

Addressing Treatment Options for Cystic Fibrosis: An Exploration of Perspectives about Lung Transplant

Community Voice Survey Results

Our survey had 107 (20% response rate) total respondents, which included 74 (69.8%) pre-transplant patients and 32 (30.3%) post-transplant patients. Seventy-nine (83.2%) participants were female and 93 (97.9%) were white or Caucasian. Thirty-nine (56.5%) pre-transplant respondents and 22 (78.6%) post-transplant respondents have agreed to help our research team in the development of a decision support tool that aims to prepare individuals with CF to have discussions and make decisions about lung transplant as a treatment option. The survey results listed below highlight a need for education and increased awareness on this topic.

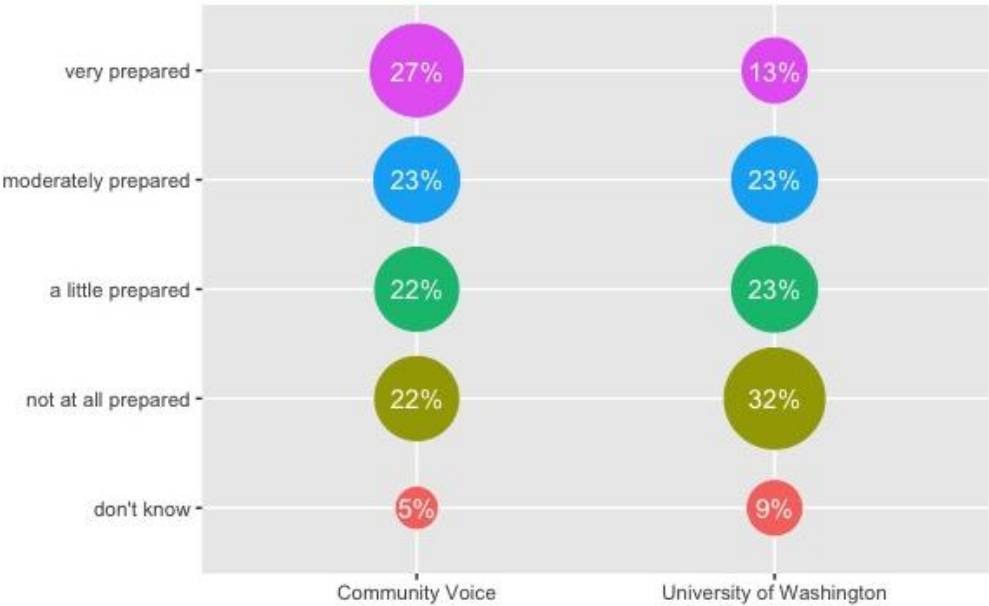
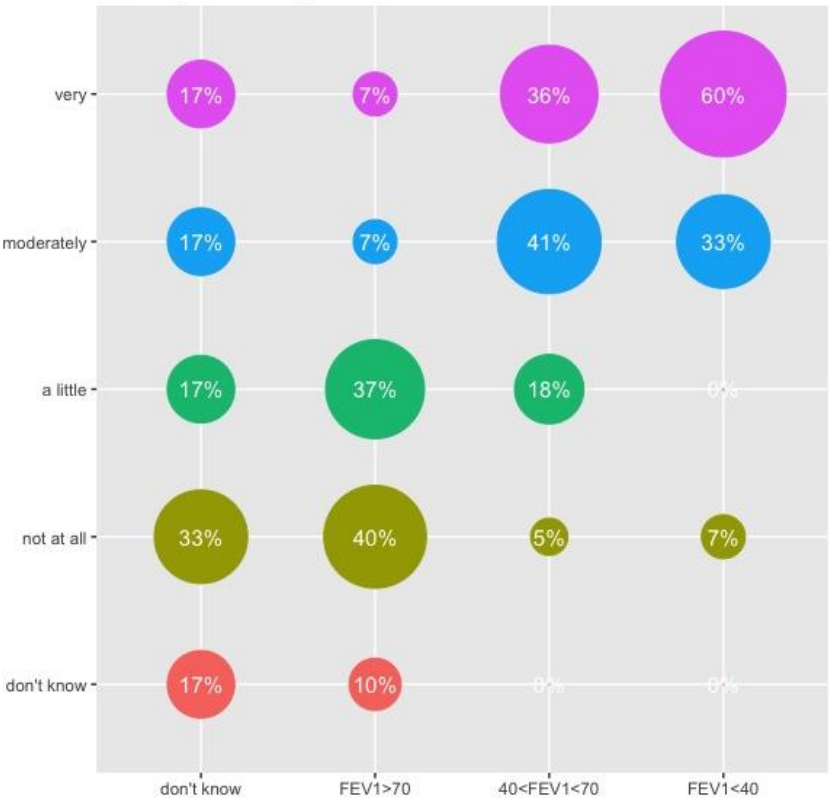


Figure 1: Community Voice members tended to feel more prepared to make decisions about lung transplant as a treatment option than survey takers at the University of Washington.

Figure 2: Looking at the breakdown of lung function of Community Voice members, those with lower lung function felt more prepared to make decisions about lung transplant as a treatment option. Those with higher lung function were less prepared to make these decisions.



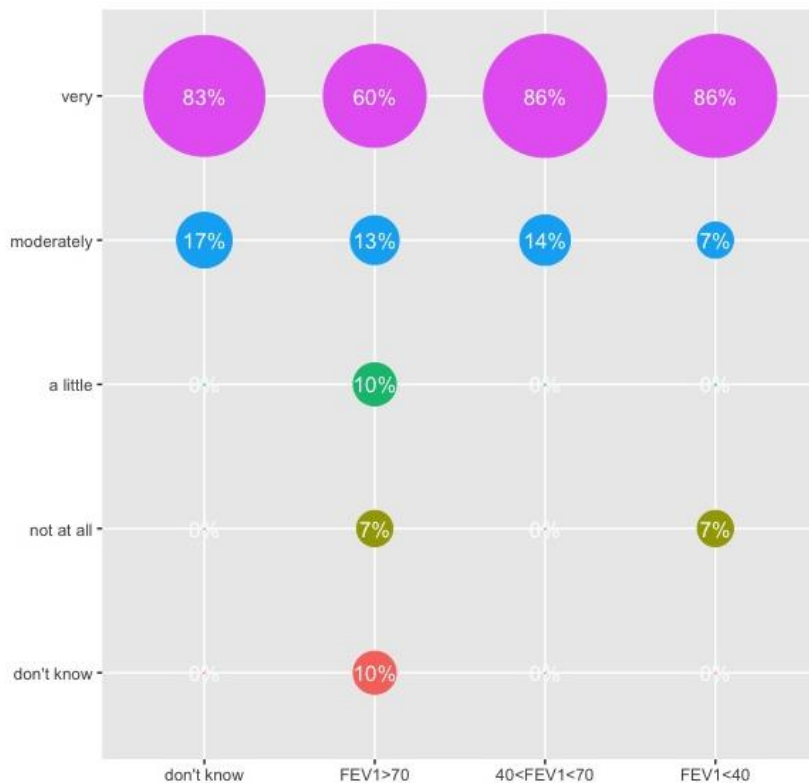


Figure 3:

Community Voice members with all levels of lung function largely felt it was very important to feel prepared to make decisions about lung transplant as a treatment option.

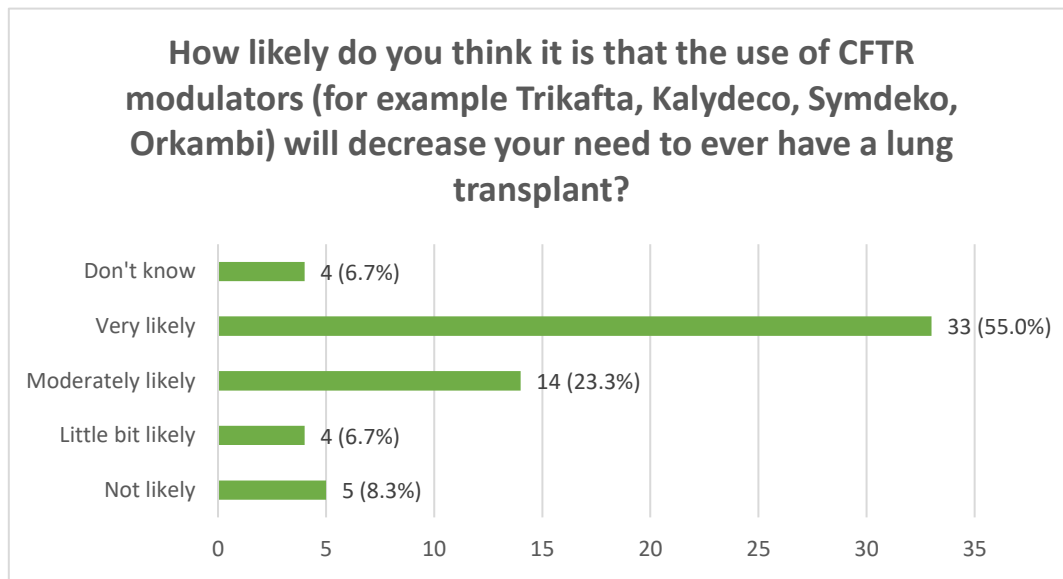


Figure 4:

Of the pre-transplant Community Voice members who are currently on CFTR modulator therapy, a majority believe these modulators will very likely decrease their need to ever have a lung transplant.

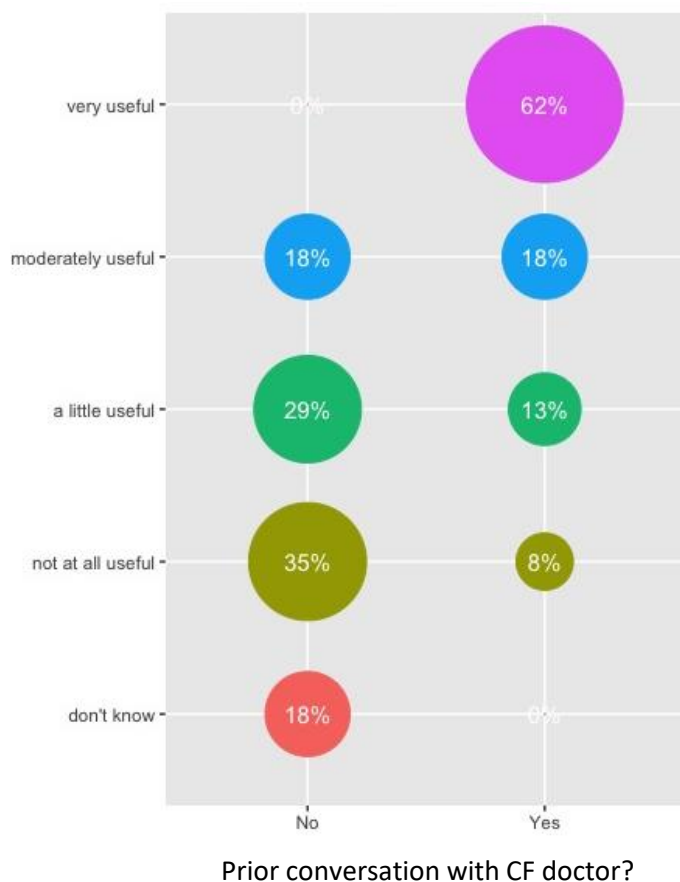
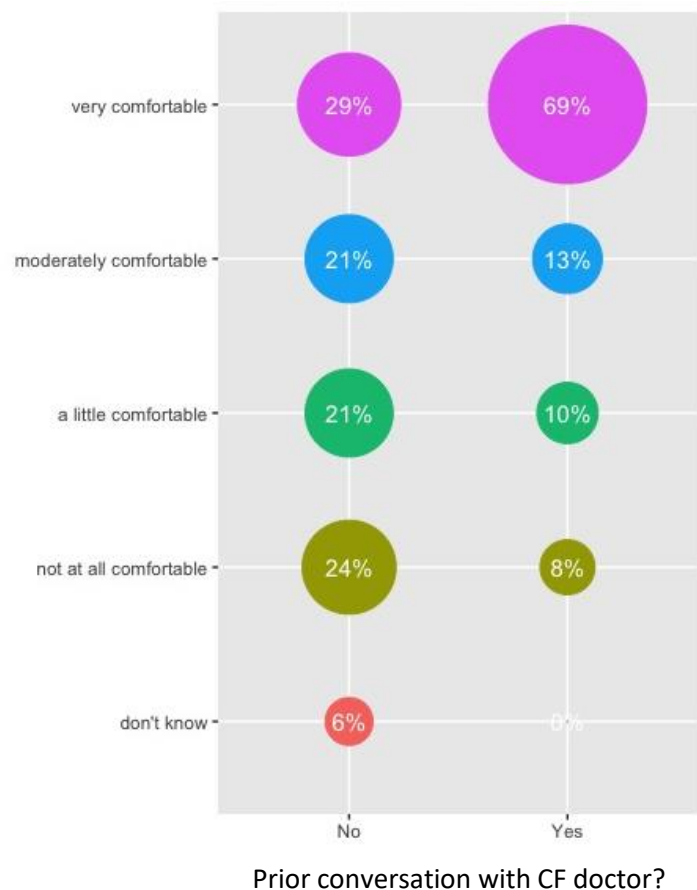


Figure 5:

Of the Community Voice members who have had a conversation about lung transplant with their CF doctor before, a majority found the conversation(s) very useful. Of the Community Voice members who have not had a conversation about lung transplant with their CF doctor previously, many were of the opinion that these conversations would not be useful.

Figure 6:

Of the Community Voice members who have had a conversation about lung transplant with their CF doctor before, a majority felt very comfortable bringing up the topic of lung transplant in conversations with their doctors again. Of the Community Voice members who have not had a conversation about lung transplant with their CF doctor previously, there were mixed findings for comfort level in bringing up the topic of lung transplant.



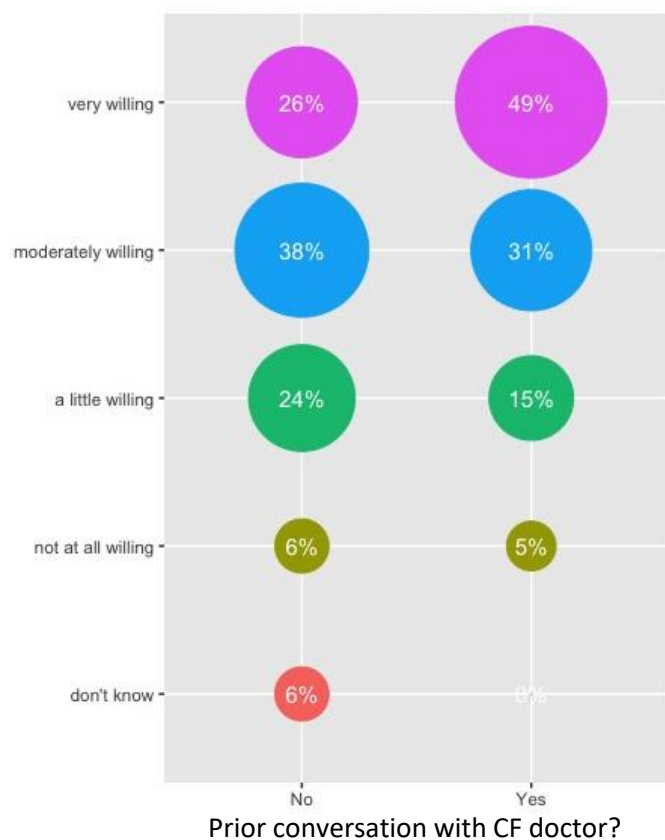


Figure 7:

Of the Community Voice members who have had a conversation about lung transplant with their CF doctor before, a majority felt willing to participate in conversations about lung transplant. Of the Community Voice members who have not had a conversation about lung transplant with their CF doctor previously, there were mixed results and moderate willingness to participate in conversations about lung transplant.

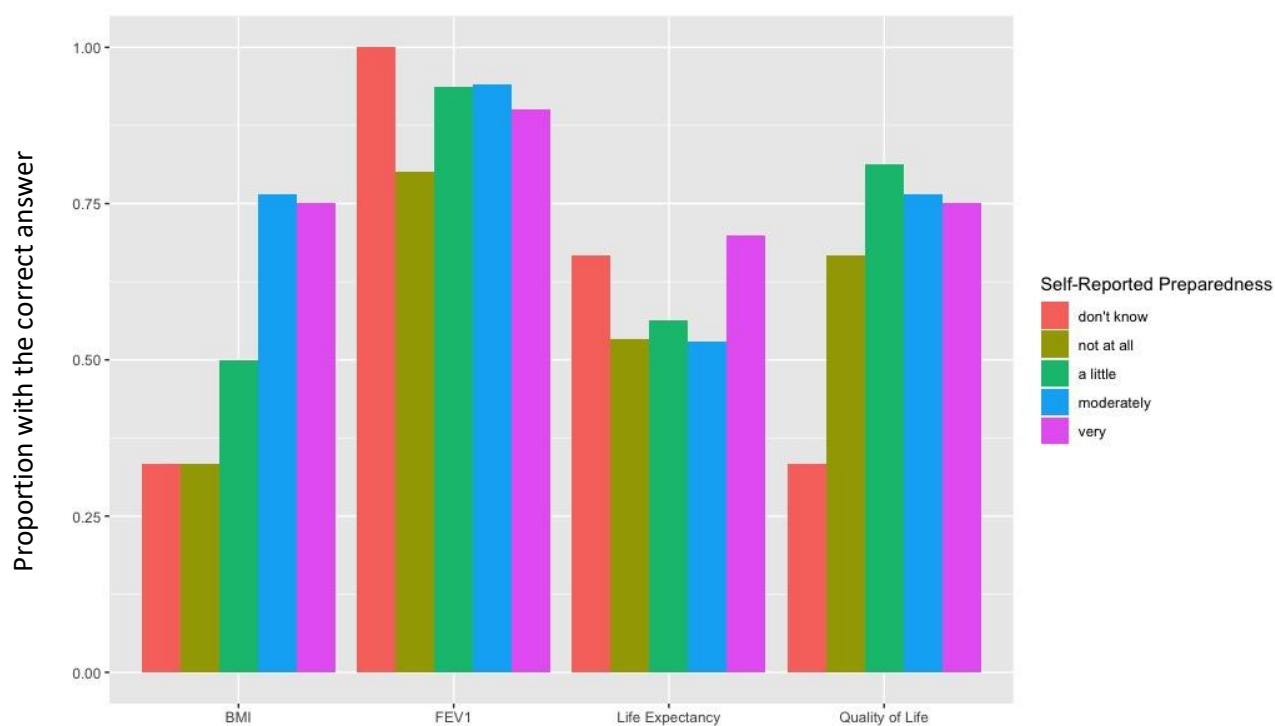


Figure 8:

A large proportion of Community Voice members knew that FEV₁ is an important component of the decision for a CF doctor to recommend lung transplant as a treatment option. However, less knew that being moderately-to-severely underweight or being obese can make a person ineligible for lung transplant. Generally those who reported feeling more prepared to make decisions about lung transplant were more knowledgeable about the later as well as life expectancy and quality of life improvements after lung transplant.