

Usability Preferences of People Living with Cystic Fibrosis About a Lung Transplant Education Website

Nick Reid, MHI¹, Kathleen J. Ramos, MD MSc², Mara R. Hobler, PhD², Lauren E. Bartlett, BS², Joseph B. Pryor, MD³, Donna L. Berry, PhD RN⁴, Melissa J. Basile, PhD⁵, Siddhartha G. Kapnadak, MD², Andrea L. Hartzler, PhD¹

¹Department of Biomedical Informatics and Medical Education, School of Medicine, University of Washington, Seattle, WA, USA;

²Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, University of Washington, Seattle, WA, USA;

³Department of General Internal Medicine, University of Washington, Seattle, WA, USA;

⁴Biobehavioral Nursing and Health Informatics, University of Washington, Seattle, WA;

⁵Northwell Health, Manhasset, New York, USA

AMIA Annual Symposium 2022, Session 111

It's All About U: Topics on User-Centered Design and UI/UX



RQ: How do people living with cystic fibrosis (CF) prefer to use an educational website about lung transplant?

Methods

Mixed-methods usability study to elicit preferences with two prototypes

Findings

Participants prefer to actively navigate information to inform preferences

Learning Objectives

Define and describe concepts:

- Didactic content
- Experiential content
- Author-Driven design
- Reader-Driven design

...and their relationship to patient-centered education

Acknowledgements



In Memory of Mara R. Hobler, PhD

Dr. Mara R. Hobler contributed significantly to the study design, data collection, and interpretation of the results, but died prior to publication.

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Lung transplant for advanced cystic fibrosis (CF) lung disease

CF is a genetic condition, leading to early death from progressive respiratory failure

Lung transplant is a treatment option

Under preparation for shared decision making about lung transplant is associated with delayed referral and risk of death^[1]

[1] Ramos KJ, Quon BS, Heltshe SL. Heterogeneity in Survival in Adult Patients With Cystic Fibrosis With $FEV_1 < 30\%$ of Predicted in the United States. *Chest*. 2017 Jun;151(6):1320-1328.

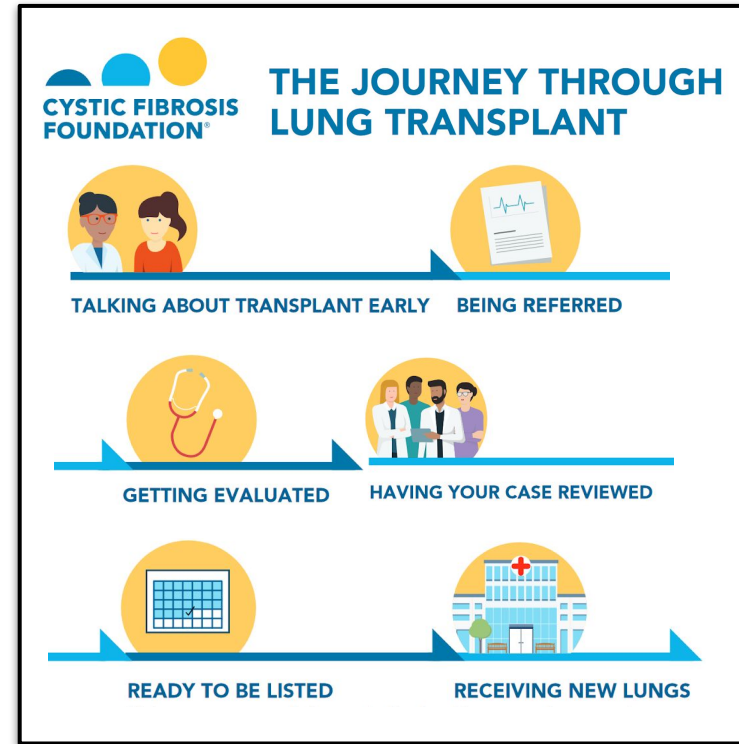


Figure adapted from: Ramos KJ, Smith PJ, McKone EF. CF Lung Transplant Referral Guidelines Committee. Lung transplant referral for individuals with cystic fibrosis: Cystic Fibrosis Foundation consensus guidelines. *J Cyst Fibros*. 2019 May;18(3):321-333.

RQ: How do people living with CF prefer to use an educational website about lung transplant?

RQ1: How are types of content used by people living with CF to learn about lung transplant?

RQ2: How much navigational control is preferred by people living with CF to learn about lung transplant?

Prior Work

Focus groups of people living with CF who received lung transplant indicated an educational website should have

- Frequently Asked Questions (FAQ)
- Patient Stories
- Resource articles

Complete design
process in JAMIA

Journal of the American Medical Informatics Association, 00(0), 2022, 1-12
<https://doi.org/10.1093/jamia/ocac176>
Research and Applications

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OXFORD

Research and Applications

Take on transplant: human-centered design of a patient education tool to facilitate informed discussions about lung transplant among people with cystic fibrosis

Andrea L. Hartzler¹, Lauren E. Bartlett², Mara R. Hobler², Nick Reid¹, Joseph B. Pryor³, Siddhartha G. Kapnadak², Donna L. Berry⁴, William B. Lober^{1,4}, Christopher H. Goss², Kathleen J. Ramos²; for the Take on Transplant Study Group*

¹Department of Biomedical Informatics and Medical Education, School of Medicine, University of Washington, Seattle, Washington, USA, ²Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, School of Medicine, University of

<https://tinyurl.com/nickreid-amia2022>



RQ1: How are types of content used by people living with CF to learn about lung transplant?



Resources articles are didactic content

Authoritative, medical fact



Patient stories are experiential content

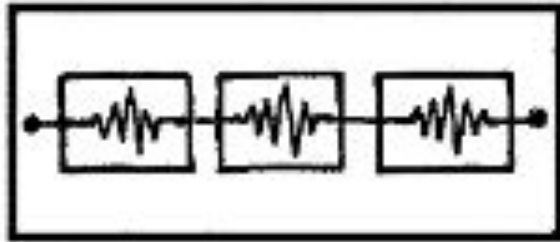
Anecdotal, an individual's experience



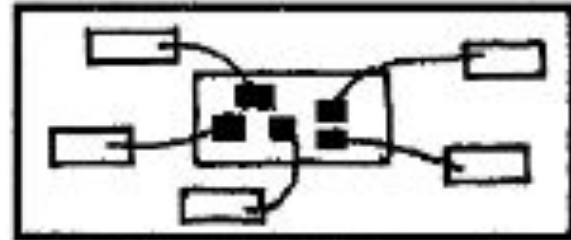
Our FAQs are both didactic and experiential

RQ2: How much navigational control is preferred by people living with CF to learn about lung transplant?

Author-Driven designs direct the order content is accessed



Reader-Driven designs allow access in any order`



Concepts and images from Segal, E and Heer, J., Narrative Visualization: Telling Stories with Data. IEEE Transactions on Visualization and Computer Graphics, 2010.

Methods

Recruit people living with cystic fibrosis
who have not received a lung transplant

90-minute session where participant

- 15 minute Author-Driven prototype task
- 15 minute Reader-Driven prototype task
- Semi-structured exit-interview

Task order counterbalanced,
but task-scenario held constant

Same content in each prototype,
but organized differently

Methods **RQ1:** How are types of content used by people living with CF to learn about lung transplant?

Recruit people living with cystic fibrosis
who have not received a lung transplant

90-minute session where participant

- 15 minute Author-Driven prototype task
- 15 minute Reader-Driven prototype task
- Semi-structured exit-interview

RQ1: Type of content viewed first during each task

Deductive qualitative analysis of benefits and challenges for

- Resource articles
- Patient stories
- FAQs

Methods **RQ2:** How much navigational control is preferred by people living with CF to learn about lung transplant?

Recruit people living with cystic fibrosis
who have not received a lung transplant

90-minute session where participant

- 15 minute Author-Driven prototype task
- 15 minute Reader-Driven prototype task
- Semi-structured exit-interview

RQ2: Prototypes evaluated with System Usability Scale (SUS)^[1] after each task

Deductive qualitative analysis of benefits and challenges for

- Author-Driven Prototype
- Reader-Driven Prototype

[1] Lewis JR. The System Usability Scale: Past, Present, and Future. International Journal of Human-Computer Interaction. 2018 Jul 3;34(7):577-90.

Author-Driven Prototype

Participant completes 6 question self-assessment survey

Then 6 survey results are shown;
2 FAQs, 2 patient stories, 2 resource articles

Scenario

Marco has CF, but his health is stable

No immediate decision

Wants to understand if his CF is worsening

Age at diagnosis:

- ☒ Younger than 2 years old
- ☐ 2 years old to 18 years old
- ☐ Older than 18

Which sex were you assigned at birth?

- ☒ Male
- ☐ Female

What is your FEV1?

- ☐ <30%
- ☒ 30-39%
- ☐ 40-49%
- ☐ 50-59%
- ☐ 60-69%
- ☐ 70-79%
- ☐ >80%

Take on Transplant

Survey Results

You have advanced lung disease with markers of increased disease severity based on your low FEV1 and frequent CF exacerbations that required IV antibiotics. The use of Trikafta (elexacaftor/tezacaftor/ivacaftor) may delay the need for lung transplant, but people with advanced lung disease are likely to benefit from lung transplant at some time in the future.

It is important to continue to talk with your doctor about lung transplant. You may want to connect with patients who have been through the lung transplant journey.

These recommendations were generated from your answers to the My CF Stage Survey, to [change your answers, click here](#).

Recommended Content

Signs that CF is Worsening

For adults with FEV1 between 30% and 40% of predicted, CF care teams should evaluate for the presence of other signs that your CF is worsening. The signs may include frequent or severe exacerbations, a low BMI, or low oxygen saturation, among others.

Will

Gender:	Age at transplant	FEV1 at transplant
Male	89 years old	22% predicted
Current FEV1:	CFTR Genotype:	
100% predicted	F508del / 306insA	
CFTR modulator status at transplant		
Not eligible for available CFTR modulators		

I really began noticing a decline in my health and an impact on my ability to do things in my 50's.

Make a decision about transplant BEFORE you're too



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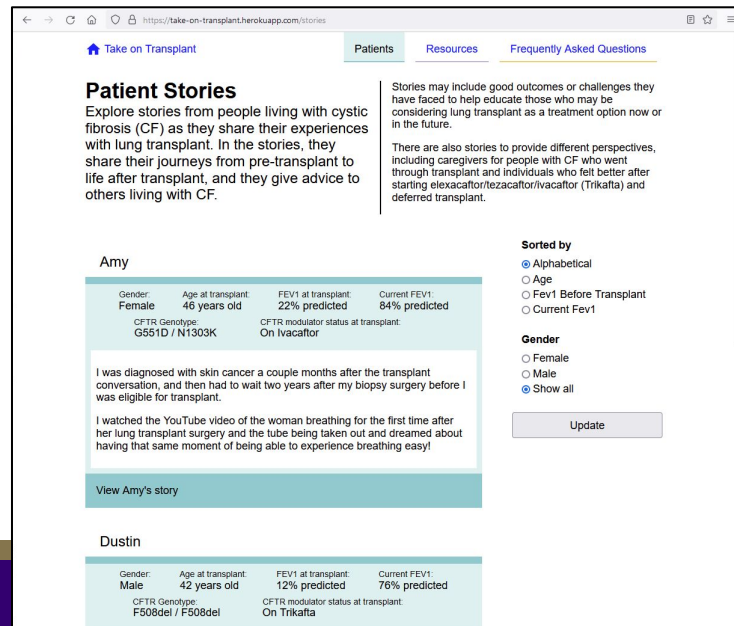
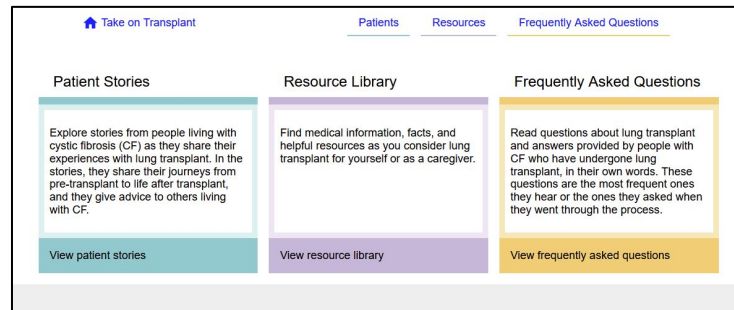
Reader-Driven Prototype

Participant chooses between 3 sections:
FAQ, patient stories, and resource articles

Each section has basic filter controls

Scenario

Tamika has CF, and her health has declined
Contemplating lung transplant
Discussing lung transplant with doctor soon



Results

Recruited 14 people living with CF who haven't received a lung transplant

Convenience sample from previous survey, where demographics were reported

Recruited participants who were prepared to discuss lung transplant

Duration of usability tasks in minutes

Mean (SD)

Author-Driven 13:38 (2:02)

Reader-Driven 12:32 (3:05)

Participant characteristics

Race

White 14/14 (100%)

Gender

Woman 11/14 (79%)

Man 3/14 (21%)

Other 1/14 (7%)

Age

20 - 30 3/14 (21%)

30 - 40 7/14 (50%)

Greater than 40 4/14 (29%)

Self-reported preparedness to discuss lung transplant

Not prepared 0/14 (0%)

A little prepared 0/14 (0%)

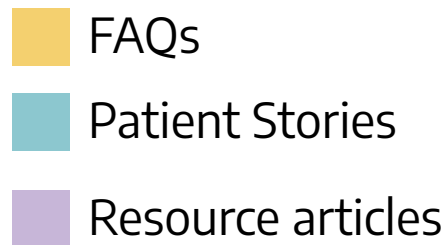
Moderately prepared 4/14 (28%)

Very prepared 10/14 (72%)

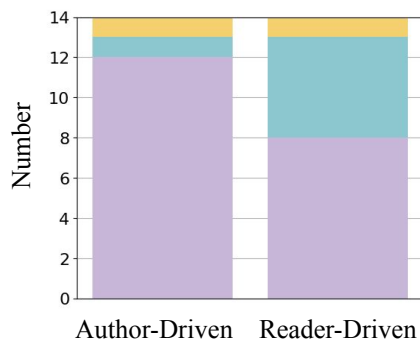


Results

RQ1: How are types of content used by people living with CF to learn about lung transplant?

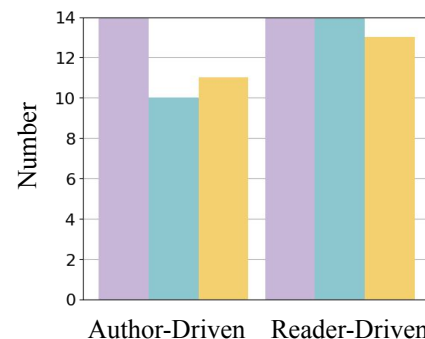


Content first viewed during each task



FAQ	1/14	1/14
Patient Stories	1/14	5/14
Resource articles	12/14	8/14

Content viewed during each task



FAQ	11/14	13/14
Patient Stories	10/14	14/14
Resource articles	14/14	14/14

Results

RQ1: How are types of content used by people living with CF to learn about lung transplant?

Resource articles more frequently viewed first and viewed in each task

Aided understanding prognosis and providing *“the whole picture”* (P4)

“helps you know what’s expected of you, and what to expect” (P11)

“Having it in a chart felt super useful, so you can see it -- and not play Bingo with it -- but be like ‘oh, I have that already’” (P9)

Results

RQ1: How are types of content used by people living with CF to learn about lung transplant?

Patient stories add emotional value that *“change scary concepts from resource articles into hope, not scientific jargon” (P4)*

“Emotionally heavy” (P12) stories were hard to consume, but valuable

FAQs were shorter, valued for variety, and easier to consume

Aided finding perspectives that *“resonated with them” (P9)*

Results

RQ2: How much navigational control is preferred by people living with CF to learn about lung transplant?

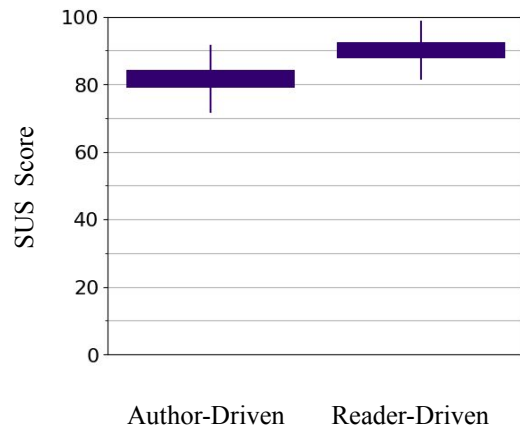
Reader-Driven higher mean SUS score than Author-Driven ($p < 0.001$)

Described wanting to be “*in control of finding information*” (P3) to search for “*hidden gems*” (P4)

Preferred to keep “*social stuff*” (P1) and “*patient perspective*” (P13) separate from resource articles

Prototype SUS scores

Boxes indicate standard error range and whiskers indicate standard deviation range



Methods **RQ2:** How much navigational control is preferred by people living with CF to learn about lung transplant?

No recommendations is
“flying blind” (P4)

Lung transplant is emotional,
Author-Driven recommendations
help avoid *“clicking around by
themselves”* (P10)

Recommendations not trusted
*“There’s more room for error
going off the survey, something
could be missed. Maybe I didn’t
answer something right... I’d
rather be able to go through
stuff myself.”* (P8)

Discussion

RQ1: Didactic and experiential content are used together, but delivered separately

RQ2: Participants prefer actively navigating lung transplant information

People living with CF usability preferences are similar to sensemaking^[2]

Didactic content affords self-monitoring

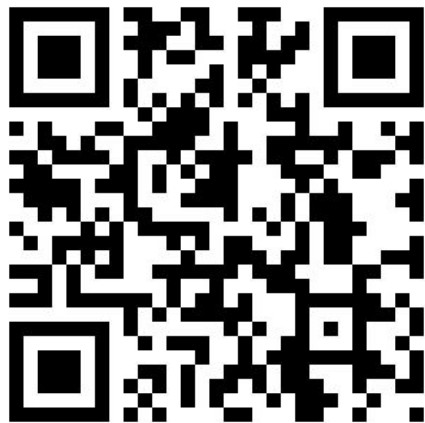
Experiential content informs preferences on decision making

[2] Mamykina L, Smaldone AM, Bakken SR. Adopting the sensemaking perspective for chronic disease self-management. J Biomed Inform. 2015 Aug;56:406-17. doi: 10.1016/j.jbi.2015.06.006. Epub 2015 Jun 10. PMID: 26071681; PMCID: PMC4626451.

Thanks for listening!

Piloting randomized control trial
of website based on this study
(*and a lot of other work ;-)*)

<https://tinyurl.com/nickreid-amia2022>



Take on Transplant

Explore stories from people living with cystic fibrosis (CF)
as they share their experiences with lung transplant.

Welcome, Nick

My CF Stage Results

- It is important to continue to talk with your doctor about lung transplant. You may want to connect with patients who have been through the lung transplant journey.

Your Transplant Discussion Urgency Status



PRINT REPORT

Begin your Take on Transplant journey with the recommended content ↓

Your recommendations are based on your responses to the questions in the My CF Stage survey (age, gender, calculated BMI, FEV₁, % of predicted, use of oxygen, number of pulmonary exacerbations, taking a CFTR modulator). Your discussion urgency meter is also determined by your health characteristics and whether you have had previous conversations about lung transplant with your doctor.

CF Stories

We Recommend



Age: 46
Transplanted

Amy's Story >



Age: 38
Transplanted

Ellen's Story >

VIEW ALL

Resource Library

We Recommend

Evaluation

Specific steps in the evaluation vary based on your age, medical history, how sick you are, the transplant program, and other factors. A majority of the tests, procedures and appointments are necessary for all candidates

Content in prototype

17 webpages of content

	Number of webpages	Word count <i>Mean (SD), range</i>	Flesch-Kincaid score <i>Mean (SD), range</i>
Resource Articles	4	989 (492), 291 - 1419	9.75 (1.5), 8 - 11
Patient Stories	5	2927 (1049), 1475 - 4266	5.2 (1.9), 3 - 8
FAQs	8	453 (167), 280 - 731	6.1 (2.1), 3 - 8



Images of each prototype

Author-Driven Prototype

(A) Self-assessment survey

[Take on Transplant](#)

Age at diagnosis:

- ☐ Younger than 2 years old
- ☐ 2 years old to 18 years old
- ☐ Older than 18

Which sex were you assigned at birth?

- ☐ Female
- ☐ Male

What is your FEV1?

☐ <30% ☐ 30-39% ☐ 40-49% ☐ 50-59% ☐ 60-69% ☐ 70-79% ☐ ≥80%

Use of supplemental oxygen:

- ☐ Yes
- ☐ No

Are you using any of the following treatments?

- ☐ Inhaled (Kalydco)
- ☐ Elexacaftor/Tezacaftor/Ivacaftor (Trikafta)

How many exacerbations have you had in the past year?

This is a prototype form that doesn't really work.

Your example patient is Marco.

Age at diagnosis: Younger than 2 years old

Sex: Male

FEV1 predicted: 30-39%

Use of supplemental oxygen: No

Using CFTR modulator: Yes

Number of pulmonary exacerbations treated with IV antibiotics at home or in the hospital in the past year: 2

(B) Recommended content

[Take on Transplant](#)

Survey Results

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It is important to continue to talk with your doctor about lung transplant. You may want to connect with patients who have been through the lung transplant journey.

These recommendations were generated from your answers to the My CF Stage Survey. [Change your answers](#). [See this](#).

Recommended Content

Signs that CF is Worsening

For adults with FEV1 between 30% and 40% of predicted, CF care teams should evaluate for the presence of other signs that your CF is worsening. The signs may include frequent or severe exacerbations, a low BMI, or low oxygen saturation, among others.

Will

Gender	Male	Female
Age at transplant	50 years old	40 years old
FEV1 at transplant	20% predicted	20% predicted
Current FEV1	100% predicted	100% predicted
CFTR modulator status at transplant	CFTR modulator status at transplant	CFTR modulator status at transplant
Not eligible for available CFTR modulators	Not eligible for available CFTR modulators	Not eligible for available CFTR modulators

I really began noticing a decline in my health and an impact on my ability to do things in my 30s.

(C) Sample resource article

[Take on Transplant](#)

Transplant Referral

Signs that CF is Worsening

Factors in the Decision to Refer

Timing of Referral

Recommended Content

Eligibility, Evaluation, and Listing

How did you know you were ready for a lung transplant?

[Amy](#)

Transplant Referral

Referral for lung transplant is a process that involves a consultation with a lung transplant center, exploring the reasons for referral, and providing medical records. Transplant referral is an opportunity for your CF care team to discuss details about your condition with experts in lung transplant.

The lung transplant center will assess whether you are eligible for transplant after they receive the referral. Sometimes the assessment will involve an in-person or telehealth clinic visit with members of the transplant team. The referral process involves you and your family taking the chance to learn more about transplant, discuss potential barriers, or "nonadherence" to transplant, and/or complete a transplant evaluation (see Eligibility, Evaluation, and Listing below).

Timing of transplant referral can be classified as "early", "timely", or "late". Early referral occurs **before** transplant is needed. Early referral gives you more opportunity to ask questions and gather information, as well as to address any possible "barriers" to transplant, some of which may take years to correct (see Eligibility, Evaluation, and Listing below). The **CF Foundation** recommends **early** referral in order to give people living with CF the best chance to fully consider lung transplant and understand it as a treatment option. For people who are referred early, the lung transplant center may decide to wait longer before starting an evaluation.

- Timely referral occurs at the time that you actually have a medical need or "indication" for lung transplant (see Signs that CF is Worsening below).
- Late referral occurs when you are too sick to undergo a routine transplant evaluation and are considered an emergency. Late referral can happen in the setting of an unexpectedly severe exacerbation from which you do not recover, especially if you require mechanical ventilation or other intensive care. Late referral can lead to dying without transplant because there is too little time to be listed, or if a donor organ doesn't become available in time. Some lung transplant programs do not offer emergency evaluations.

Reader-Driven Prototype

(D) Home page with siloed content

[Take on Transplant](#) [Patients](#) [Resources](#) [Frequently Asked Questions](#)

Patient Stories

Explore stories from people living with cystic fibrosis (CF) as they share their experiences with lung transplant. In the stories, they share their journeys from pre-transplant to the after transplant, and they give advice to others living with CF.

Resource Library

Find medical information, facts, and helpful resources as you consider lung transplant for yourself or as a caregiver.

Frequently Asked Questions

Read questions about lung transplant and answers provided by people with CF who have undergone lung transplant. In their own words, these questions are the most frequent ones they hear or the ones they asked when they went through the process.

[View patient stories](#) [View resource library](#) [View frequently asked questions](#)

You are participating in the Take on Transplant usability study.

Teruko as had a difficult decision in her health status and she and her doctor are contemplating whether it is time to pursue lung transplant as a potential treatment option. Search for and highlight information about the lung transplant evaluation process.

[Login](#)

(E) List of patient stories

[Take on Transplant](#) [Patients](#) [Resources](#) [Frequently Asked Questions](#)

Patient Stories

Explore stories from people living with cystic fibrosis (CF) as they share their experiences with lung transplant. In the stories, they share their journeys from pre-transplant to life after transplant, and they give advice to others living with CF.

Stories may include good outcomes or challenges they have faced. Lung transplant stories also may be considering lung transplant as a treatment option now or in the future.

There are also stories to provide different perspectives, including caregivers for people with CF who went through transplant and individuals who felt better after starting elexacaftor/tezacaftor/ivacaftor (Trikafta) and deferred transplant.

Amy

Gender	Female
Age at transplant	40 years old
FEV1 at transplant	20% predicted
Current FEV1	94% predicted
CFTR modulator status at transplant	CFTR modulator status at transplant
On transplant	On transplant

Sorted by:

- ☒ Alphabetical
- ☐ Age
- ☐ First / Before Transplant
- ☐ Current FEV1

Gender:

- ☐ Male
- ☐ Female

☐ Show all

I was diagnosed with cystic fibrosis (CF) at the age of 13 and my first exacerbation and hospitalization came when I was 14. At that time, I was told that my life expectancy would be until about 40-45 years old and knowing that at such a young age had a profound influence on the decisions that I made going forward. I was the first person in my entire family history to have CF, so it was a big adjustment, but I really enjoyed my life and always loved growing up.

It was very important for me to live life to the absolute fullest and not be defined by CF. When I became pregnant, I was asked to go to college, and was told, "how or never" by the doctors. I decided to have a child. And she was the best thing that happened to me. I also decided that one day, I would go back to college and get my degree.

I had a little of working in the corporate sector (until the stress made my health worse and I had to go on disability), getting my college degree, starting a business with my husband, being a PTA mom, and dog rescue and gardening, and going to many CF house events as I could. My only off day during my first trimester was CF coming up to participate in an exercise group that I could attend being diagnosed. I also knew that I wanted to donate my old lungs to someone someday.

I was holding closely with my FEV1 in the upper 30s for quite some time and was quite active. I knew over the years that I was in a slow decline and that eventually my story would come to an end. For some reason, I did not think transplant was an option for me and that I would be stuck with the sick and slow.

(F) Sample patient story

[Take on Transplant](#) [Patients](#) [Resources](#) [Frequently Asked Questions](#)

Amy

Pre-Transplant & Evaluation

Call, Call, Transplant, & The Recovery

Post-Transplant

My Take on Transplant

Pre-Transplant & Evaluation

I was diagnosed with CF at the age of 13 and my first exacerbation and hospitalization came when I was 14. At that time, I was told that my life expectancy would be until about 40-45 years old and knowing that at such a young age had a profound influence on the decisions that I made going forward. I was the first person in my entire family history to have CF, so it was a big adjustment, but I really enjoyed my life and always loved growing up.

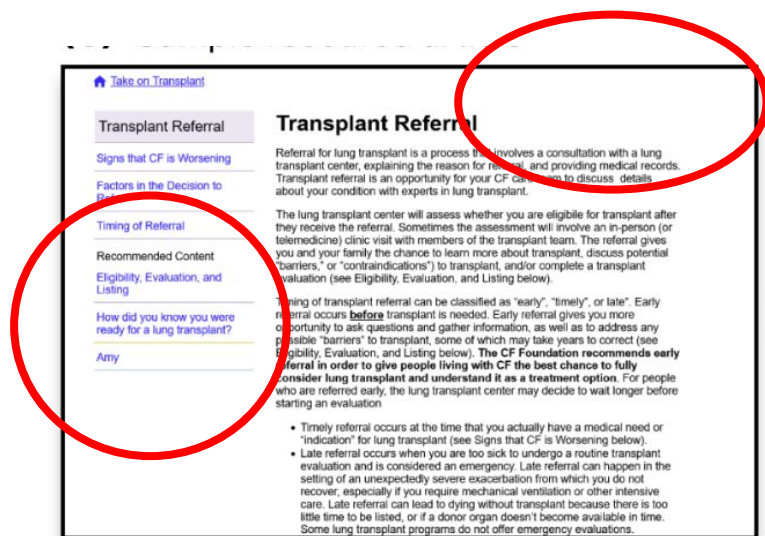
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Small differences of each prototype

Author-Driven Prototype
Had additional recommendations



Reader-Driven Prototype
Had top-level navigation

