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

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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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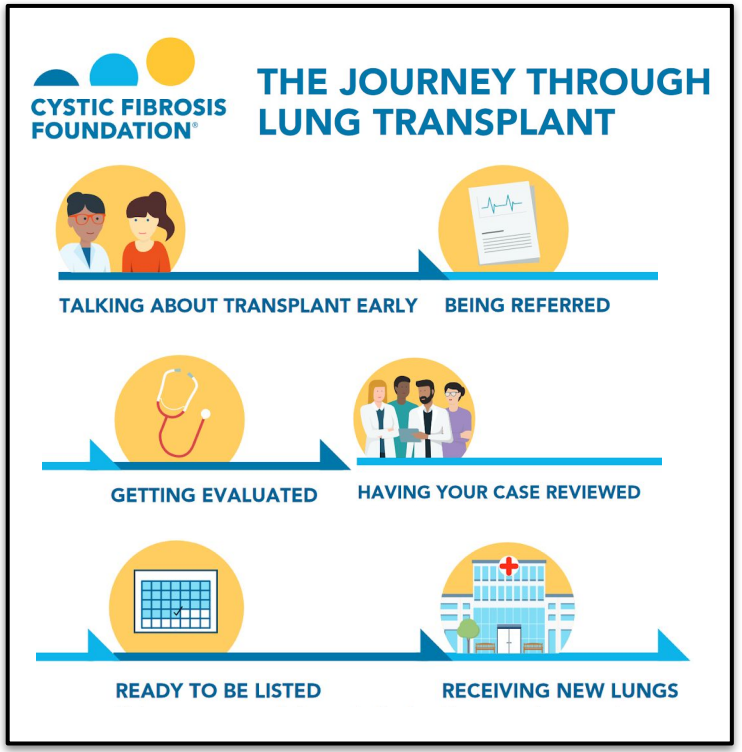
Lung transplant for advanced cystic fibrosis (CF) lung disease

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?

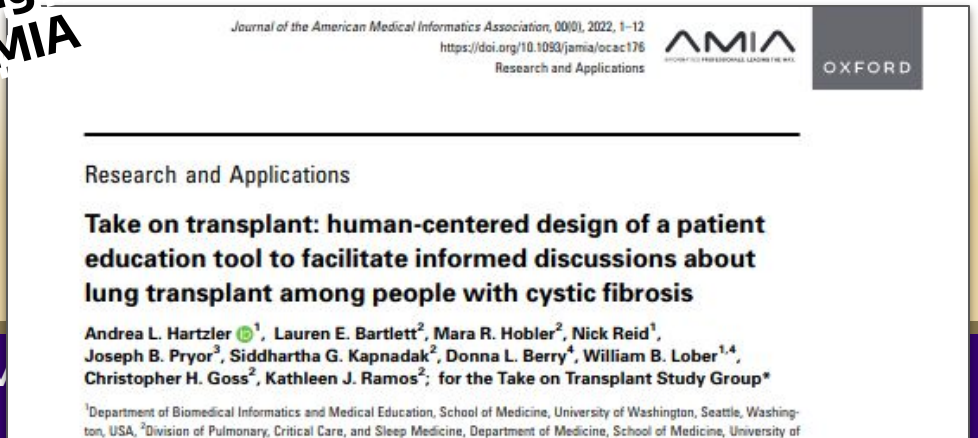
RQ2: How much navigational control is preferred by people living with CF to learn about lung transplant?

Prior Work

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

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

Complete design process in JAMIA



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Research and Applications

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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

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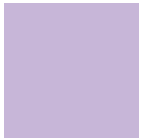
https://tinyurl.com/nickreid-amia2022

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

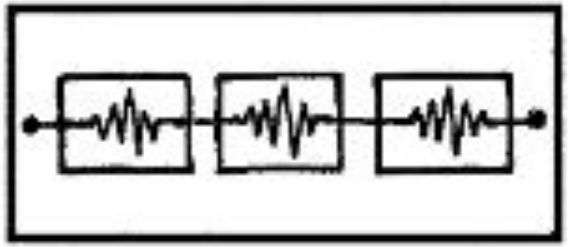
Patient stories are experiential content

Anecdotal, an individual's experience

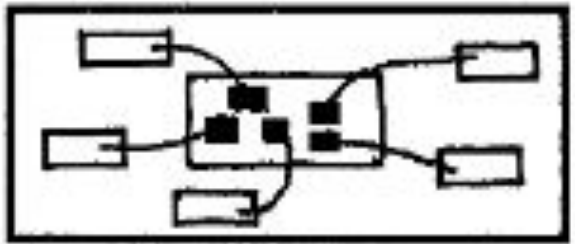
Our FAQs are both didactic and experiential

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

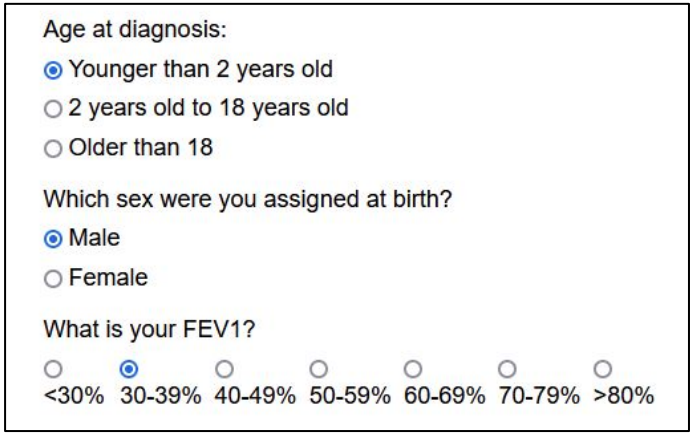
[1] Lewis JR. The System Usability Scale: Past, Present, and Future. International Journal of Human–Computer Interaction. 2018 Jul 3;34(7):577–90.

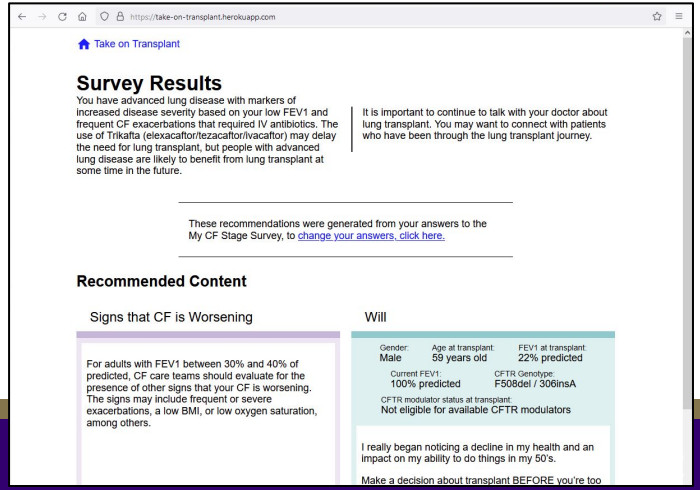
Author-Driven Prototype

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



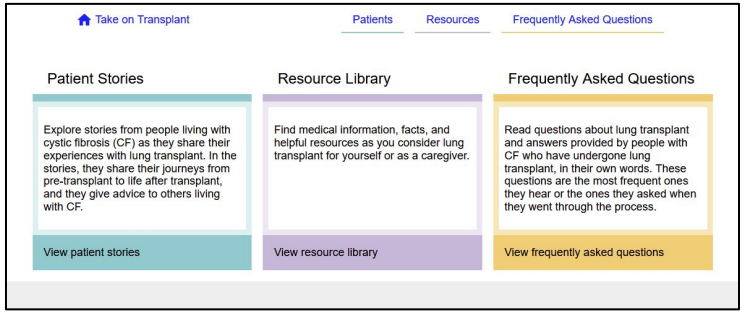


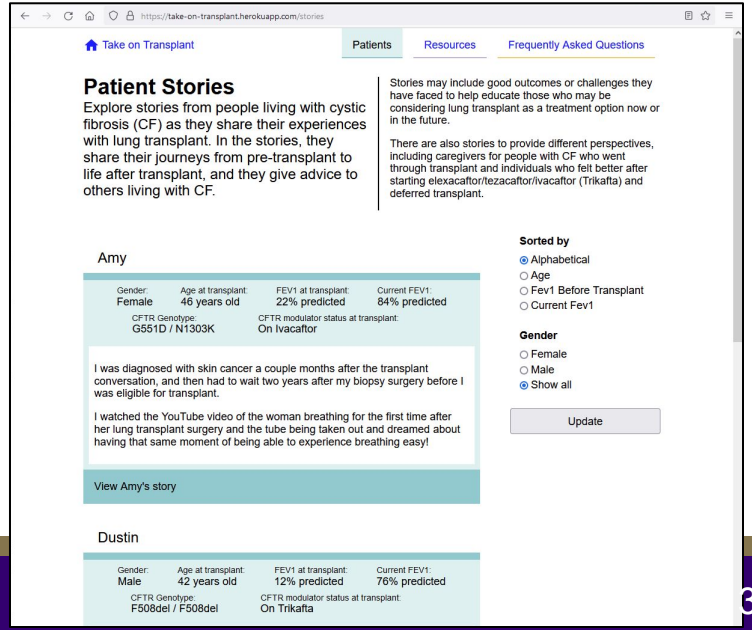
Reader-Driven Prototype

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

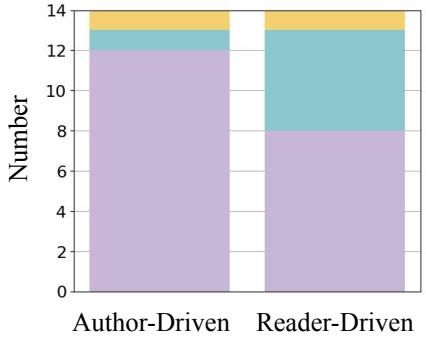
Race	
White	14/14 (100%)
Gender	
Woman	11/14 (79%)
Man	3/14 (21%)
Other	1/14 (7%)
Age	
20 - 30	3/14 (21%)
30 - 40	7/14 (50%)
Greater than 40	4/14 (29%)
Self-reported preparedness to discuss lung transplant	
Not prepared	0/14 (0%)
A little prepared	0/14 (0%)
Moderately prepared	4/14 (28%)
Very prepared	10/14 (72%)

Results

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

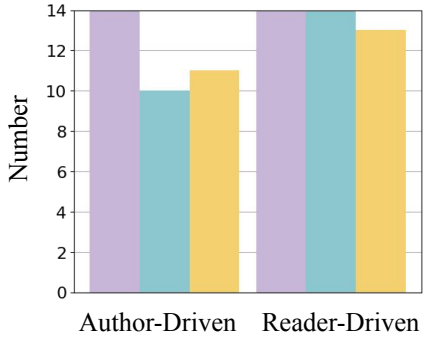
- FAQs
- Patient Stories
- Resource articles

Content first viewed during each task



	Author-Driven	Reader-Driven
FAQ	1/14	1/14
Patient Stories	1/14	5/14
Resource articles	12/14	8/14

Content viewed during each task



	Author-Driven	Reader-Driven
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)*

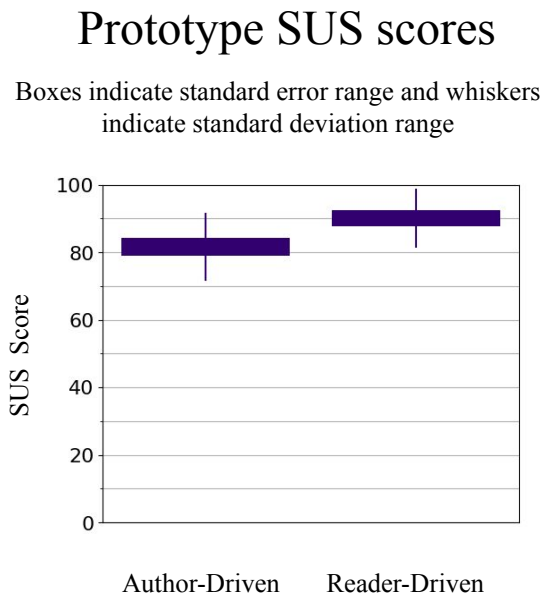
Results

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



SUS Score *Mean (SD), range, interpretation*	81.6 (10.0), 67.5-97.5, "Ok"	90.0 (8.8), 70.0-100, "Excellent"

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

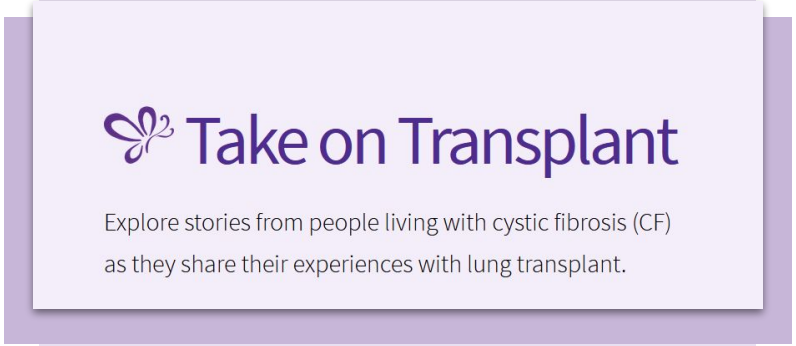
Experiential content informs preferences on decision making

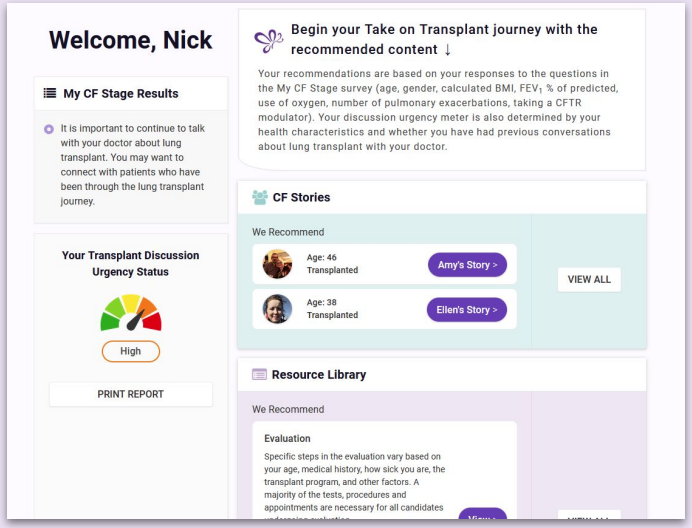
[2] Mamykina L, Smaldone AM, Bakken SR. Adopting the sensemaking perspective for chronic disease self-management. J Biomed Inform. 2015 Aug;56:406-17. doi: 10.1016/j.jbi.2015.06.006. Epub 2015 Jun 10. PMID: 26071681; PMCID: PMC4626451.

Thanks for listening!

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

https://tinyurl.com/nickreid-amia2022





Content in prototype

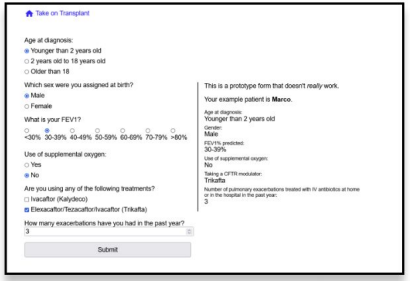
17 webpages of content

	Number of webpages	Word count *Mean (SD), range*	Flesch-Kincaid score *Mean (SD), range*
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

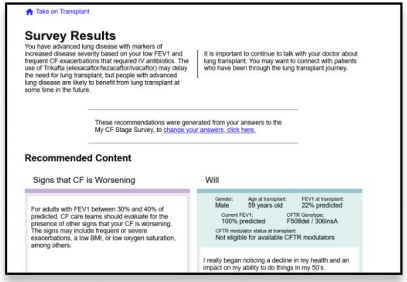
Images of each prototype

Author-Driven Prototype

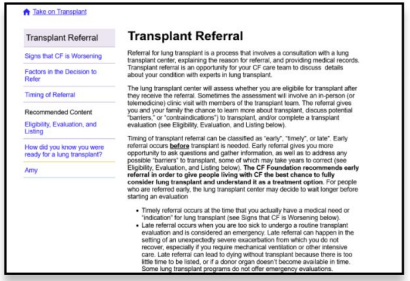
(A) Self-assessment survey



(B) Recommended content

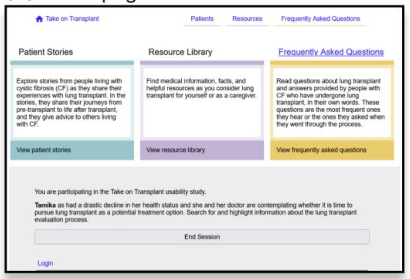


(C) Sample resource article

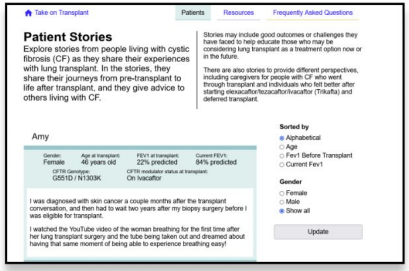


Reader-Driven Prototype

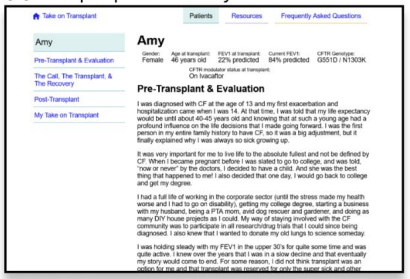
(D) Home page with siloed content



(E) List of patient stories

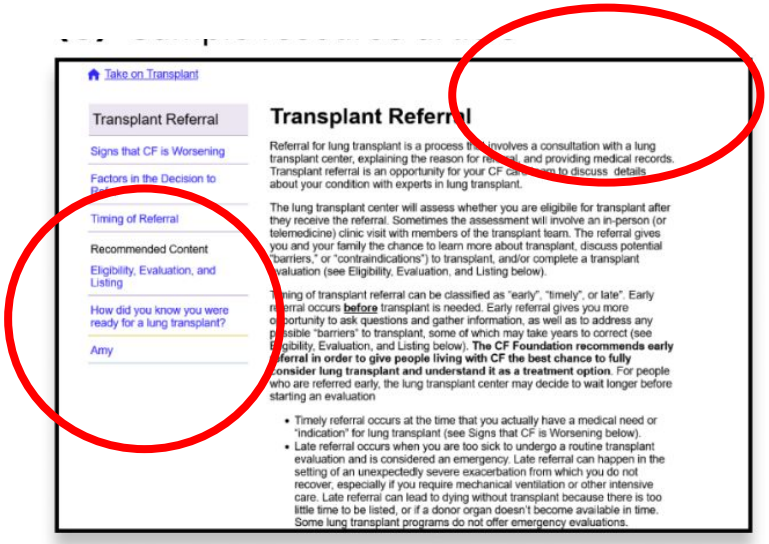


(F) Sample patient story



Small differences of each prototype

Author-Driven Prototype
Had additional recommendations



Reader-Driven Prototype
Had top-level navigation