**Methods**

The CF Foundation invited a multidisciplinary team including adult and pediatric pulmonologists, a clinical psychologist, social worker, an adult individual with CF post-lung transplantation, a former CF nurse, and a transplant coordinator to participate in the development of these consensus guidelines. Committee members were identified through the Lung Transplant Consortium and discipline specific call for applications. The discipline specific call for applications was distributed over the CF listservs. All committee members adhered with the CF Foundation’s conflict of interest policy and disclosed any potential conflicts prior to the initiation of the guideline. The committee met for a virtual kickoff meeting on September 26, 2017 to determine the scope of the work and divide into three workgroups. The workgroups focused on: timing for transplant referral; early referral and modifiable barriers to transplant; and transition to transplant care. Several PICO (Population, Intervention, Control, Outcome) questions were developed by each workgroup. The workgroups performed individual literature searches in PubMed with search terms specific to their topics.

Workgroup A (Understanding the timing for transplant referral) conducted their search on November 20th, 2017 using the search strategy: ((((cystic fibrosis) AND lung transplant) AND survival) AND mortality) AND English [Language]. This resulted in 635 articles, after reviewing the literature, they excluded 535 articles. 366 articles were excluded at the title level, 126 at the abstract level, and 43 at the full text level.

Workgroup B (early referral and modifiable barriers) conducted three searches. Search 1 focused on referral and used the following search terms: ((cystic fibrosis) AND lung transplant) AND referral. limit: humans. This search was conducted on January 31, 2018 and resulted in 74 articles. Of those 74 articles, 42 were excluded: 23 were excluded at the title level, 9 at the abstract level 9 at the full text level, and an additional 9 were excluded as the language was not English. Search 2 focused on barriers, and used the following search (("lung transplant") AND (("contraindications") OR "barriers") ) AND "English and humans"[Filter] 01/01/1988-current. The search was conducted on February 5, 2018 and found 85 articles. A total of 60 of those articles were excluded; 39 articles were excluded at the title level, 20 at the abstract level, and 1 at the full text level. The third search focused on Advanced Planning Tools. Three separate searches were conducted on February 20th, 2018, the first search (cystic fibrosis AND lung transplant AND decision aids); limited to English and yielded 14 articles. The second search (advanced care planning AND lung transplant) and was limited to English. This search yielded 20 articles. The third search (lung transplant AND decision aids) was limited to English and yielded 76 articles. A total of 110 articles were found in the Advance Planning Tools searches, of those, 15 articles were removed as duplicates. In total 95 unique articles were found in these three searches. Eighty-eight of those unique articles were excluded; 88 articles were excluded at the title level, 0 at the abstract level, and 0 at the full text level. The remaining 7 articles were used for the development of the associated recommendation statements.

Workgroup C (transition to transplant care) conducted three literature searches and met with a focus group comprised of adults with CF who have undergone a lung transplant, and family members of transplant recipients with CF from the US and Canada. The focus group met 7 times to discuss various aspects of the transition to transplant care: 1) timing of transplant information presentation, 2) transplant-related expectations, 3) treatment team transition issues, 4) stigma associated with the need for transplantation, and 5) concerns regarding social support during the transition to transplant. The three literature searches conducted used the following search strategies: Cystic fibrosis AND transplant AND readi\* ; Cystic fibrosis AND transplant AND transi\*; and Cystic fibrosis AND transplant AND psych\*. These searches were conducted on January 3rd 2018 and February 22nd 2018 and yielded a total of 97 articles. A total of 76 of those articles were excluded; 33 articles were excluded at the title level, 26 at the abstract level, and 7 at the full text level. This workgroup (transition to transplant care) several “hand searched” articles that were also included. This added an additional 24 unique citations that were reviewed. The results of qualitative analysis of the focus group transcripts will be discussed in a subsequent paper.

The literature search resulted in 914 unique citations and 24 found by hand searching. This yielded a total of 938 unique citations. Articles were excluded for the following reasons: Descriptive or review or editorial papers, does not relate to the question, article did not relate to transplant and/or cystic fibrosis, case reports, basic science, or the paper only addressed post-transplant factors.

The workgroups developed draft recommendations based on the results of the literature search. The committee discussed the workgroup recommendations on monthly phone calls. The committee reconvened on May 11, 2018 to revise and adopt the draft recommendation statements developed in the workgroups. The committee established an a priori voting threshold of 80% agreement.

The manuscript was reviewed by the whole committee and the focus group, before distribution for public comment on September 19, 2018. The public comment document was distributed to the Cystic Fibrosis Community using the CF Foundation’s medical list servs (these listservs included disciplines both represented and not represented on the committee), the European Cystic Fibrosis Society’s email distribution list, and Community Voice (<https://www.cff.org/Get-Involved/Community/Community-Voice/> )- a platform for individuals with CF and their family members to provide feedback on the Cystic Fibrosis Foundation’s initiatives. The public comment was also distributed to the ISHLT pulmonary listserv, the Cystic Fibrosis Lung Transplant Consortium Steering Committee, and selected international CF Center Directors.

The committee reviewed and acknowledged and/or addressed each of the comments received during public comment. The committee held a virtual meeting on Friday, November 16th to discuss the next steps for updating the manuscript based on the public comment. Due to some of the feedback the committee reconsidered 8 of their recommendation statements. Of these statements, one statement was voted on to be removed, and one was split into two statements. A virtual committee meeting was held on December 7th to discuss the revised recommendations and vote. Those who were unable to attend the meeting emailed in their votes separately.

After the revised statements were approved by the committee, the text was revised to reflect these changes. The revised manuscript was then sent to the committee for final approval before submission to the journal.

## Searches

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| --- | --- |
| Search | PubMed |
| (((cystic fibrosis) AND lung transplant) AND survival) AND mortality) AND English[Language] AND ( ( "0001/01/01"[PDat] : "2017/11/20"[PDat] ) ) | 635 |
| ((((cystic fibrosis) AND lung transplant) AND referral ) ) AND "humans"[Filter] AND ( ( "0001/01/01"[PDat] : "2018/01/31"[PDat] ) ) | 80 |
| ("lung transplant"[All Fields] AND ("contraindications"[All Fields] OR "barriers"[All Fields])) AND "english and humans"[Filter] AND ("1988/01/01"[PDAT] : "2018/02/18"[PDAT]) | 87 |
| ((cystic fibrosis AND lung transplant AND decision aids)) AND "english and humans"[Filter] AND ( ( "0001/01/01"[PDat] : "2018/02/20"[PDat] ) ) | 14 |
| (((Cystic fibrosis AND transplant AND readi\*)) OR (Cystic fibrosis AND transplant AND transi\*)) OR (Cystic fibrosis AND transplant AND psych\*) AND ( ( "0001/01/01"[PDat] : "2018/02/22"[PDat] ) ) | 98 |
| ((advanced care planning AND lung transplant)) AND ( ( "0001/01/01"[PDat] : "2018/02/20"[PDat] ) ) | 21 |
| (((lung transplant AND decision aids)) ) AND "english"[Filter] AND ( ( "0001/01/01"[PDat] : "2018/02/20"[PDat] ) ) | 76 |

Full search results are available: See attached Excel Spreadsheet

## Focus Group Members:

* Heather McCoy
* Kasey Seymour
* Tyler Patterson
* Jennifer Staashelm
* Lindsay Bishop
* Cassie Snyder
* Amy Lucy\*
* John Roddy
* Scott Hastie
* Fanny Vlahos

\*Focus Group Co-Lead with psychologist Patrick Smith and a patient representative from the Guidelines Committee