Cystic Fibrosis Patient and Caregiver Mental Health Survey

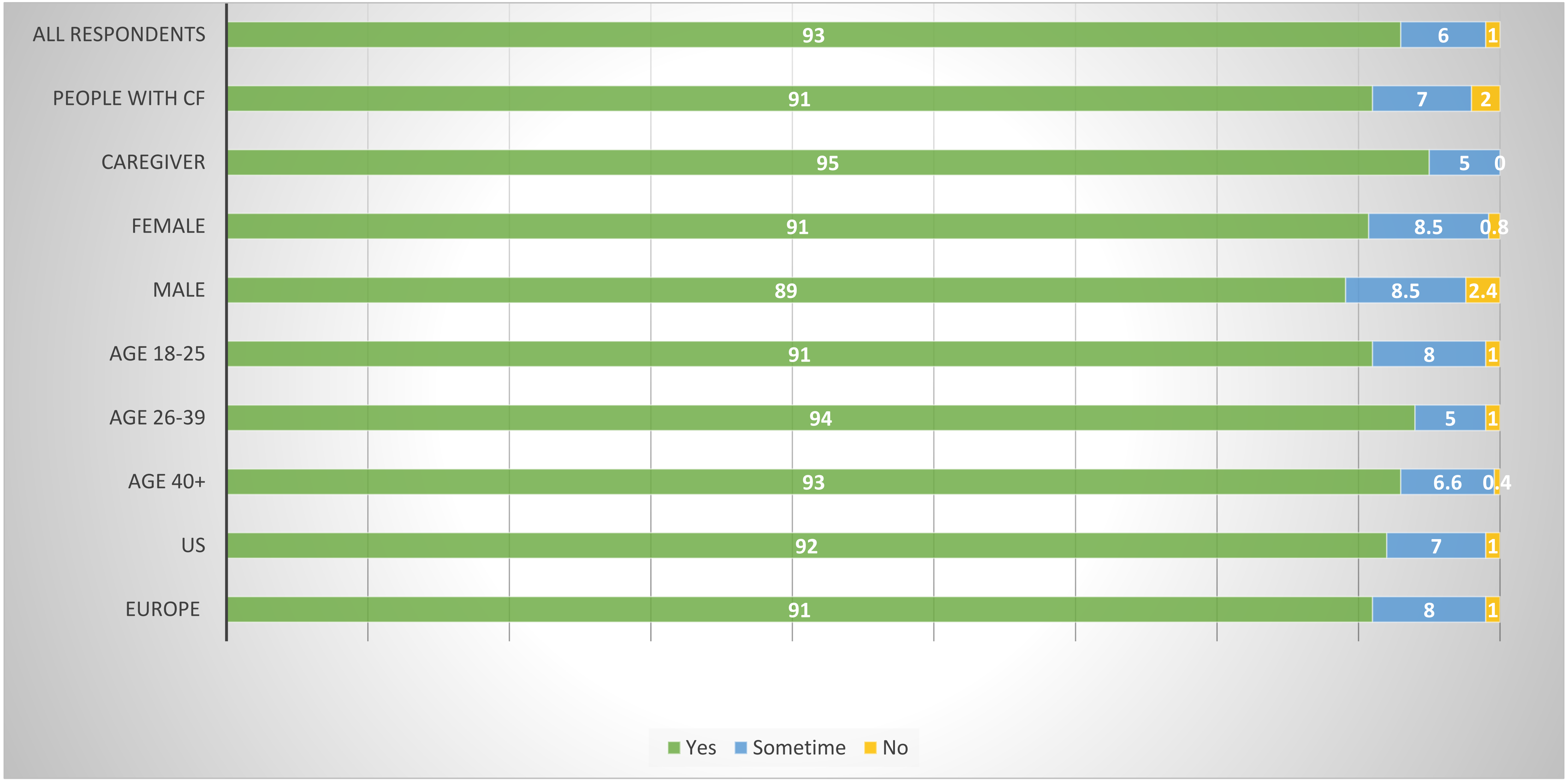
ECFS Mental Health Working Group and
CFF Mental Health Advisory Committee

Data collected November 2019 to February 2020

Total sample size n= 474: People with CF n=240, Caregivers n=233.
Male n=86, Female n=374. Europe n=271, US n=203.

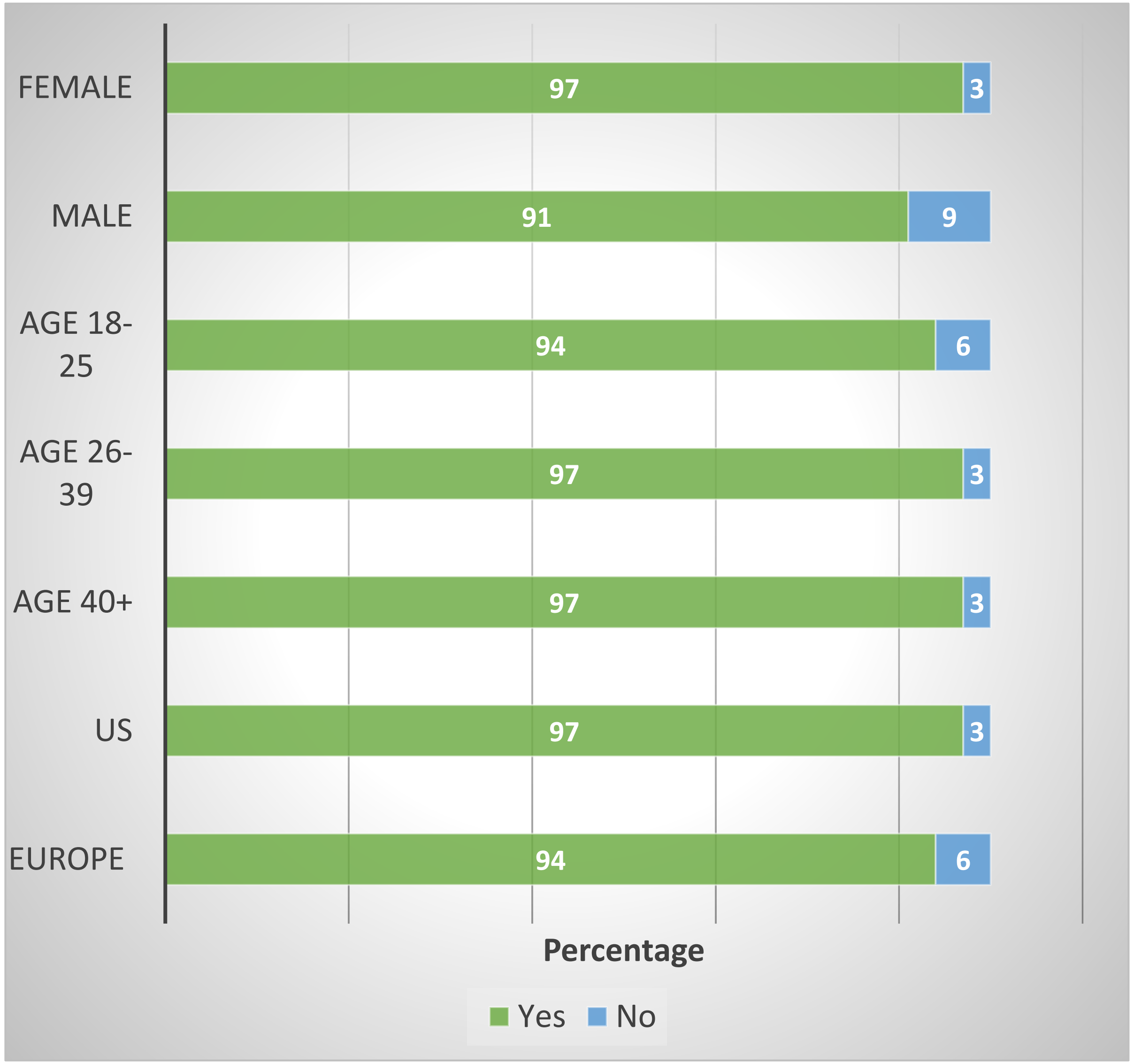
Do you think your mental health is an important aspect of your health?

Universal agreement that MH is important

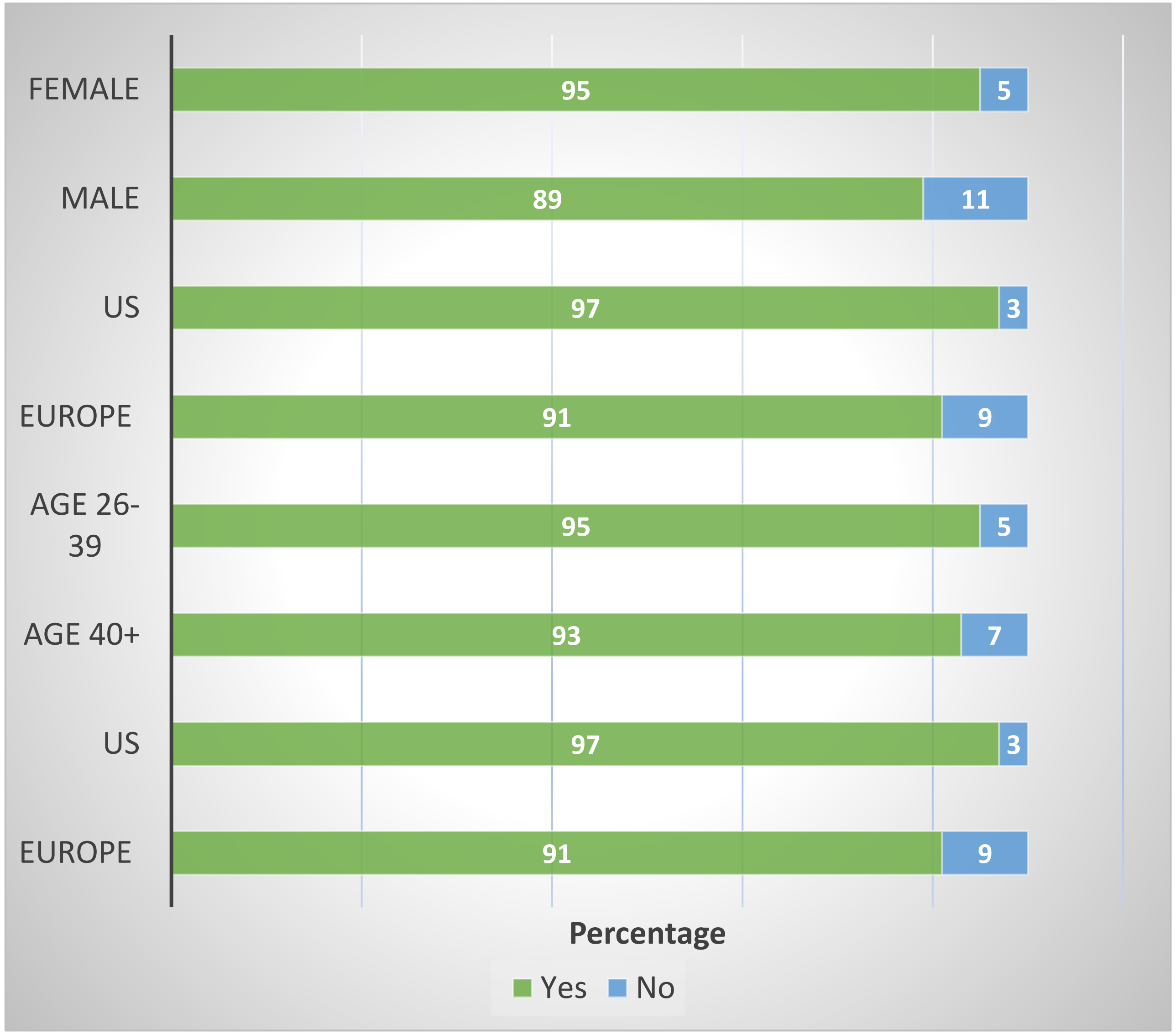


Is it important to be asked about your MH when you come to clinic?

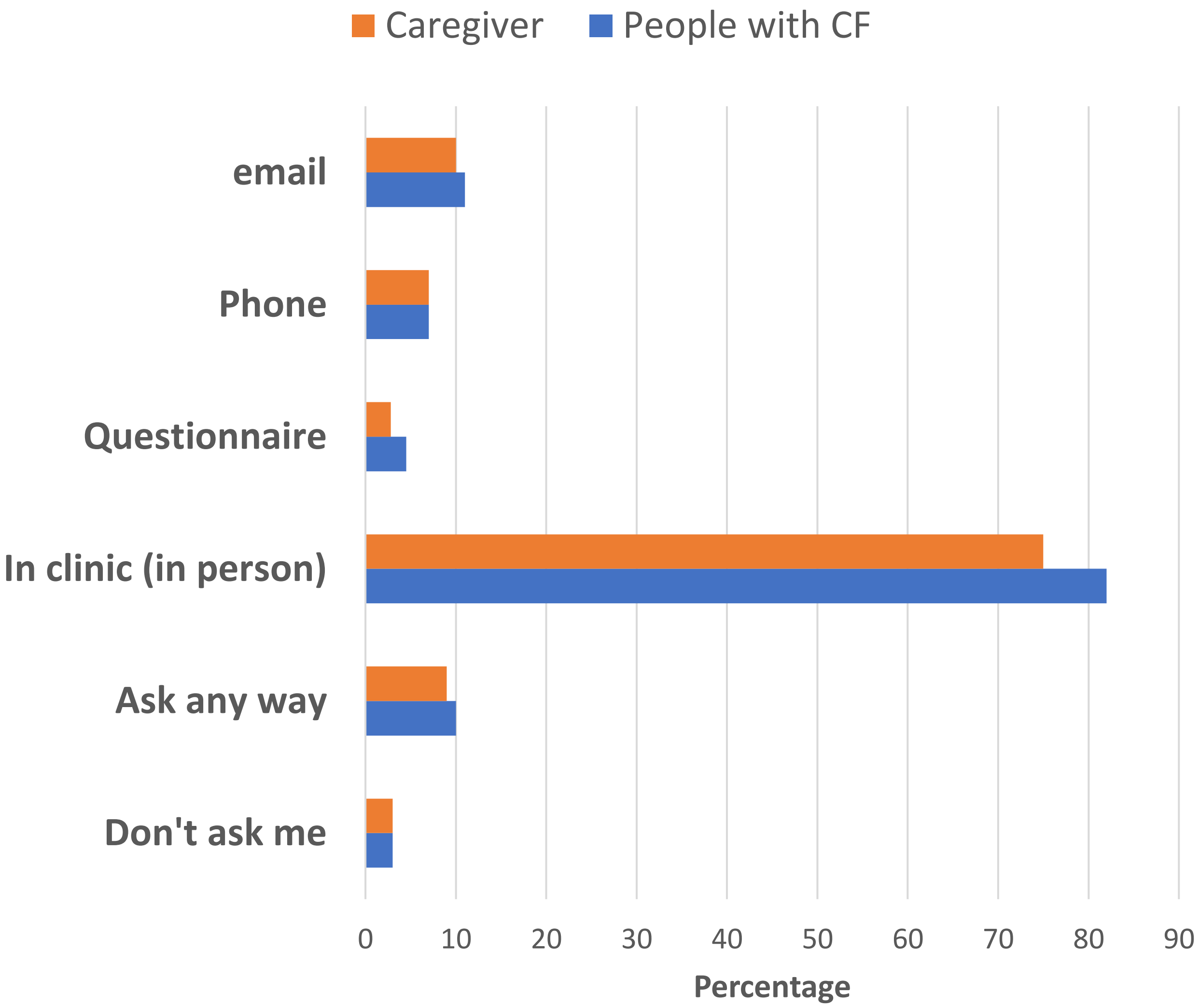
People with CF



Caregivers



In what ways would you prefer to be asked about MH issues?



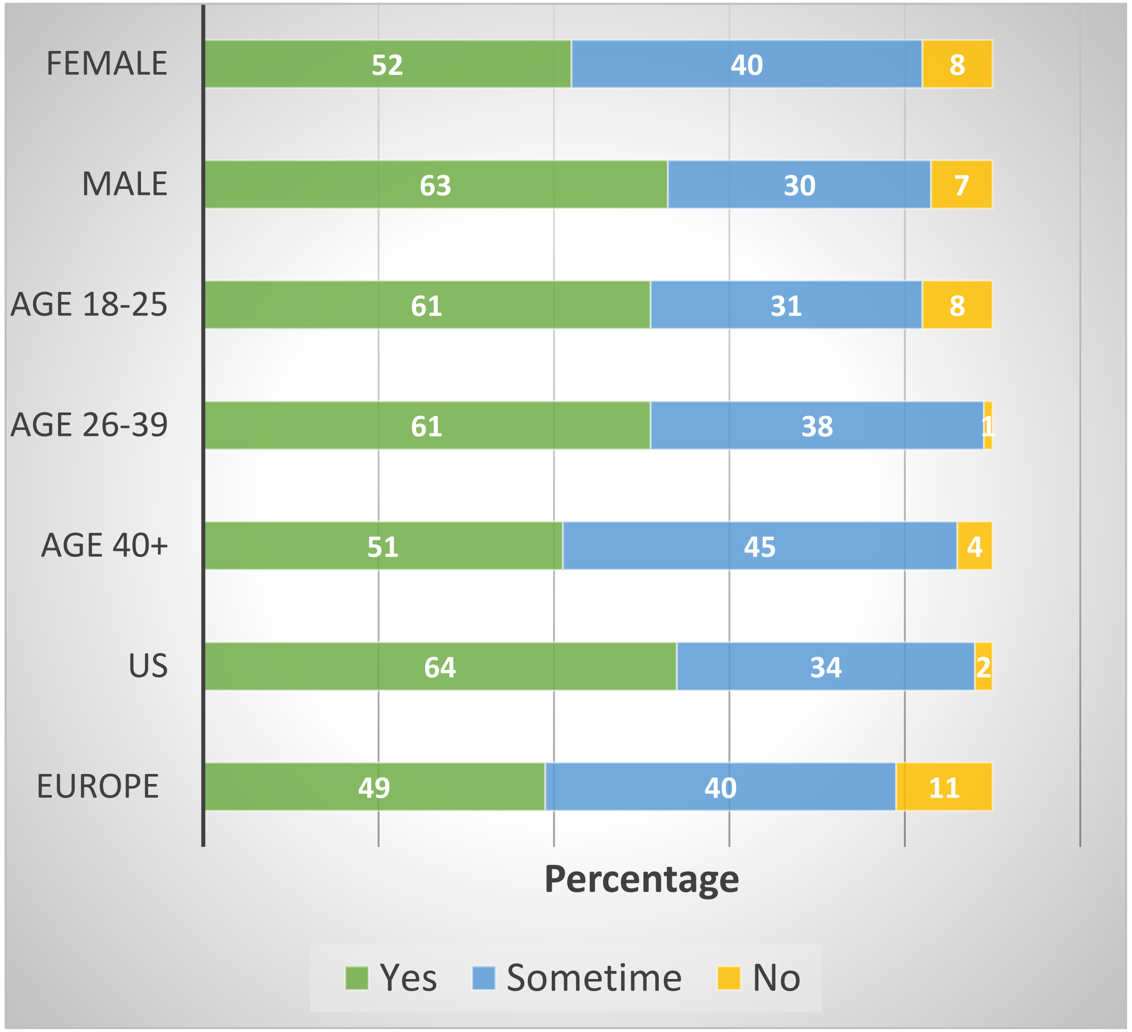
'During hospitalizations, it would be helpful to be offered a discussion with a mental health professional'.

'Important to ask and assess, but I would prefer not to be asked in front of my child, as to not place more stress on them. My thought is they may perceive themselves and their care as too much of a burden. Although this may very well be the case, I don't feel as a parent, you want your child to feel this'.

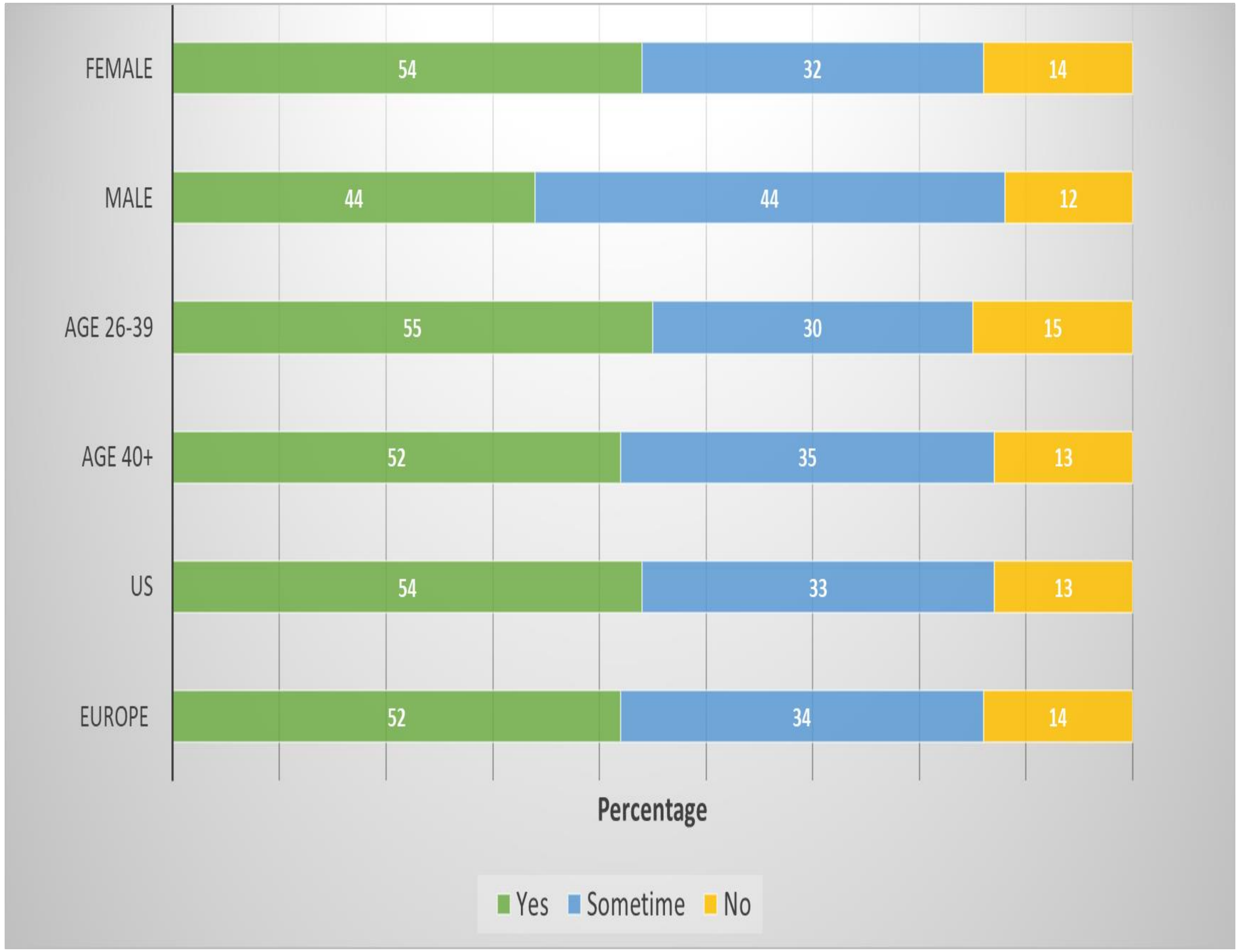
'It's difficult to be asked about mental health with a room full of people when I attend clinic visits. And also in front of family who attends with me. You're not going to say you are depressed in front of others'.

Do you think your CF Team are interested in your mental health?

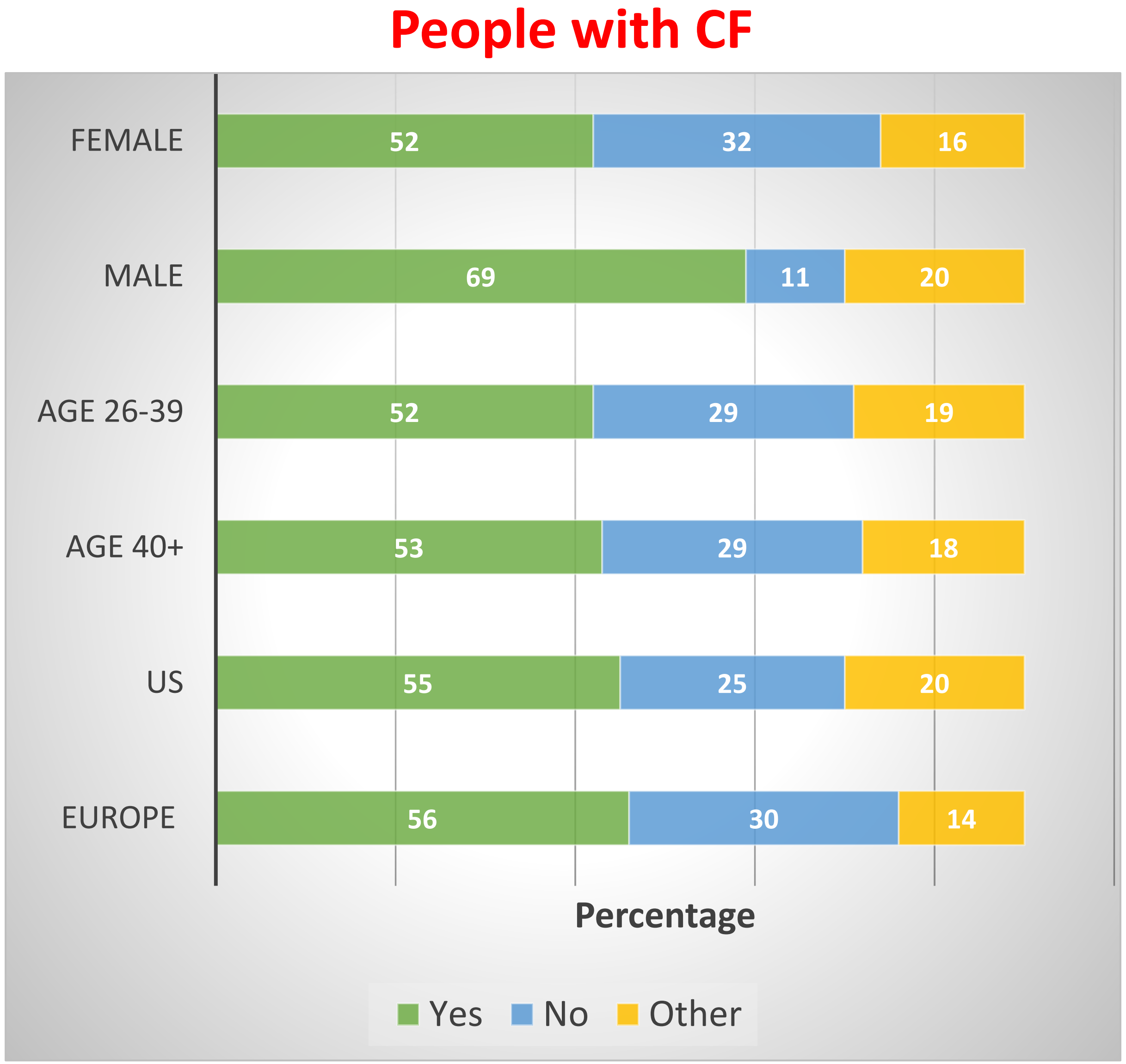
People with CF

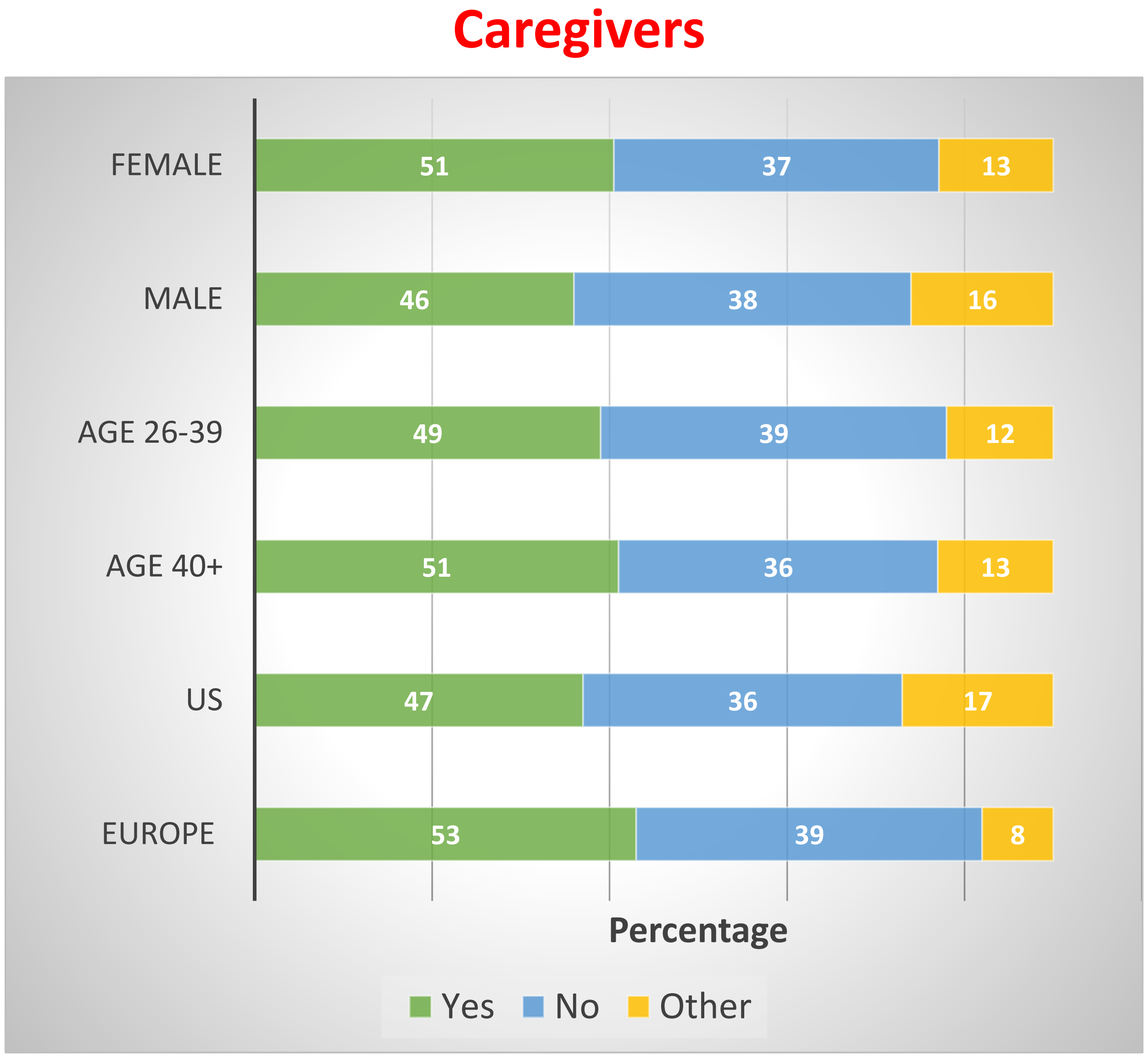


Caregivers

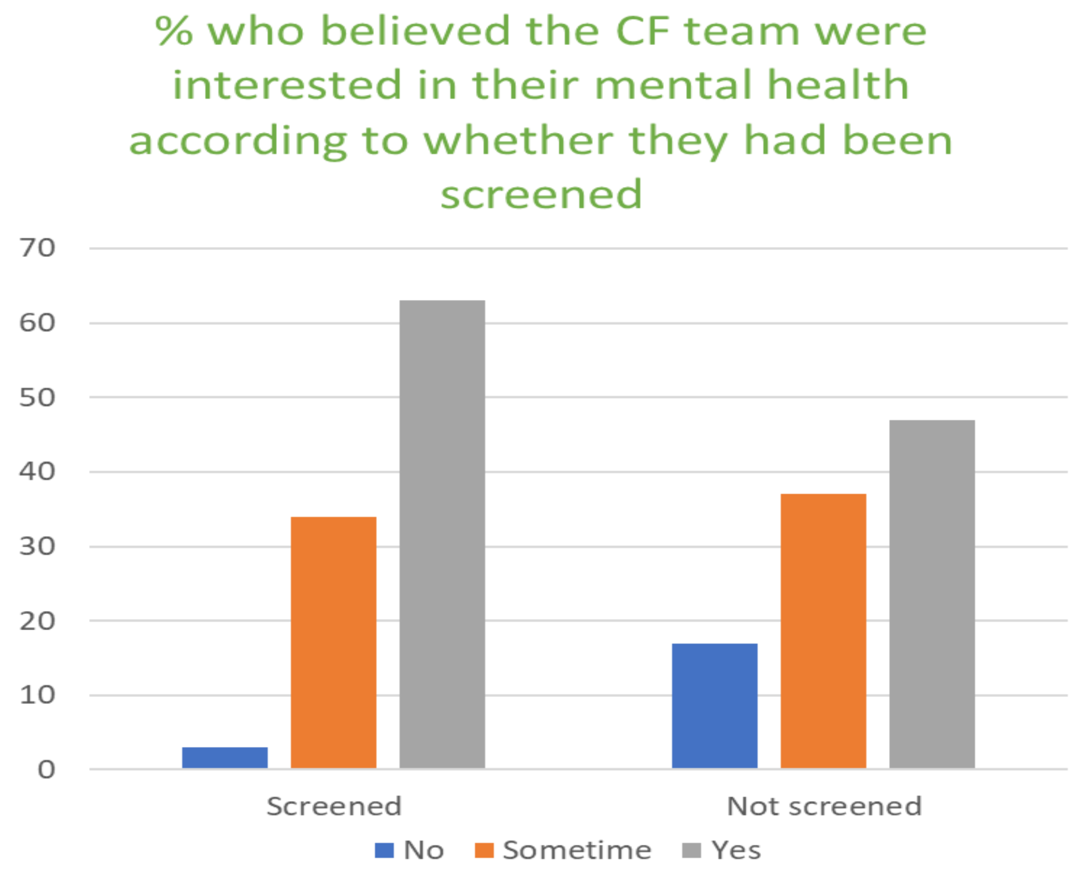


Do you received enough support from your CF team when needed?





42% of the sample had completed the screeners (n=199).
58% reported that they had not (n=276).

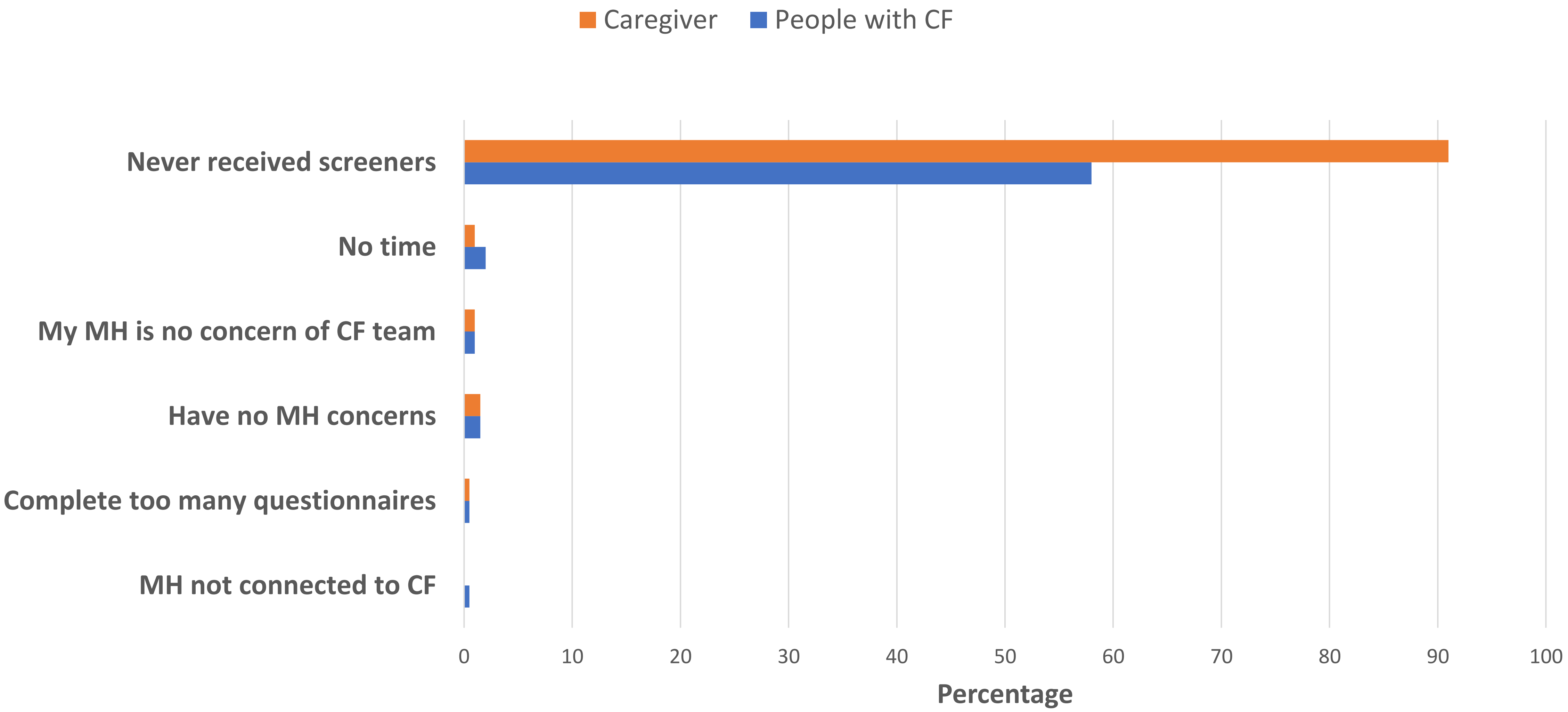

% who believed the CF team were interested in their mental health according to whether they had been screened

People who had been screened were more likely to believe the CF Team were interested in their mental health


% who believed they received enough support for their mental health from their CF team according to whether they had been screened

People who had been screened were more likely to report that they received enough support from their CF Team

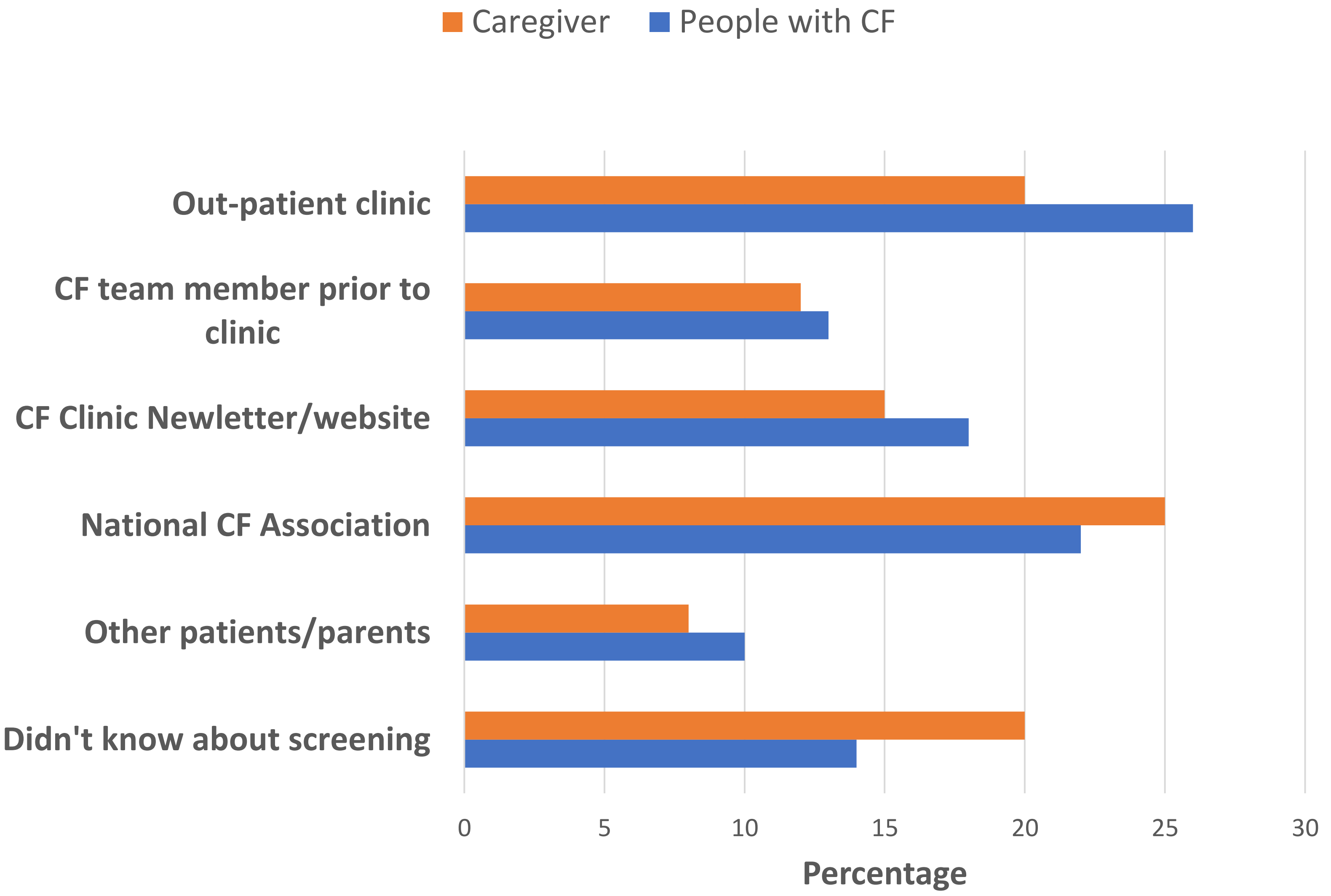
Reasons why screeners not completed



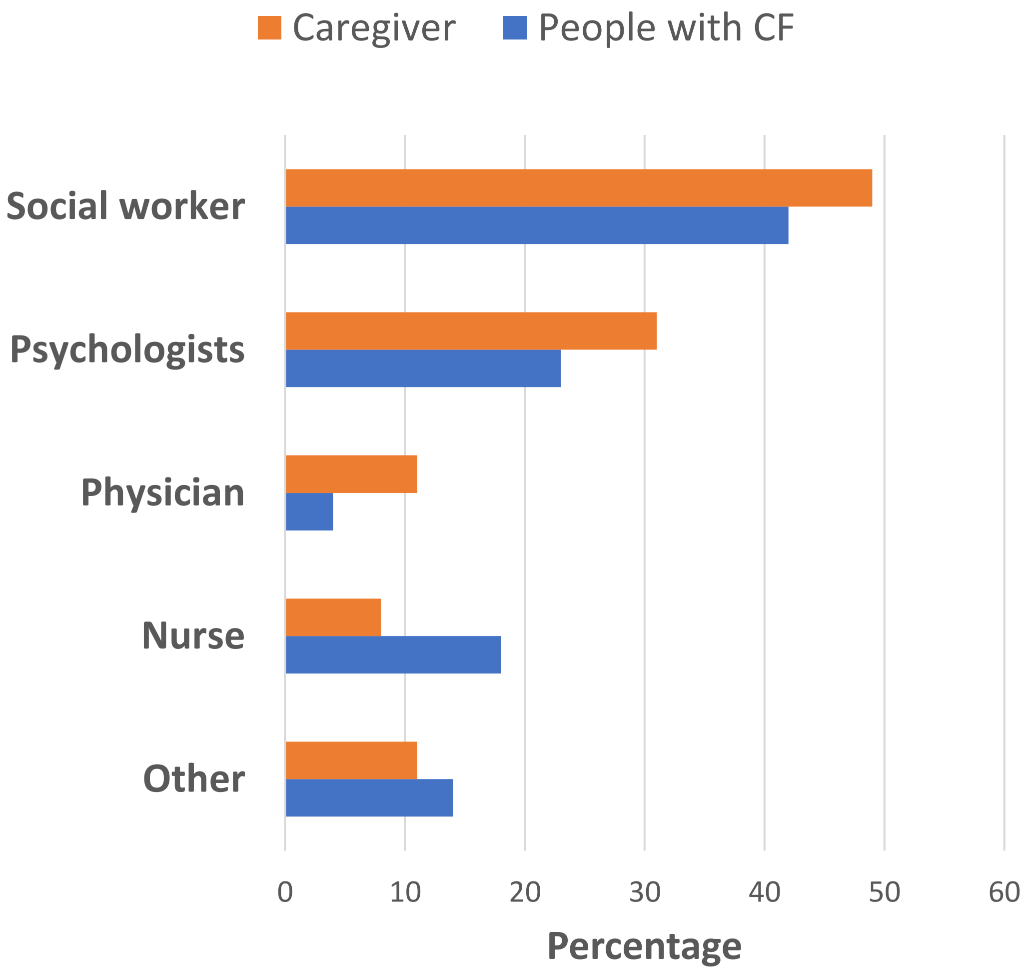
How did you hear about MH screening?

Those completing the screeners comprised:

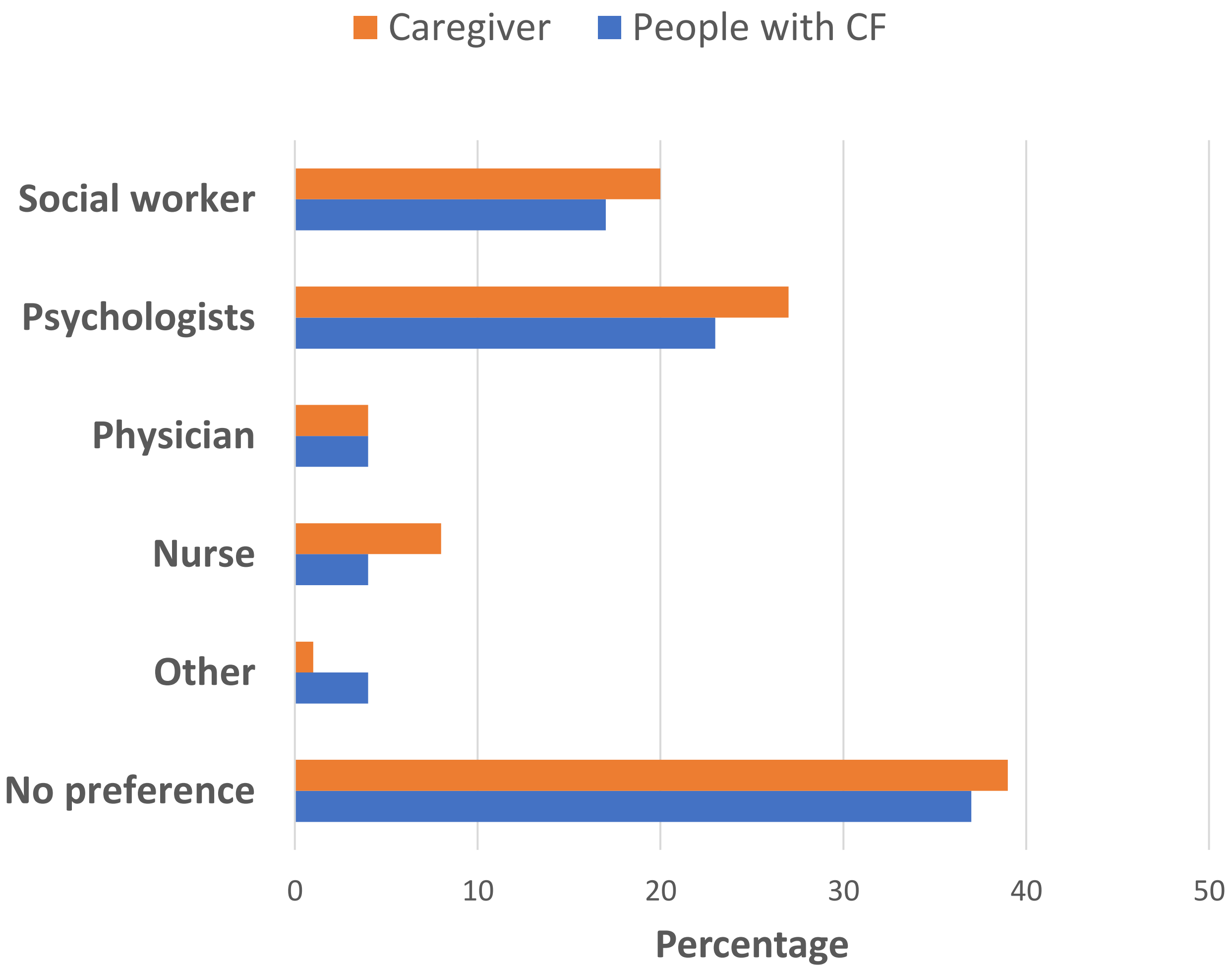
People with CF n=127, Caregivers n=72.
Male n=34, Female n= 160.
EU n=79, US n=120.



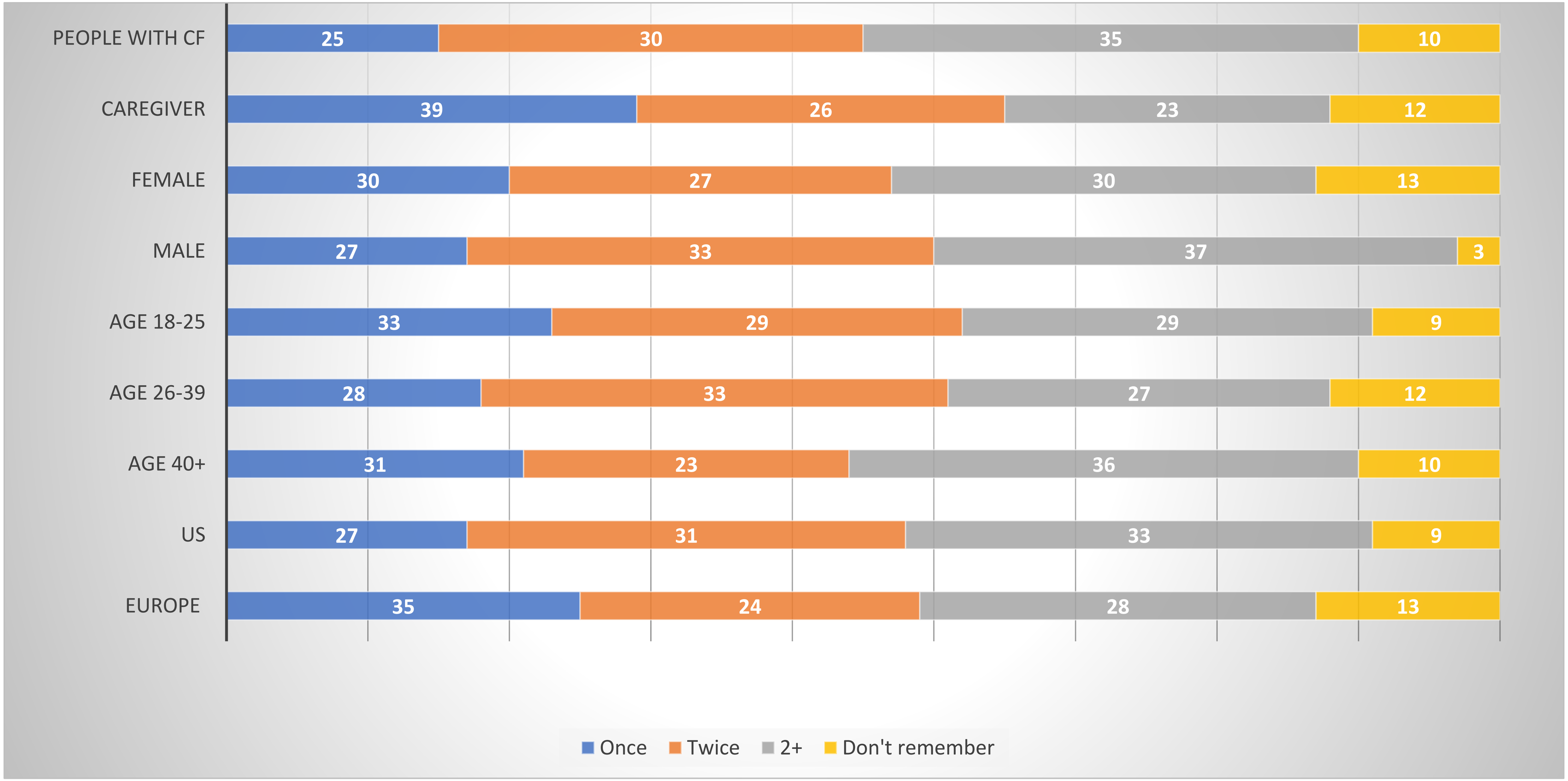
Who asked you to complete the screeners?



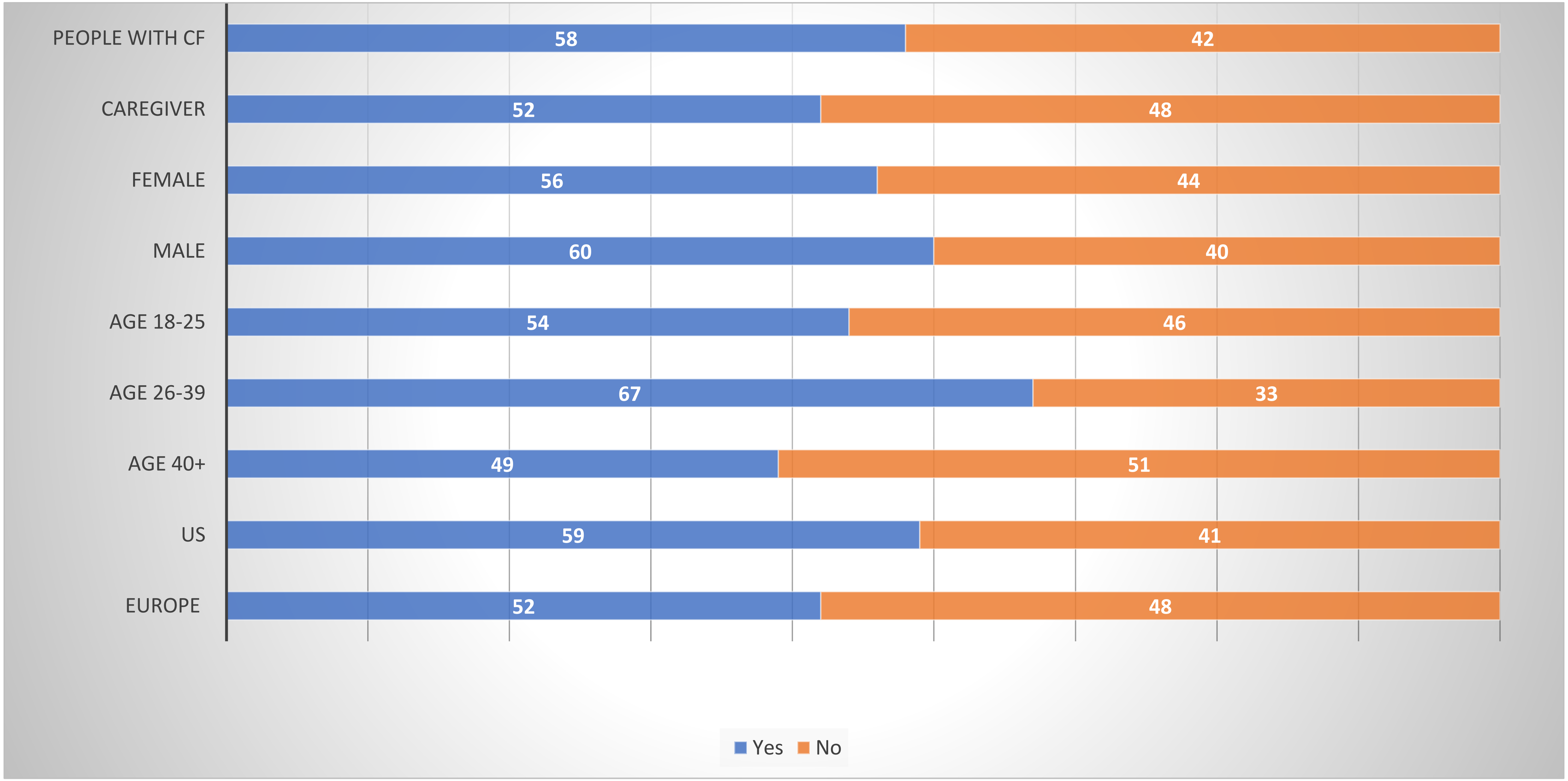
Who would you like to ask you to complete the screeners?



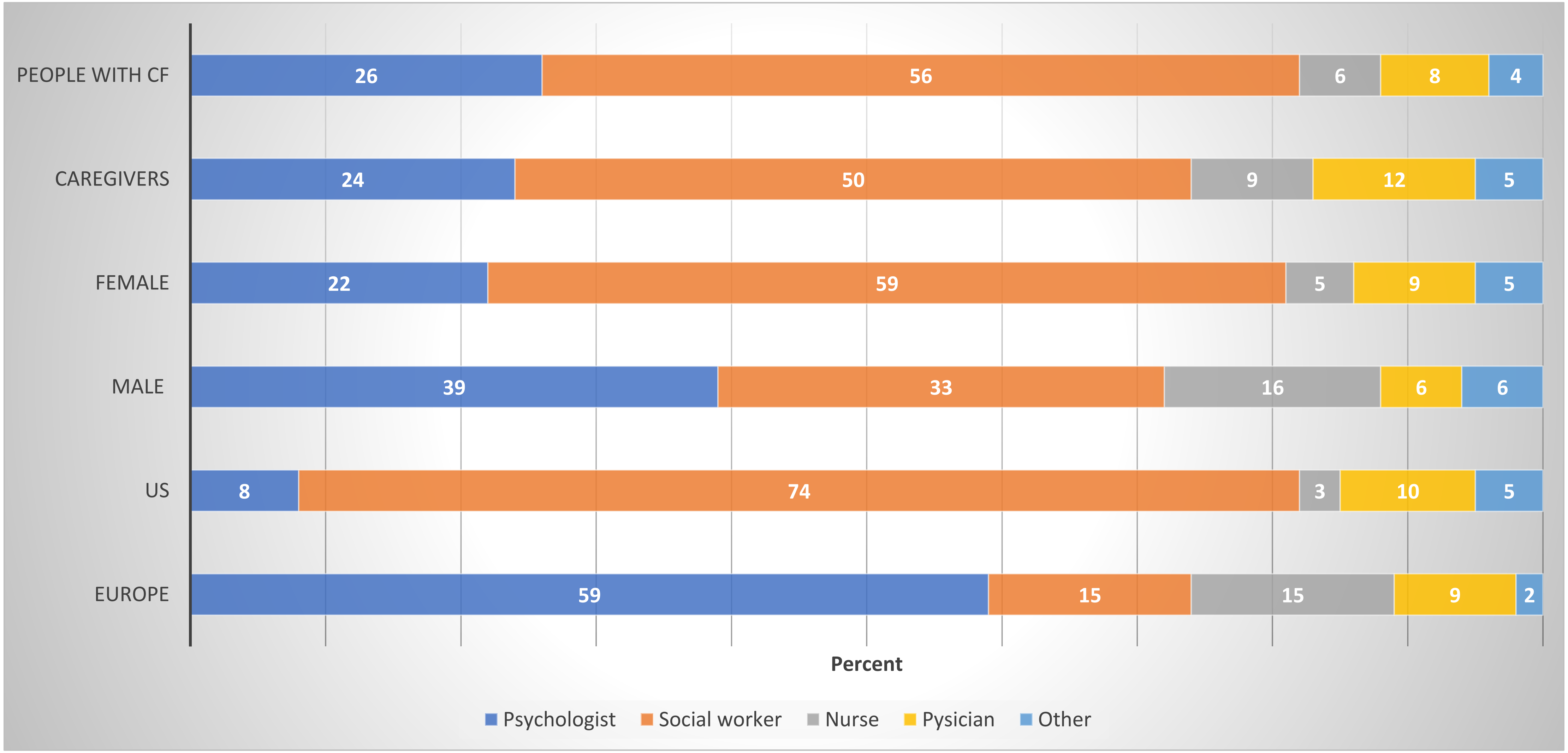
How often did you complete the MH screeners?



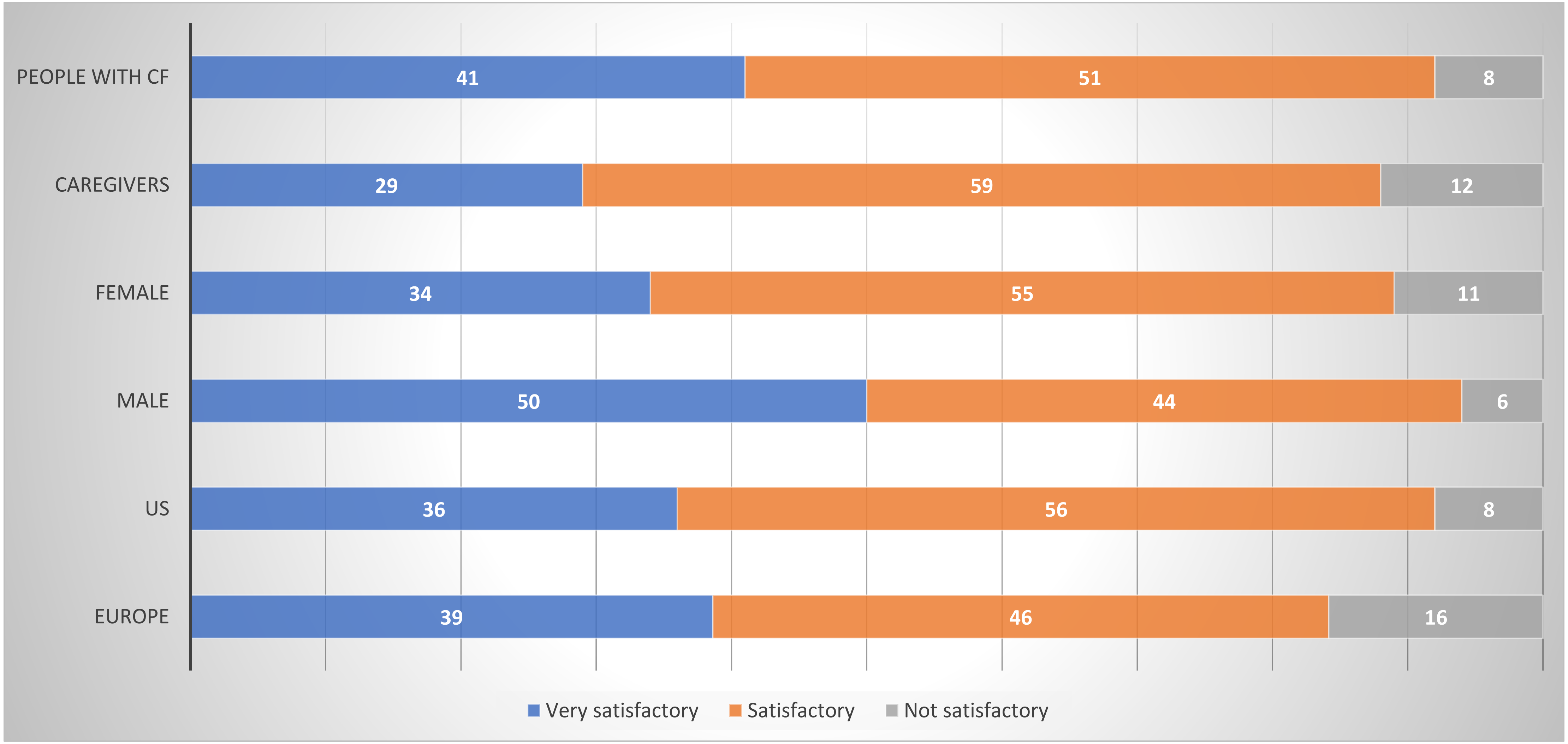
Was there a conversation after completing the screeners?



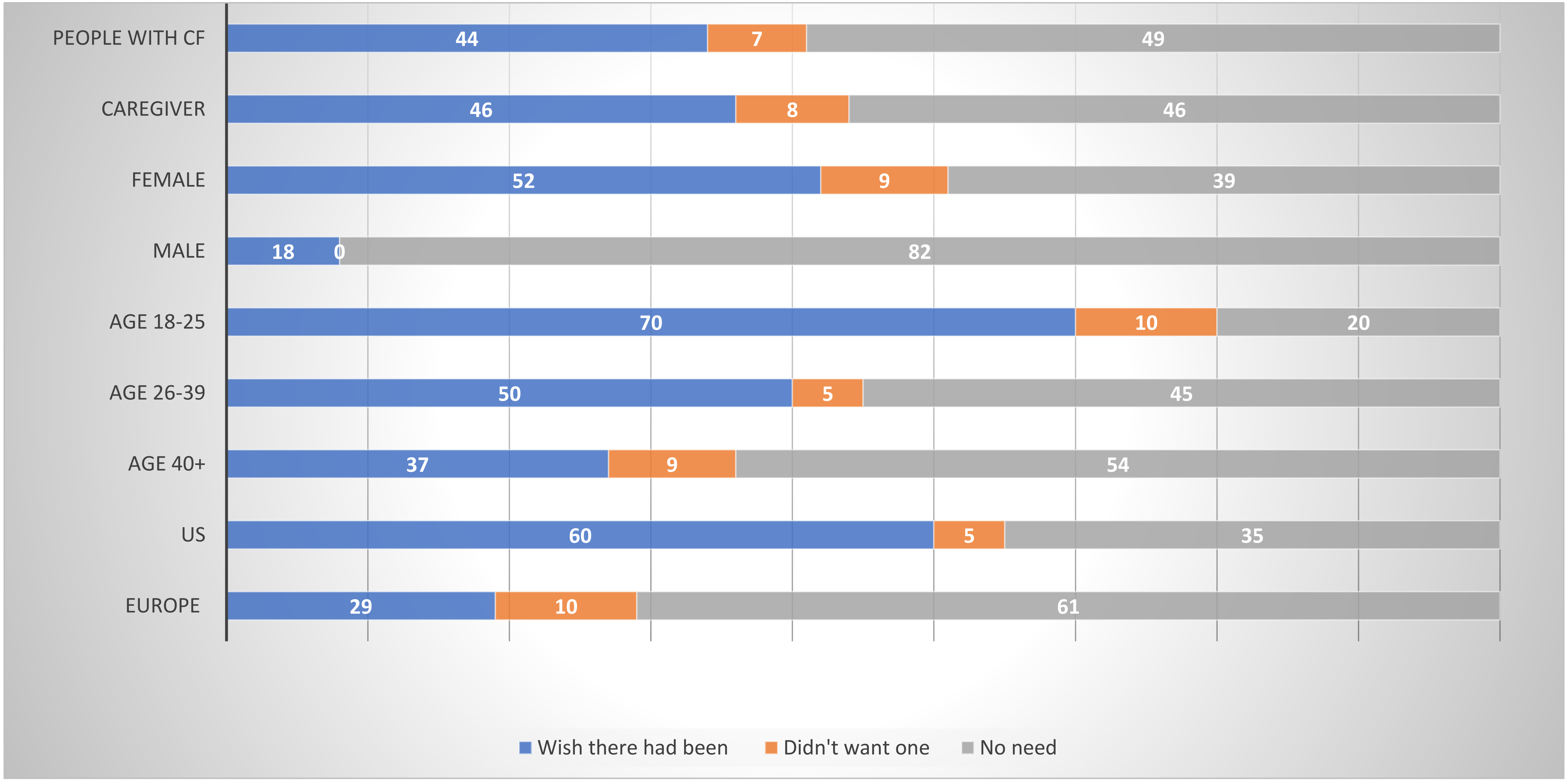
Who was the conversation with?



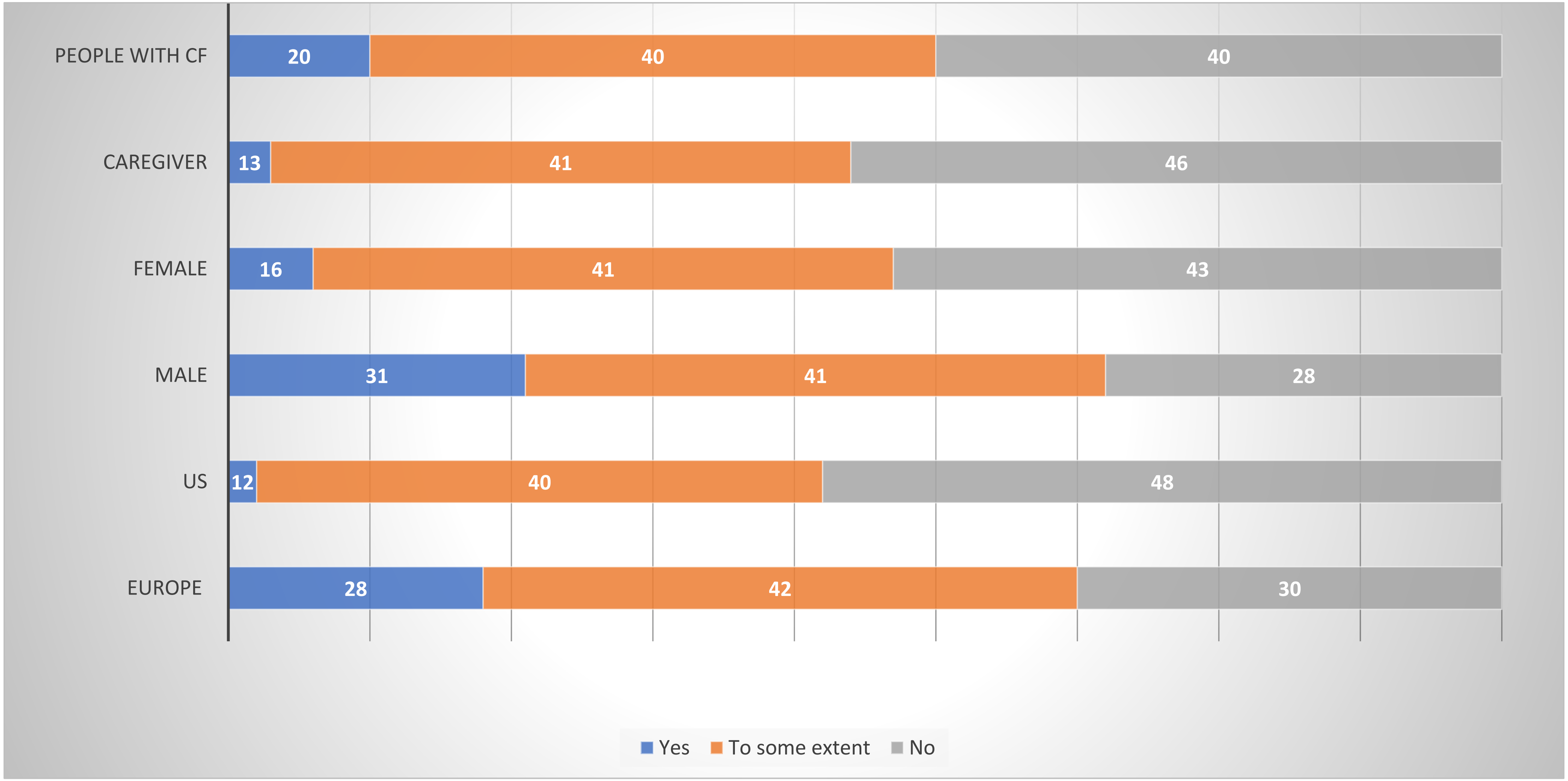
How satisfactory was the conversation?



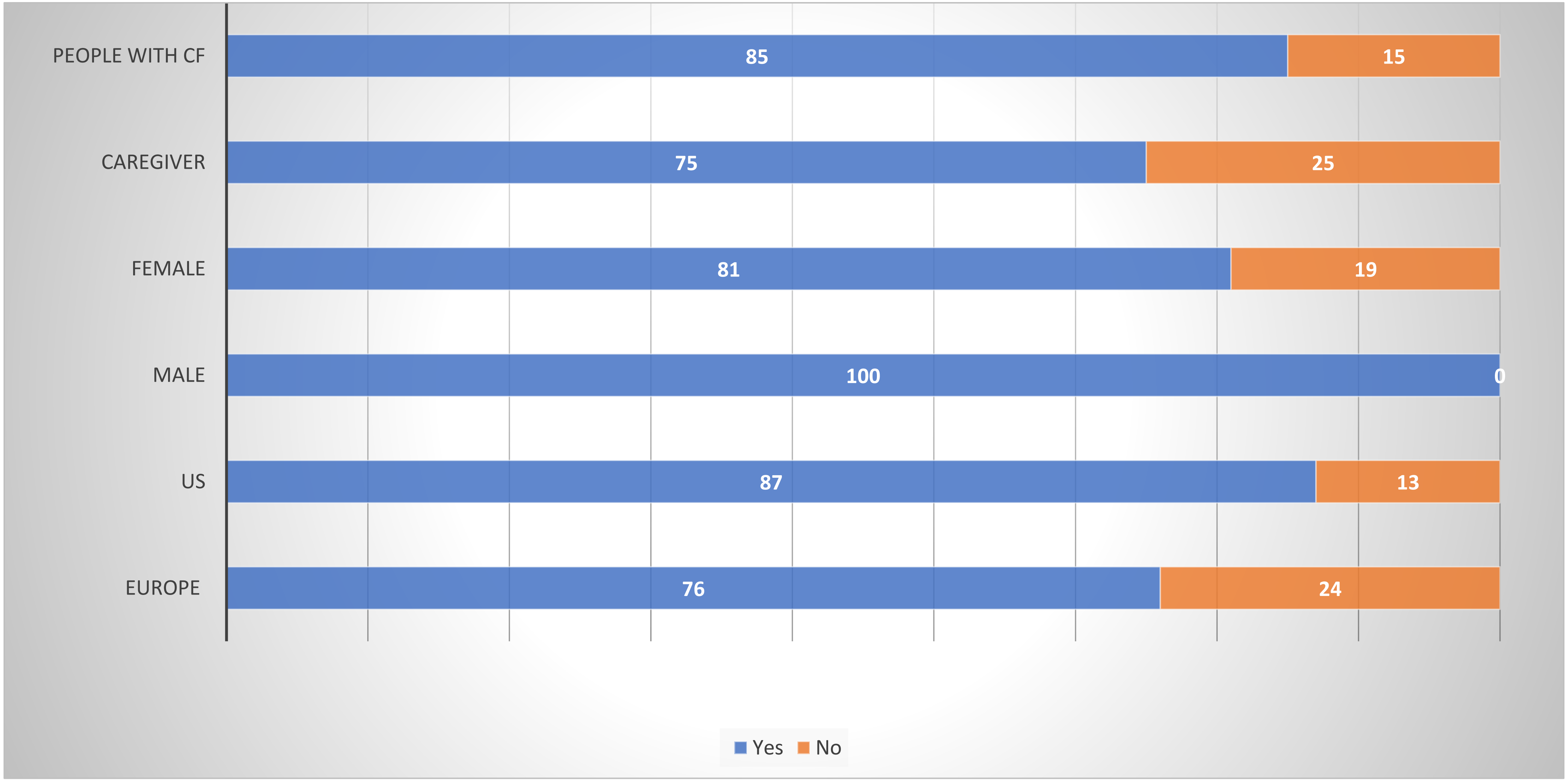
If there was no conversation…



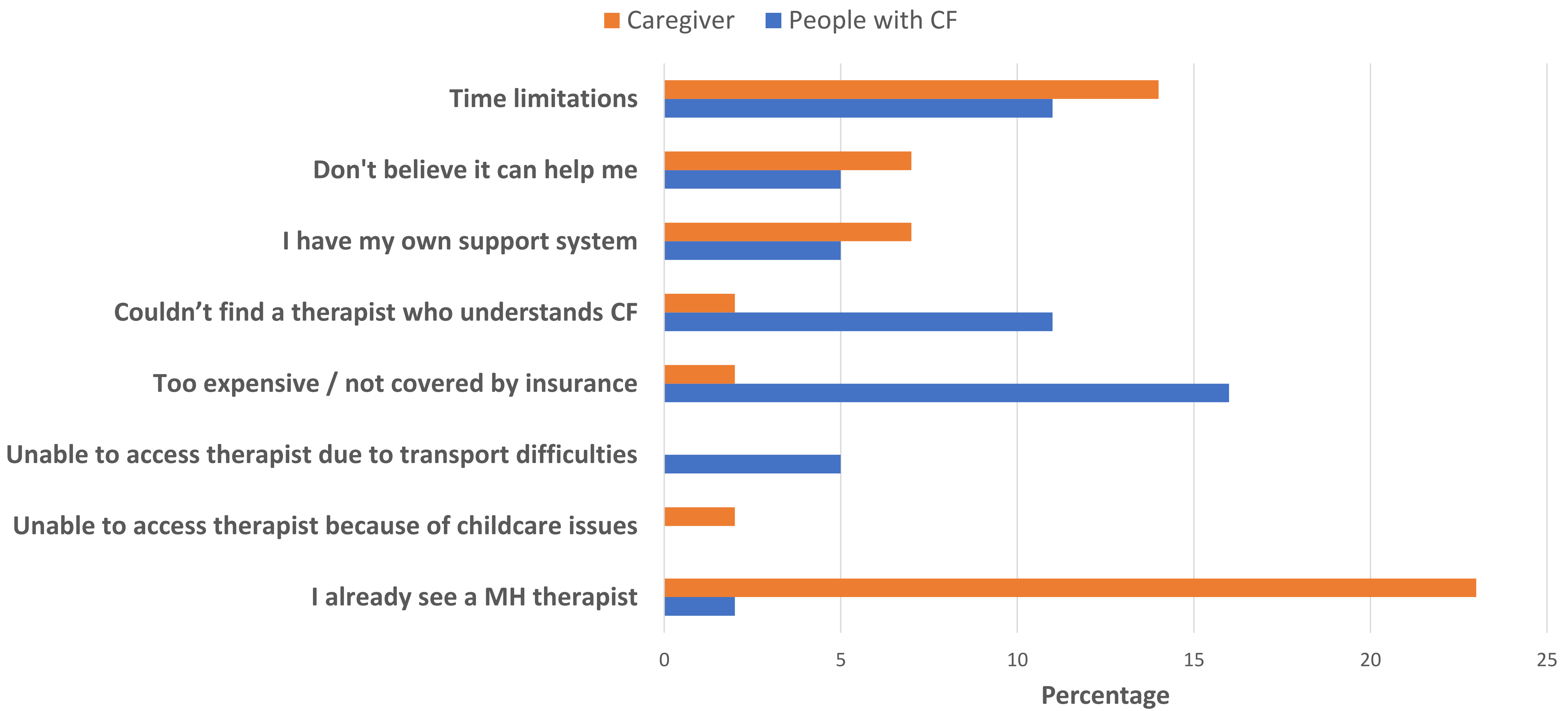
Did the screeners help you understand your feelings better?



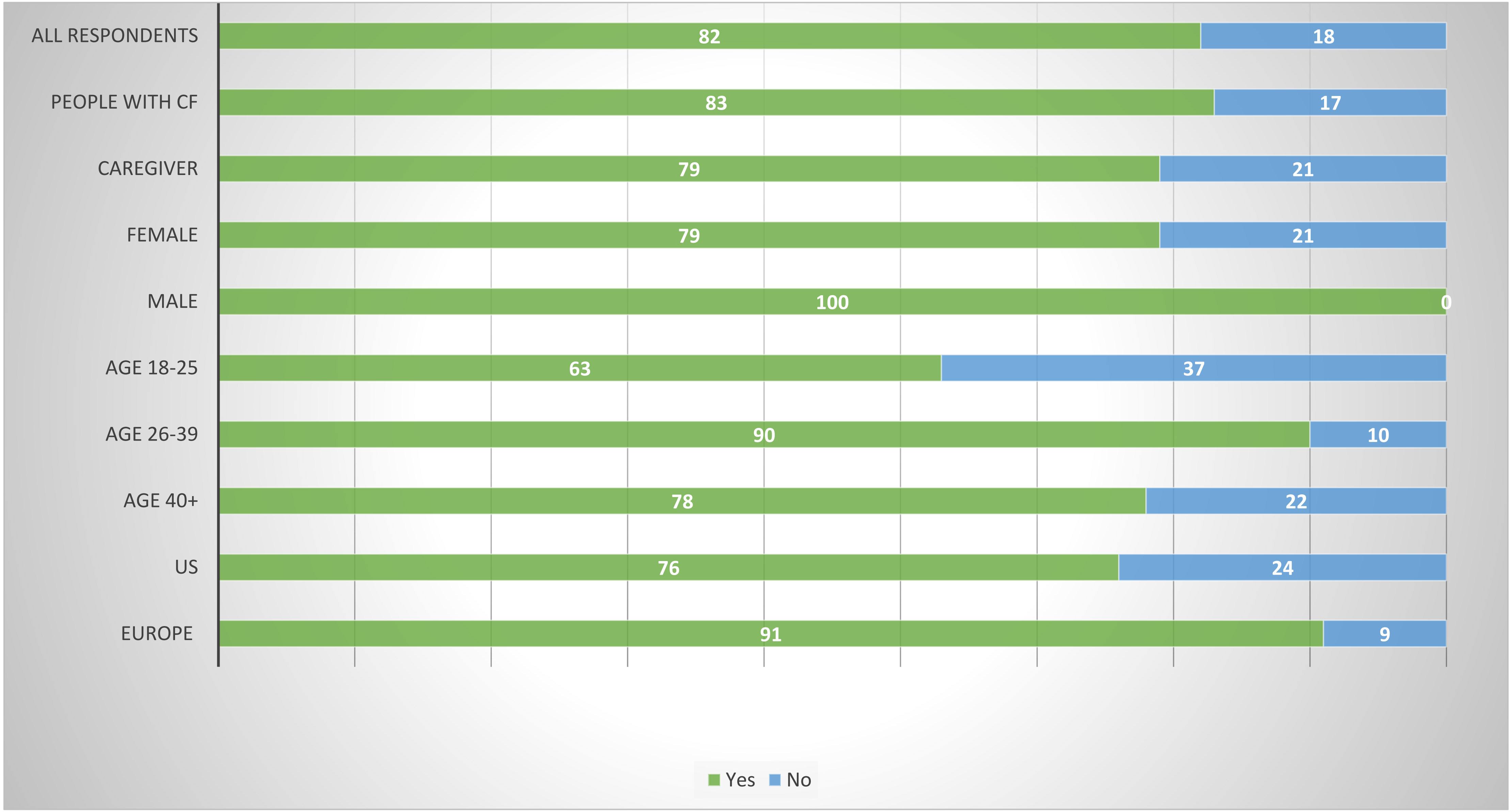
If advised to seek MH care, were you open to persuing it ?



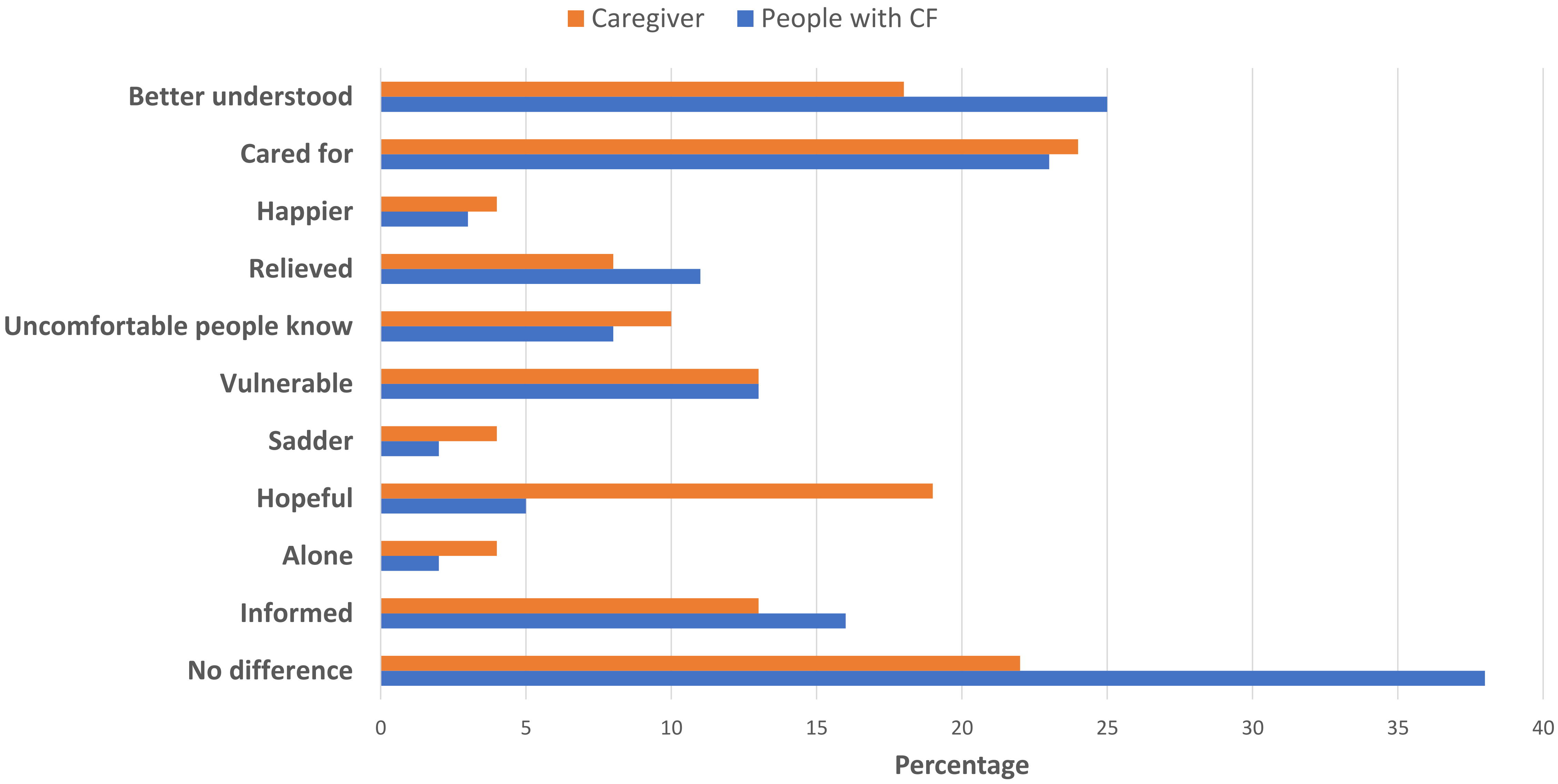
If advised to seek MH care, but didn’t, can you explain why?



Was the advice given to you useful?



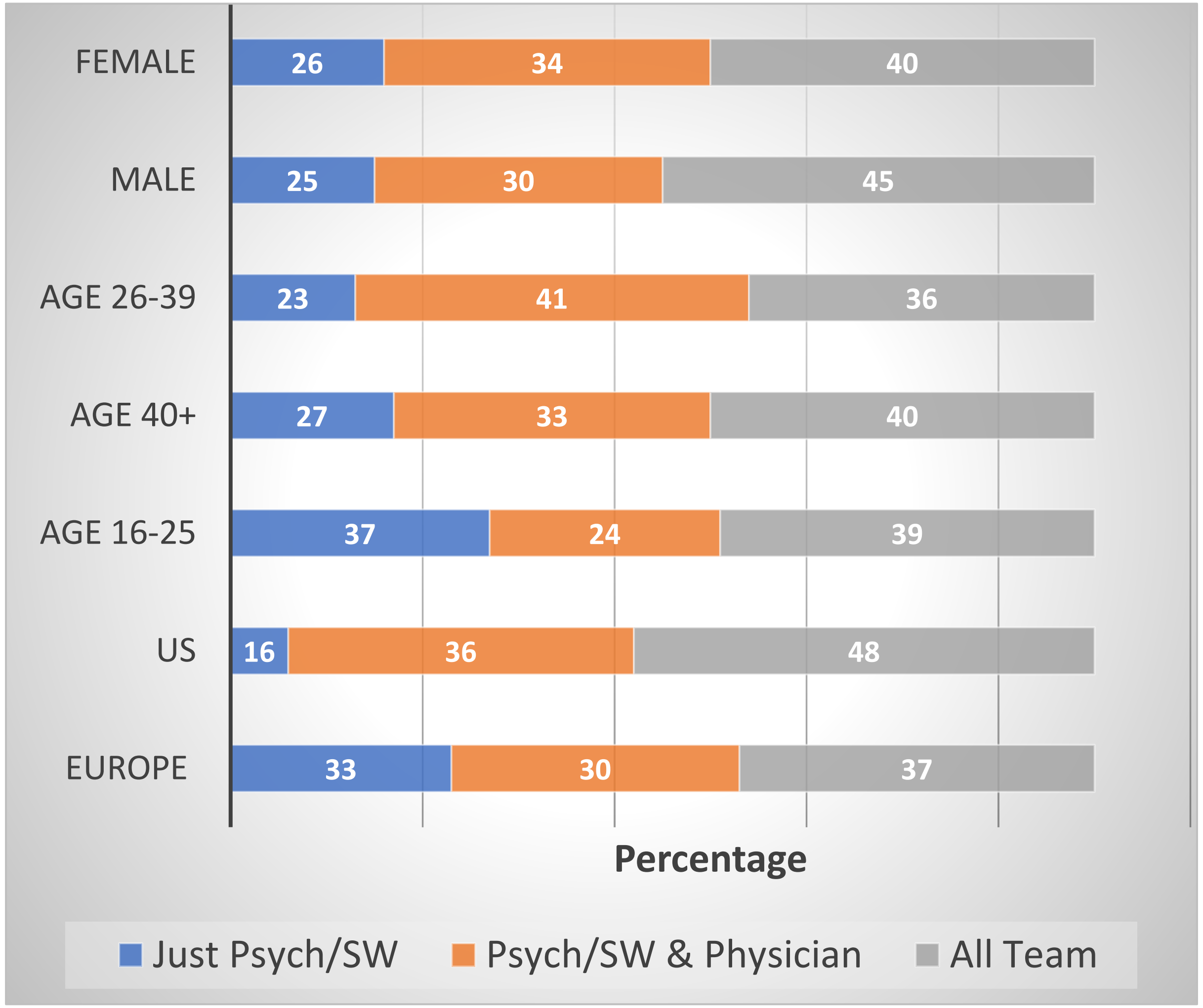
After screening I felt…



Privacy

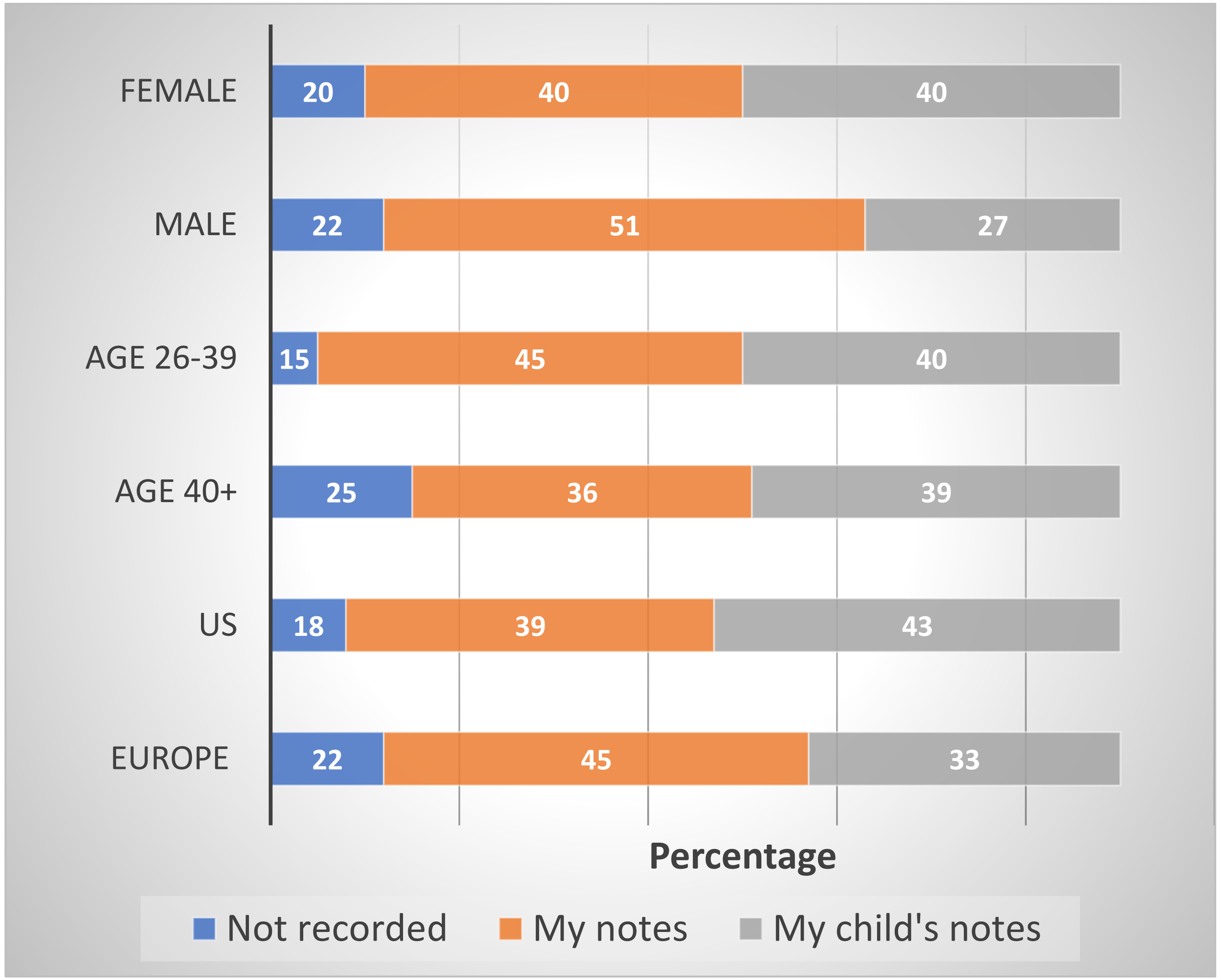
People with CF

Who should have access to your MH screening results?

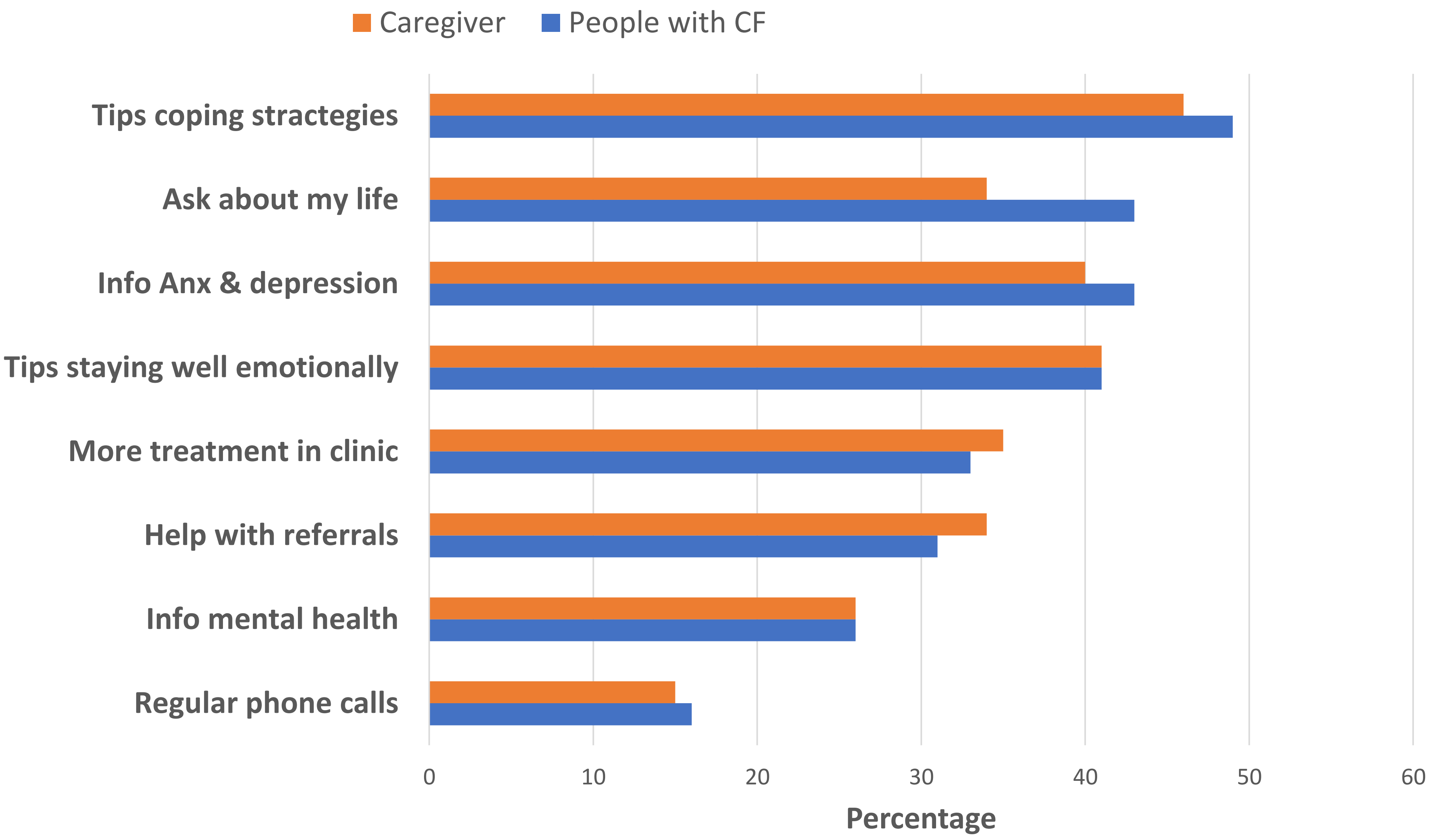


Caregivers

Where should your MH screening data be recorded?



What more can we do to help?



Anything you would like to add?

Numerous people with CF and caregivers said ‘thanks’ for the amazing mental health screening and care

People with CF - Focus on mental health as well as physical health

I am so glad that I was asked about my mental health. I can deal with all the treatments and things I have to do everyday to keep well but it is the emotional side of it all that I struggle with so it is good that this is being thought about.

I appreciate the focus on mental health for patients and family. It's a different journey to have a chronic illness and professional guidance is very helpful for everyone. I wish it would have been an ongoing option prior to now.

Mental health is just as important as physical health, so every CF patient should have help when needed. A social worker or psychologist who knows CF is essential for the right help.

I am glad that there is a correlation being made by medical professionals about mental health affecting physical health and vice versa. I doubt many centers think of this as CF is so consuming physically. But having a good perspective on emotional health and health in general can be a useful tool in remaining hopeful for those with cf. And it is easy to become depressed about one's health challenges but a positive outlet or a recognition by one's center about sadness and depression is important to better understand the full impact of CF on people, their families and significant others.

I'm glad that mental health is becoming a priority in the community!

Mental health is critically important, and up til now support in the CF community has been lacking. It’s going to be more important than ever we make this a top priority. Even with these modulator therapies we are going to be facing new challenges that will affect our mental health.

I believe hearing stories of how others cope with this disease would be important. I am an adult who was diagnosed later in life. It was very hard to adapt to treatments and frequent doctors appointments. Knowing that someone else may have experienced this, would have definitely improved my mental health during that time

I am happy that CFF is focused on mental health, but we are not done. There is so much work to do!

People with CF – Focus on screening and treatment
Following the death of two CF friends I kept thinking why I am still here. I was so down, so depressed. I didn’t feel worthy of being alive, but I was too much of a pansy to end my life suddenly. At my outpatient appointment I filled in the questionnaires asking me how I was mentally. My results were probably alarming because I then had a long chat with the psychologist about my suicidal thoughts. She was amazing and after seeing her for three months I have my mojo back. I feel life is worth living whatever CF throws at me
I did not realise that I was suffering with depression and anxiety until I completed the questionnaires. I just thought the way I was feeling was all part of having a life threatening disease like CF. Since I have been seeing a psychologist I feel much happier. I still have the odd dark day but I no longer think that I would be better off dead. I feel life is worth living whatever CF throws at me.
It’s great that they’re doing this now, but, it has to actually be integrated into care, not just something once a year where they have to tell the CF Foundation that they’ve done it.
Just that discussions about the individual questions on the instrument should happen, not just an assumption that a person is depressed. Ask why did a person answer the questions that caused a low score, don’t just assume it was because of “depression”.
While the questionnaires are a start, I sometimes think that the questions don't actually address some of the things I might be dealing with or feeling. It might be better for a clinician to ask open ended questions like "What was something that was hard for you since the last time we saw you?" or "How does your family/friends support you?" Those types of questions would help better uncover areas that might need more support/resources.
I hope this is more than just another thing to collect data for statistics and they get to work with the answers.

People with CF – Focus on screening and treatment
I feel the screenings are somewhat useless in that anyone can see what is going to be a positive screening and what is going to be a negative screening. Example: if a depressed individual does not want to talk or have it known that they are depressed they know how to answer the survey. I'm not sure you are getting a true picture of who needs help.
I’m not sure asking anyone “How are you doing” will do anything, because chronic illness patients often lie (either for appearances or being used to living a crappy quality of life). Focus more on building relationships between patients and care team — so that every patient feels they have at least 1 member of the team they can be open with. Then ask more specific questions, like a questionnaire, that you can track overtime, like PFTs.
In CF CLINIC, every person is very kind, very helpful, very busy. If the mental health issues were bigger than they are, I am sure we would seek help ourselves and we would bring it up. CF is a tragic childhood disease but the new advances in medication are making everyone more hopeful for a longer healthier happier life!
There should be a list of referrals or a mental health professional on staff. Until insurance allows mental health to be more accessible, there should be more of an effort to provide or refer services
Would be good to have a referral list of therapists that know something about CF.
It’s very difficult finding competent mental health professionals who understand the complications of CF. We’ve even tried some that specialize in coping with chronic illnesses and they just don’t get it!
I prefer therapy to be an option before medications. CF has more than enough medications to deal with and shouldn't be an automatic go-to. Makes you feel like a lab rat

People with CF – Focus on relationships and talking with the CF Team

I think it important to feel comfortable enough with your team to talk about emotional problems in your life, CF-related or not because it absolutely affects your health. Also, the more I join in on virtual CF groups (cfreshc, mini-cons, focus groups) I feel supported, less alone.

I wish there were a person at clinic to talk to.

Mental health is so important. I switched care centers two years ago after being belittled and not listened to and it being blamed on mental health. The sad part is, I didn’t have issues then. It was because it was so poorly handled that it developed.

I feel CF is my life and I want a close relationship with my physician and clinical staff.

More contact between doctors and psychiatrist or psychologist. Especially when they are not in the CF Centre by example in Your home town 1.5 hour drive away from CF Centre. A lot of specialists also in CF centres are on their own ‘island ‘.

With CF, there are highs and lows. Care teams need to be cognizant of mental status when receiving negative news like lung function decline, positive throat culture, weight loss, etc.

There is no special mental health care in my CF Centre in X. What should be provided to adult patients? Everything I wanted to know about Mental Health care, I found myself during my life. For example alternative therapies, workhsops, meetings with different therapists, in books…

Physician has never asked how we're doing. Only the clinic nurse. Not a social worker or anyone else.

It’s important for patients to know that what they tell their mental health provider cannot be used against them in clinic (transplant or CF).

I know others with cystic fibrosis who have noted mental health side effects with the new CF modulator drugs. It seems that their doctors are disregarding this and it's worrying many. Mental health should be just as important as everything else.

People with CF - Further needs, hopes & dreams

If there is something CF centers (with help of the hospitals) should do is to provide and pay for psychologist on regularly basis.

Would not be against having a psychologist/psychiatrist as part of the CF team. My current social worker is amazing, since she has done a lot of mental health work, but prior to her my social worker was not open to also providing a mental health service.

I miss a psychologist in the CF center, there should be one regularly for all patients and caregivers during hospitalisation an there should be planned an extramural psychological care with the social worker of the hospital

I'd like we have more better CF center with all doctors we need, all treatments, all medicines we don't have, good therapists and CF specialists, pulmonologists, psychologists, training our family members how to do massage, training how to do physio, cleaning and sterilization issue in hospital, patient's wards and blocks, and at the doctor's office

I have moreover treatment provided in institute of Chinese tradition medicine which I consider as very helpful and meaningful. In my center I can only use psychologic help but no information about other sources (meditation, Ayurveda, herbs, nutritition).

I think that learning strategies to deal with things like PFT related anxiety in clinic would be very helpful. Also, I would like my care team to have a fuller appreciation for the mental health challenges surrounding treatment burden.

There is a need for support groups. This could be done via internet.

I think this is a serious problem. I feel it has gotten way worse with the start of the new isolation protocols. The fear and stigma of having CF has been amplified by the constant bombardment of the new protocol with no way for the patient to connect with someone who is experiencing the same thing.

CF is an isolating disease due to the concerns of cross infection. More needs to be done to create an alternative / antidote for that isolation. Throwing pills at a person doesn't get to the root of the problem. Even one-on-one therapy won't provide what a group can achieve. Good luck & thank you!

Caregivers – Focus on caregiver mental health and support

I really appreciate this survey and attention to this topic.

I feel as if the mental state a caretaker can be in is not enough included in the well being of à CF child. I tried to speak about my helplessness and my deep sadness, but the medical staff didn't know how to handle this. Though they provided encounters with a psychologist the last few years once every 18 month for my child. She never felt enough concern for her personal situation to open up to those.

The caregiver health is essential for the well-being of the sick person. There are a mutual Influence between them and sometimes even Symbiotic relationship. Difficulties for the caregiver might cause crisis for the sick person.

Empathy goes a long way, when you receive it from your care team. It will help the caregiver open up with the team when they need help. I feel talking to other caregivers really makes you feel less alone in this journey. Offering connections with other parents/caregivers really has helped me. None of my family or close friends would know how it truly feels but another CF parent/caregiver really gets it.

Not enough is being done to help new parents cope with caring for someone with CF. I had to have a friend that is an LPC tell me that I was "grieving" the other children I will never have because my husband didn't want to have any more children. That also put a strain on our marriage. The clinic knew this and did nothing to help us.

In our CF center the psychologist has too many patients to see and so no time for CF patients and our family. Also, I think it is needed to have more than one person that is responsible for this in a CF center. You have to have a connection with that person and that is not always the case.

Caregivers – Focus on screening for themselves and their children

I am fearful to answer truthfully to the questionnaires. I feel my honest responses would be blown out of proportion. I don't know what that would lead to, who would know, what actions would be taken, etc. Some knowledge beforehand about what actions may be taken might help me be less fearful. Handing out preventative tips to all CF caregivers might be helpful.

I do believe kids can suffer from PTSD if they have gone through complications, had a lot of hospital stays, are at high risk for more complications, and overall have a lot of medical needs

My child is seen at the X clinic (where we live) as well as the Y clinic (every 6 months). The X clinic has not touched the surface of mental health and seems to have limited engaged support staff/clinicians; however, the Y clinic has a wonderful social worker who has discussed mental health with us several times. I think this should certainly be a part of the clinic team approach.

Mental health screening should start UNDER age 12 which is when most trauma occurs for patients with CF and their families. By the time a person is 12, the trauma can be harder to address and help b/c 12 yr old are going through so many additional changes they're less likely to be open. Start mental health support from birth for patients and families.

Start younger. Please help parents learn how to deal with children who refuse to eat or take medications. Help with caring for a child with CF and supporting them emotionally would be so helpful! How do you tell your child if they don't eat, the doctor will cut a hole in their stomach so they can be fed at night while they sleep. It's tricky, and parents could use guidance.

The only time doctors told me to seek for mental help was the time before diagnosis when I knew we had CF but no one believed me. I was told to let go of old things since my child is healthy. I did not give up on having the sweat test done. We got the diagnosis and after that no more talk about mental issues.

Caregivers –Further needs, hopes and dreams

I feel it imperative for the CF Foundation to provide funding to all CF Care Centers to maintain mental health support as a part of the CF care team.

Importance of family guidance. Brothers and sisters, grandparents are also impacted. Information in understandable language.

I think centers should have knowledge of and possibly even courses on mindfulness / meditation. It has changed my son's life. Those are this words, not mine. Why not start visits with a moment of stillness?

Maybe using EHealth would be an option for parents

I have a sister with cystic fibrosis and mental health issues (adult). When in crisis, it is a ridiculous challenge to find facilities that can deal with mental health issues and general cystic fibrosis care. Because of some of the unique aspects of cystic fibrosis care, in my ideal world - a CF care center would exist (centrally located) that would solely function as a mental health facility for CF patients.

Make sure you have all the staff you need at the CF-centers. If you lack a social worker or therapist, make an effort to fix one!

Thank you to everyone who responded to the survey