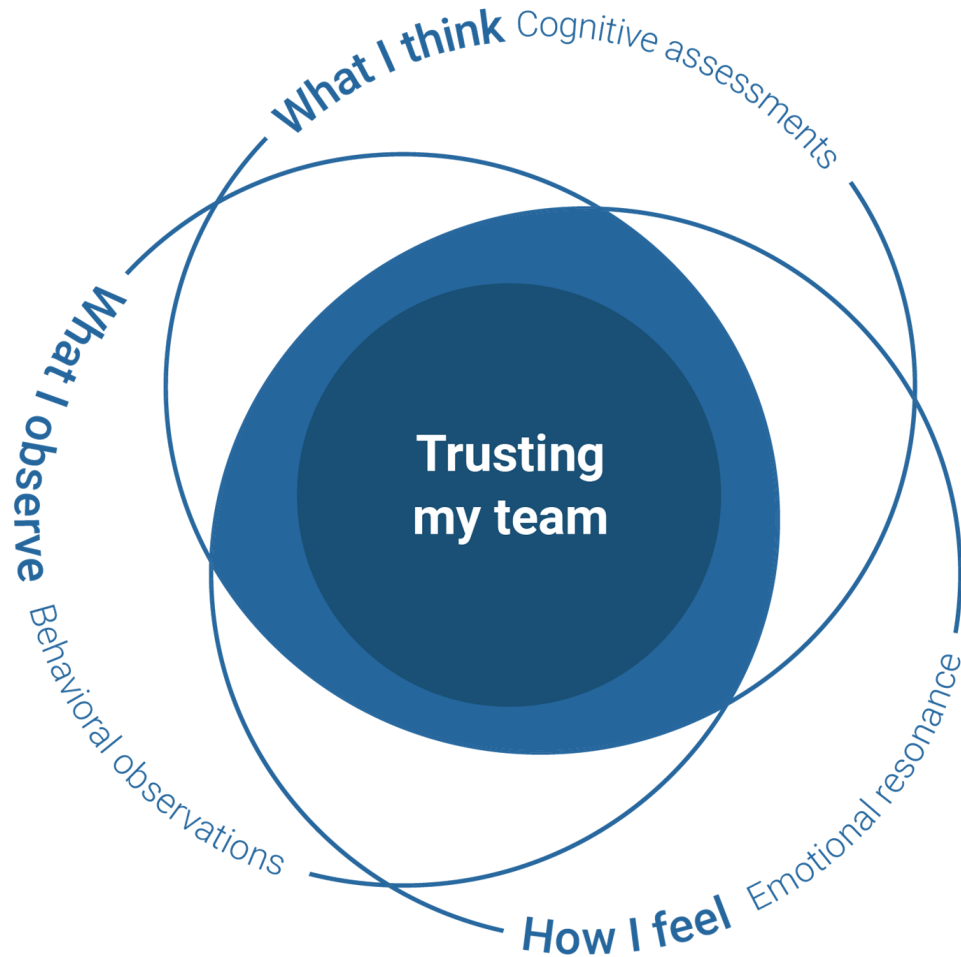
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Please tell me in your own words what do you like best about the CF center.

“ My health care team and I can be very honest with each other. I always feel like they really care about me and the outcome of whatever problem is at hand. **It is hard trusting someone with your life expectancy.** When new people are thrown at you it can be frustrating, and I personally don't want to deal with it. Here I have my people and they know who they are. (Adult with CF, Age 25 to 34)

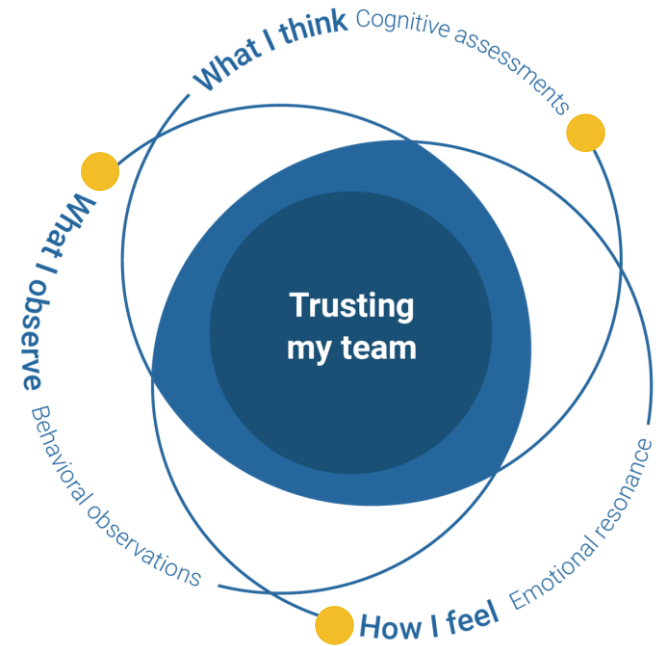
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Themes | Trusting my Team



“ The team members that take time to listen and genuinely care. They possess up-to-date knowledge of current research and treatments. I trust the members of the CF team with my health care decisions. ”

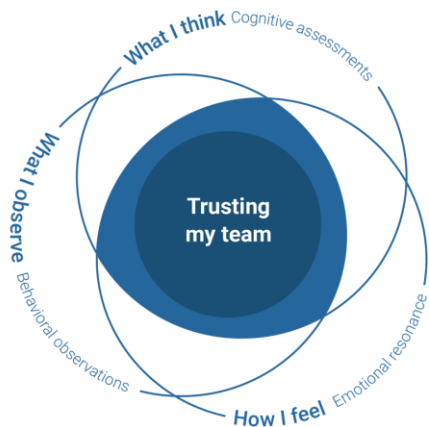
(Adult with CF Age 25 - 34)



Factors that Support Trusting my Team

- Competence
- Reliability
- Knowing me
- Caring
- Listening
- Communicating

Competence + Knowing me



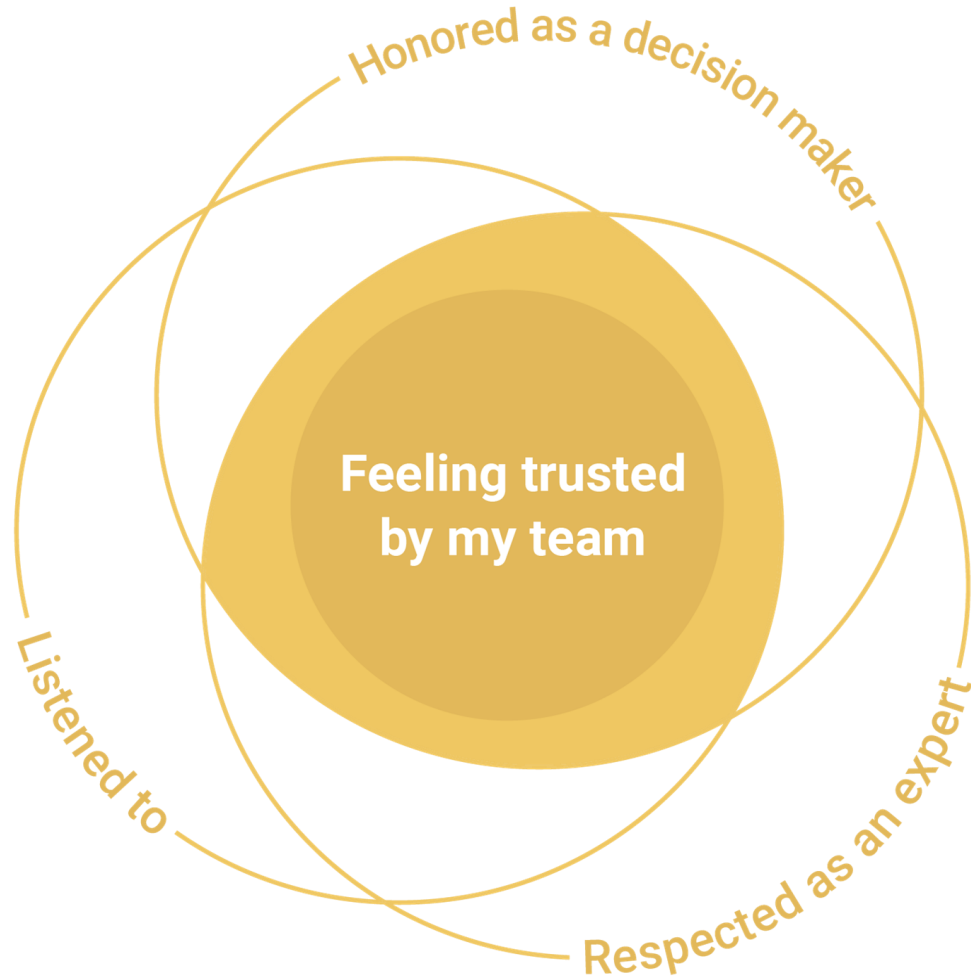
“

... I trust her judgment and care with all my heart. She understands that while CF is a large part of my life, **there are many other issues I face that impact my health.** (Adult with CF Age 25 - 34)

”

Feeling Trusted

Extending Trust | Please tell me in your own words what do you like best about the CF center.



Listened to

“ My doctor **listens to me and trusts that I know my body**

(Adult with CF, Age 35 to 44)

”



Respected as an expert

“ The CF center is responsive and helpful. **They trust my opinions as a parent.**
(Parent of a child with CF, Age 11 to 17)

”

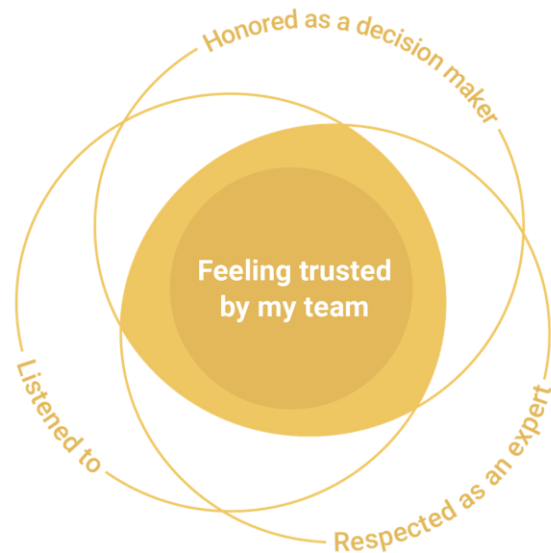


Honored as a decision maker

“ They make the effort to get to know me and **really trust my decisions about my health.**

(Person with CF, Age 25 - 34)

”



Distrust

Distrust

- Lack of desired factors
- Lack of partnership
- The need to be trusted
- A CF management strategy

Wanting to be trusted

Do you have suggestions for the CF center to improve the care and services?

“ I do wish there was a **better level of trust that the family often knows** what might help, especially after 16 years of CF.
(Parent of a child with CF, Age 11 - 17)

”



Distrust as a management strategy

Please tell me what have you learned or found to be helpful in managing your CF.

“

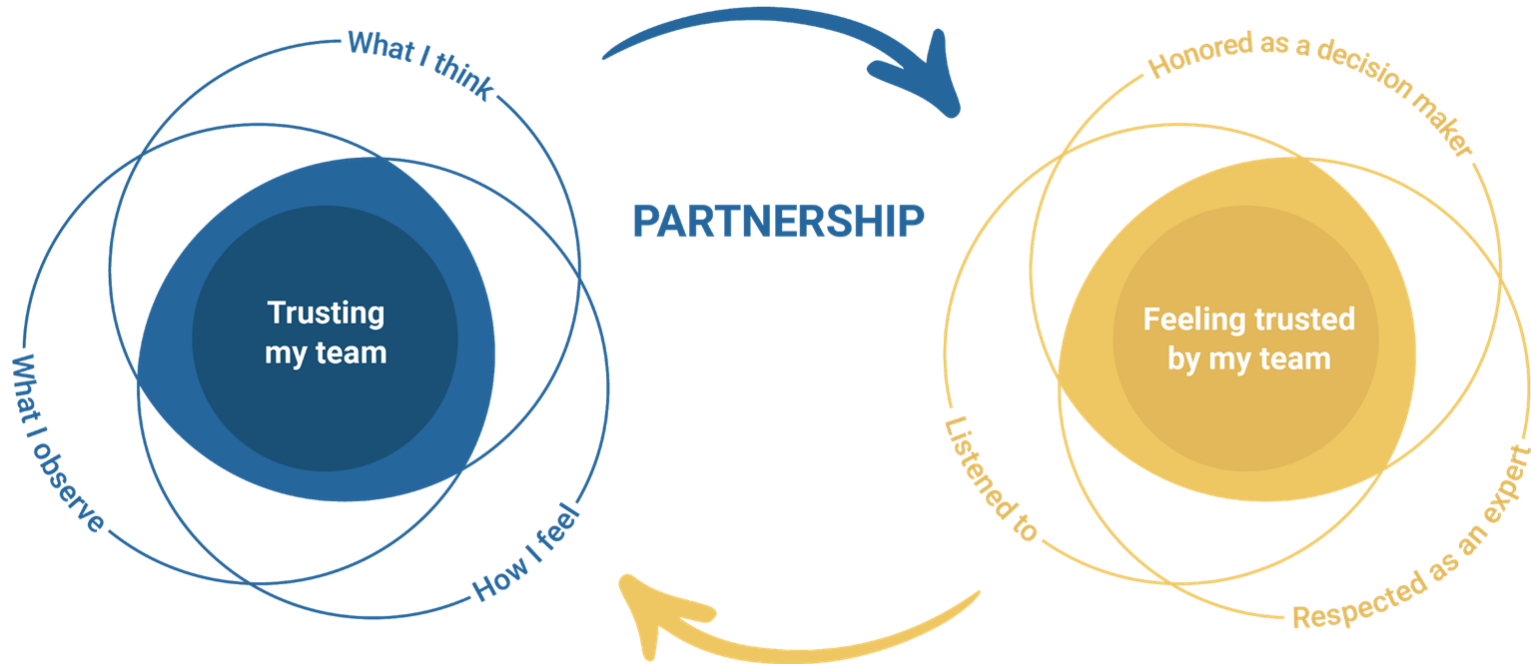
Don't trust the medical teams to do their jobs. Realize medical teams **don't follow established medical guidelines** and your health is at risk. It's up to you to know the guidelines and enforce them.

Always double check their work. Do your own research. **Realize the medical teams don't care about you at all.** Understand office politics will always come before patient care.
(Adult with CF, Age 45 – 64)

”

Partnership

Trust and partnership

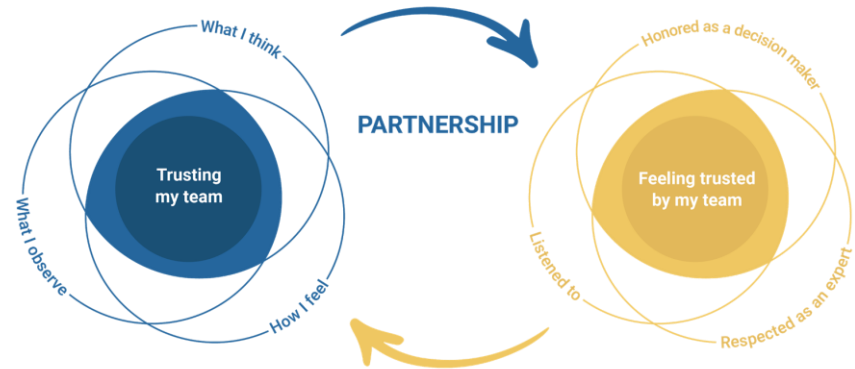


Trust and partnership

“ They know my daughter very well. They trust me, know me very well. We always **work things out** to her best advantage. **We keep her very healthy working together.**

(Parent of a child with CF, Age 6 to 10)

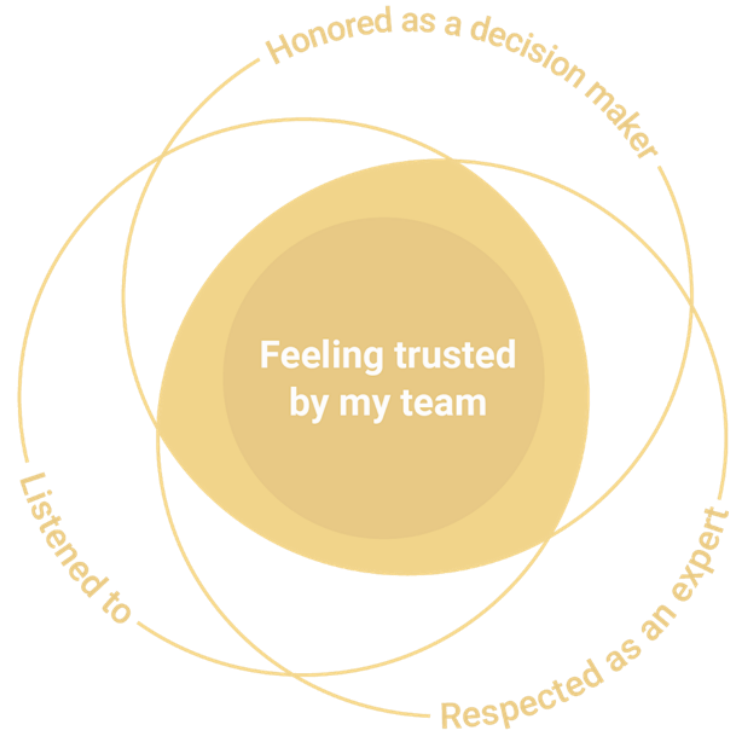
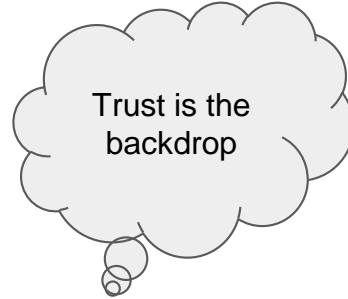
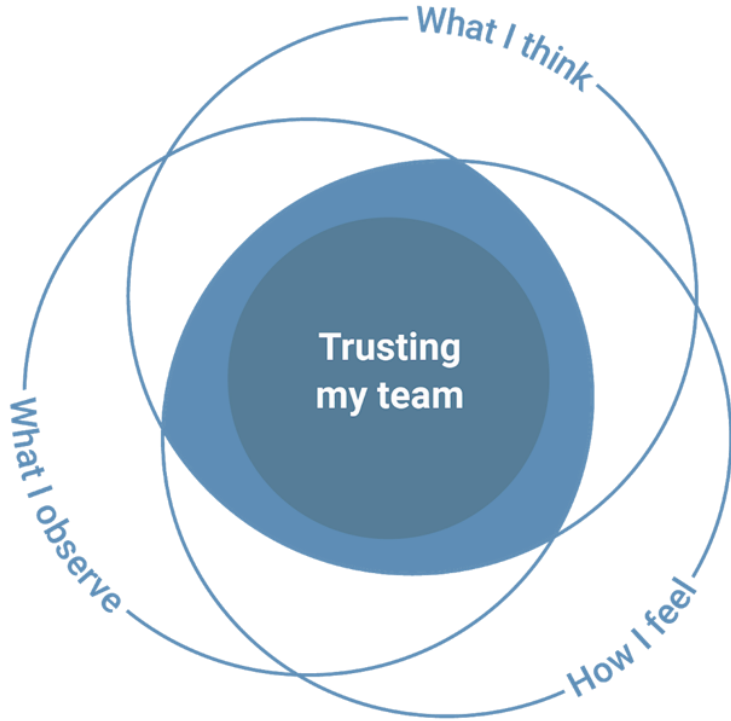
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Trust and partnership

“ My doctor offers suggestions of additional care to add to my regimen, explains the benefits and side effects as well as why I should add it but ultimately the decision is up to me to accept the plan or reject it.

This has built an incredible level of trust and truly feels like we are working together as a team for my care.”
(Adult with CF, Age 45 to 64)



Thank you!
