[Researcher\_1] 0:04

We're part of the Newcastle MIC, funded by the NIHR. But with this project in particular, we're working with a big charity called LifeArc, with the CF trust, obviously, and with the Manchester medicines discovery catapult, to hopefully bring all the information together from speaking with clinicians, with people with CF, family members of people with CF, and with other stakeholders such as the people that are involved in doing the finance decisions for the NHS or GPs. And we're hopefully bringing all this information together to help us develop kind of like an outline, blueprint, or guidance document to help new test developers, companies, or clinicians understand what it is that they would need from a diagnostic test, in order to make sure it's actually going to be useful, that it's going to be adopted correctly into the NHS, and that it will actually make an impact on care. So what this project is then, is to work out what these blueprints - what we call TPPs - target product profiles, should look like. This will include all of the characteristics of a test – like the time it takes to do a test, the accuracy, the user of the test, all the kind of values that you might want to know about a test in order to meet the clinical needs, your needs family member’s needs, and the needs of the NHS. We also want to make sure that all of this fits within the budget and capabilities and capacity that the NHS has. Does anyone have any questions about what I do or what the purpose of this discussion is? No. Okay, wonderful. I'll hand back over to [Facilitator\_1] then.

[Facilitator\_1] 2:22

That was great. Thanks,[Researcher\_1]. And I just like to welcome [pwCF], lovely to see you. Thanks for joining us. I've just started the recording. We've just gone round and done introductions. So we've got representatives here from the community [pwCF]. You all know me, we have [Researcher\_3] and [Researcher\_2] here, and [Researcher\_1] who is leading this project, so lovely to welcome you too. So just to kick off, as [Researcher\_1] was saying, the purpose of developing these target product profiles is basically a checklist or sort of minimum requirements of how a test is carried out or how it's developed, and the information about a test that is relevant to you, that helps you understand about your infections, when they're diagnosed, how they're diagnosed, how they're monitored, whether you know that the treatment is working, so perhaps the level of infection. So I think it's probably easier if we start off thinking about how you receive that information at the moment. So how you know when you're growing an infection, or perhaps you've got chest infection starting? Is it something that you're feeling yourself? And then you contact your CF team for them to check? Or is it something that is collected when you attend a clinic appointment, and obviously, clinic appointments have been so different over the last couple of years anyway. So there may have been changes made during that time that have improved that experience for you or made it harder. And also thinking around the changes that are happening in CF, not just care and treatment. But how that is differing for people depending on what medication they're on. So whether they're receiving CFTR modulators and that made a change to their health and therefore making it harder for them to identify the sort of infection they have or if they're not on CFTR modulators and say the changes that we've experienced in provision of care, particularly through the pandemic. So, [[pwCF\_1]], I was going to come to you first if that's okay. Did you want to just say a bit about how, what your experience is at the moment, what works well, what frustrations there are, and perhaps your thoughts on more information you'd like about your infections?

[pwCF\_1] 4:58

Yeah, thank you. I'm gonna try I can keep this concise so I’ll also pop in the chat if I think of something else.

[Facilitator\_1] 5:05

Yeah, please feel free to use the chat as well, if you want to.

[pwCF\_1] 5:07

Awesome, thank you. So the first infection I had after starting Kaftrio early last year, actually was not picked up for three months. And it was so severe by the time that we found it that the only way that we knew it was there was because I was presenting with so much pleuritic pain I could barely breathe. And an x-ray showed an area of infection that looked like a big doughnut on my lung. And really, my only indication of that was when I started to get the pleuritic pain. And they think that was something that was developing for about three months, which is about the time since I took my first dose of kaftrio. So what we think happened was that kaftrio improved some of my sort of wellness scores. Meanwhile, the infection was bringing my functioning down. And so actually, it just looked like I was remaining stable. And I was kind of questioning why am I not seeing improvement. And that's why we think. With that the diagnostics was really mainly X-ray and then a CT scan. And it really wasn't until I started IVs, that I started to bring up any sputum at all that could be tested. So that was quite tricky. Since then, the way that I noticed infection has changed a lot. And really, it wasn't until 18 months after I started Kaftrio that I started being productive at all. And now I have what my other half says is like a normal person cough or cold, where if I have something on my chest, I go [cough], and it moves, and I can test it. But other than that, I'm pretty dry. And it's very hard to get any kind of sample to test for my lungs. And another sample that I have had tested, however, not from my lungs was a sinus sample where I felt something dislodged and managed to kind of get it out. And that was actually the only place that I have showed infection that I really didn't know was there. And that was pseudomonas, and then that was treated. And then another culture showed that the infection had gone. So that was actually quite, maybe for the first time in my entire CF life was a really straightforward and successful process of now we see it now we don't. And that was great. And I think that was partly sort of pseudomonas, which is something I don't usually culture. Whereas typically my normal has been NTm, which is obviously much harder to establish what's going on in NTm lungs, or at least that has been in my experience. Otherwise, the only other way that I detect infection is I noticed my resting heart rate remains elevated for a long period of time. Occasionally, my appetite changes but really the only thing that my one thing we've really had to do with my clinic is have regular MRIs, because so much seems to get missed because I feel so good. That I'm relatively asymptomatic besides the resting heart rate thing. I think that's probably all I'll leave with for now.

[Facilitator\_1] 5:19

That was brilliant. Really interesting what you said about the sinus sample as well, because that's a bit sort of ad hoc, you know, sort of, like you say, almost at rest, unexpected. It's not a sample that's being produced on demand. So how did you capture that? Were you at home or were you in clinic? Or did you have like a pot at home?

[pwCF\_1] 8:31

I did have a pot at home. My clinic are really good at making sure I've got a stock I usually have about three pots at home with postal packages that are ready to go. And for me, I have always experienced things in my sinuses first, and I haven't really suffered, [pwCF\_2] I saw you put on social media asking questions about people's sinus experiences with CF. And mine has never really been formally diagnosed as sinusitis. I've never been told I have polyps or anything. But occasionally if there's bad allergies, if I have a cold that will be the first thing that flares up for me. And it usually seems to be for me, and I think a lot more people than we realise with CF, where all infection starts. I then get the post-nasal drip and then I get chesty. And occasionally, I will feel pressure at the back of my sinuses and know that some chunk of something is dislodging sorry, that's so gross. Occasionally, I'll feel it in my throat and if I do a really good job and get the right angle, I can cough it into a sputum cup, but those things are few and far between when I actually feel it because it would have to be quite a big bit. And yeah, it just so happens I got one of those and I was doing a medical trial at the time. So the team were extra responsive to what was going on with me and they got that tested pretty quickly. I then did something that as I understand it is maybe a bit unconventional but my team suggested IVs and I actually said no, can I first try inhaled antibiotics through a mask, which I've never had before, I've only ever done it through a mouthpiece. But knowing that everything starts in my sinuses, we tried it. And it was a really quick culture conversion to negative. So I'd love if that could be further explored in research. And also related to that knowing that Nasal Breathing is so important for addressing infection. And, you know, because of all the processes that are involved with the nasal breathe versus mouth breathe, I really feel like that should be encouraged more. And I've always had to really fight to get a mask to do my nebulising or to fight infection that way. So, yeah, hope that answers the question.

[Facilitator\_1] 10:41

Yeah, brilliant. And when you got the negative result, the sample for that? Did you then have to produce a sample on demand? Was that then a sputum sample? Or did they swab your nose for that as well?

[pwCF\_1] 10:55

No one ever done a swab, just I did either 20 or 30 days on colomycin through the nebuliser. And they were just like, get us another sample if you can. And luckily, I did at the end of that. And yeah, that was just honestly, that was just lucky, if I had to give, a sample today. Even if I was symptomatic, I'd really struggle. So that was a bit of a fluke. So I would love if, in future, there were ways to efficiently test that, and not have to wait pretty much two years until you've had a chunk build up that finally released. Not usually practical, but I guess as this is relevant to you, I would so much rather be able to test my sinuses before it goes to my chest, then wait for something to manifest that could be serious, or could even be a bit hidden because of the way that things manifest differently with Kaftrio. See, I hope that's useful to you. I'd love to see that if I could swab a sinus and get something.

[Facilitator\_1] 10:55

And were you happy with the result going from positive to negative? Or would something in between some sort of count have been beneficial or motivational when you were doing your treatment in that time period?

[pwCF\_1] 12:05

I love these questions, they are amazing prompts to me because when I did the medical trial this year, that was the first time anyone had ever mentioned, CFUs and being interested in like gut bacteria and stuff, I knew what that meant. And I understood the implications. And I didn't know that was something that they could measure. In my samples, I always tend to get a positive or negative result. But I love the idea of being able to monitor colony forming units and seeing that decrease. And I think it was really only because of being on a medical trial, that they really needed to look in that much detail. I don't know if that's done. Otherwise, I have no idea if that's just a trial thing, or if that's a regular thing, but I'd love it to be a regular thing.

[Facilitator\_1] 12:47

I see [pwCF\_2] you've got a thumbs up, I'll come to you next, I'm gonna come to you anyway, firstly, because of a sinus mentioned.

pwCF\_2 12:54

Because we're at the same unit and they do normally do that if you have a long term chronic infection I’m just reassuring you.

[Facilitator\_1] 13:02

So [pwCF\_2], I was gonna come to you. So you were obviously asking about sort of like sinus infections. Does this experiences that [pwCF\_1]'s just mentioned sort of resonate with you?

pwCF\_2 13:13

Sorry, I only put my thumb up because I've had a long term infection, the colony forming units they count regularly and I get told that a lot. So sorry, that was all I was saying.

[Facilitator\_1] 13:25

No, that's fine. No, that's fine. I didn't know whether you wanted to talk about what's interesting and important to you. When somebody's telling you you've got an infection and are considering whether the treatment is working, whether that's motivational to you, as you were saying to have those counts in between whether it helps you to continue to carry out that treatment because some of them [treatments] are pretty... It's pretty rough time, isn't it?

pwCF\_2 13:56

So I'm in a different sort of place. I find that the colony units are actually very distressing sometimes because I have Burkholderia, and its 17 years old. The numbers just go up, there isn't a down. So it's a different end of the spectrum. I think I would find it helpful, only if it was a way of showing that things are getting better. Whereas I'm more about symptoms, that’s more of a thing for me. That's what keeps me going with treatment rather than CFU... but I do I do think that [pwCF\_1] is very right. And if it was a start with an infection, that would be good.

[Facilitator\_1] 14:32

Yeah, and when you're monitoring that long term infection, are they also picking up other infections that you might have at the same time, like fungal infections, perhaps?

pwCF\_2 14:45

generally just haemophilus or just generally just the basic ones. Because the Burkholderia is just rampant. So it grows all over the place, things that it shouldn't grow on even, and it's a bit of a silly situation. So I'll monitor through my own symptoms. And that's how I know that I've got an exacerbation and the exacerbations do tend to come on when a different infection has arrived. But the Burkholderia kind of overpowers that, and then, so they'll grow, say, a bit from haemophilus influenza, and then a week later be like, oh, actually you have this many units of Burkholderia that have grown as well. We think there's a bit of fight going on here. Yeah. And then they'd IV that, because just haemophilus influenza, I'd be fine with.

[Facilitator\_1] 15:34

Yeah, so treatment for Burkholderia, obviously takes priority doesn't say that kind of superiority, I suppose. Yeah. Yeah. I did have a question for you then. And it's gone out of my head. But I'm sure it'll come back to when we're talking. [pwCF\_3], I was going to come to you next, if that's okay. I know you've had some regular ongoing treatment. And again, just wanted to see, [pwCF\_1] or [pwCF\_2]'s experiences were familiar to you.

[pwCF\_3] 16:13

Yeah. So I've had six sinus surgeries to remove polyps. And like [pwCF\_1] said, the stuff that comes down at times is horrific. And the pain is actually so excruciating, is obviously too big for the nostril. Always pseudomonas, predominantly Pseudomonas in my lungs, you can feel the drip, I completely agree. And I would love to get a swab up there, rather than having to have the whole camera and look like E.T with the red light in my hand. Yeah, that would be a great way. I do quite like the blood test. I know, this is a really weird thing to say, but your red blood cell count, just, you know, when it goes up, there's a great satisfaction of when it's come down. And like, Yes, I'm on top of this. And I think that does motivate you to kind of like keep pushing to kind of get it even lower. I would say since starting Kaftrio, it's harder to pick up, I completely agree. Your symptoms are slightly different. I tend to see the cough tends to start increasing. And maybe at night, when I go to bed, I feel a bit more like short of breath. And I'm a bit like something's not quite right. But I have [a spirometer] to do your lung function, I think is a great way because I'm like, even if there's a dip, I probably really annoyed the Bronch team. So I'm like, Oh, by the way, there's a bit of a dip, what are we going to do? And they'll say its still 100, Can you just calm down, but because it's gotten mine was 66% my lung function, which wasn't bad, bad, but now it's like 110. So that's a huge, huge increase. So when it does drop, I'm like, I want to get on it as quickly as possible, rather than it escalates into something that I know is going to be like three, four weeks stay in hospital. But I have managed just with orals, they have been kind of sorting me out. But again, I agree with [pwCF\_1], I think the mask is actually better. Because if you can kind of hit that, the lungs might get better, kind of over time, because you're still inhaling and it's still going into your system, which is essentially what you need. But yeah, I think having the lung function machine at home that you can kind of jump on top of things quickly has been great. But again, because of COVID, like when you go to the hospital, I wouldn't be very productive. So it was a cough swab, and cough swabs aren't really reliant. You know, if it comes back? Well, it's nothing. But I know there is. So it's hard to then say, you're kind of feeling like, Well, what do I do? Like, I don't know what the infection is. But I'm assuming it's a Pseudomonas flareup. But it could be staph or NTm. You know, there's so many other things and as you say, The NTm you're waiting like six, eight weeks for results. So by the time you get that you've already had it for possibly two, three months. And it's kind of been sat there. So yeah, if you do feel, I suppose it's handy now that they can send the cough swabs out and you send it back. And that's, that's a lot easier, managing it and jumping on top. So although you don't have the face to face contact, the hospitals and the clinics do seem really good with being on top of responding to you, if you're saying there's just something not quite right. I don't know how the others feel. But I always feel like when I've got something, there's just there's a gut instinct that you're like, This isn't normal. So any test, whatever the test is, I'm sure it will be brilliant at discovering things butit's that gut instinct that eventually is like, that's what tells you what's wrong.

[Facilitator\_1] 19:51

Yeah, and I think a lot of what you've said there sort of alludes to confidence. It's confidence in the tests that you can do at home. Confidence in your FEV1, and obviously, you're used to that, you know, there's some people that sort of say, well, actually, I can't really see much change in fluctuation with my FEV1, it's less meaningful to me now. But you say that at least having a home test, it gives you some confidence there. And like you say, the numbers in your red blood cell count, again, kind of gives you confidence that the treatment is working, if you can see it going down. So although I know most people don't like having a blood test, there's something in that isn't there to help. And, you know, I guess if any of those were available, easily at home, that you can then take straight to your team. Again, you're saying the confidence of being able to get in touch with your team and then knowing that, your body and that gut instinct as well. Yeah. You've, reminded me of what I was going to ask [pwCF\_2] about, but I'll ask you first, do you recognise any difference in taste at all? Or do you really notice a taste perhaps when you're when you've got an infection, you say, particularly if you've got some sort of like nasal drip or something?

[pwCF\_3] 21:11

I was meant to have sinus surgery just before COVID hit. And they obviously just didn't go ahead with it. So I've actually haven't had anything since then. So it's just been Fluticasone and sinus rinse and everything. But yeah, the pain, the headache, and I suffer from migraines as well. So it's not very helpful. I call it like a normal headache, and then my sinus headache. I get two types of different headaches.

But yeah, I mean, loss of sense, and taste and smell has been on and off for years. So when COVID happened at first, and they were like, this is a symptom. I was like, I was there before you guys. The trend was already set. CF people definitely set the trend. Coughing and like taste and smell and temperatures, we were there first. But yeah, so I think that's something that it just fluctuates all the time, just depending on ... one day, you'll get to smell a perfume. Oh my god, that's so nice. And the other day, another day of like, can't smell anything, did I put it on? Yes, it's very random. Right? Yeah.

[Facilitator\_1] 22:22

I know, some people have said... [pwCF\_1], you might be able to comment on this. This is kind of what I was gonna say. Some people said they've known when they've growing Aspergillus because they can taste it. It's got a kind of different, a different taste in their mouth generally. And I didn't know whether that was something that one of the sort of like, perhaps methods of diagnostics that I think [Researcher\_1] was probably looking at is sort of like, breath. And it didn't know whether if you could taste something, whether that would be if that could be captured on sort of like a breath card or something like that, whether that would be of help or of interest to people. Thanks, [pwCF\_3]. [pwCF\_4], I'll come to you next, whether you'd had anything to add around those experiences as well.

[pwCF\_4] 23:12

Some similarities, but quite a lot of differences for me, I think. The only test now I’ve had in recent memory is cough swabs. So even before Kaftrio, I was never that productive. Even if I had a cough, it was either quite often a dry cough or I would just I find it very difficult to actually cough stuff out, it would tend to just disappear down the throat. So they have always relied on cough swabs at the clinic. And generally they're just doing a clinic, so I wouldn't go in, in between, they would just do that. Probably 90% of the times I ended up getting treatment for pseudomonas, I would just know I had it, I had generally, cough might be a little bit worse. But for me, it would be more about like body pains, or feeling really exhausted, it's very difficult to describe, but you can just tell when you had it. And I just very often say I need IVs and I might go and I might do a cough swab, which would probably normally come back and say I had pseudomonas, but I kind of already knew I had it anyway, so that up until Kaftrio, that's pretty much how it worked. I don't remember having any other extra tests or being really proactively told if I had pseudomonas. So quite often, if I said I felt fine, and I did a cough swab and it had Pseudomonas on it, the hospital wouldn't particularly get in touch until the next clinic. They'd just wait for me... probably because I would probably not have agreed to have IVs if I didn't feel bad. And that seemed to work quite well for me.

After starting Kaftrio, I haven't really been ill... I've had one cough since I started. And when I got it, I thought it was quite weird, because I had kind of forgotten what it was like to actually have a cough. I thought it's a bit worrying, have I got a chest infection? Turned out to be COVID actually, but I didn't immediately call the hospital, I just thought I'll just see what happens. It got bad, not bad at the point where I thought I need to do anything, and then improved. And really the sort of hotspots in clinic I will say that ever, particularly with anything I did used to get horrendous sinus issues. Were just like [pwCF\_3] described, the pain was just insane. I was on codine for it and all sorts. And I'd know if I had an infection in the sinuses, rather than just baseline issues that I had, because I'd start blowing blood out my nose. But it didn't necessarily mean I could go and get a cough swab while I had it. And it wouldn't necessarily come out with anything. It seemed like to me there was a line drawn between my head and my chest, and having an infection in my chest wouldn't necessarily trigger the sinuses, or the other way around. They kind of happened independently. There wasn't any sort of test, I didn't really have any tests at all for the sinuses, it was purely just... sometimes the taste in the sinuses, I think Pseudomonas does have a particular taste that you would know about, from my memory, but definitely sinus infections, it would just be how I felt. There would be no way for them necessarily to back it up with anything.

[Facilitator\_1] 26:44

So not really tested for?, but it was used almost as a prompt?

[pwCF\_4] 26:49

Yeah, I mean, I've never been routinely tested after treatment, either. So if I was in clinic, and you know, either started on IVs, or, you know, did a cough swab and produce pseudomonas, I'd have two weeks of IVs at home, and then I wouldn't be retested. I was just in the clinic six weeks later, so that's never been part of my treatment regime at all.

[Facilitator\_1] 27:21

And have you ever had any incidences, then when you've had like two week course of IVs, and perhaps that you've had a flare up quite quickly again afterwards?

[pwCF\_4] 27:28

Yeah. Yeah. Just really to the point where, although my experience of having IVs, I mean, they used to make me ill in itself, having them, but in a different way than the pseudomonas. So I would expect to feel crap at the end of them, and probably more exhausted than when I started. But if the cough wasn't better, or my chest didn't feel a bit more open, you know, I would expect it not to be 100% by the time the two weeks is up, but to be improving in the other areas. And if that didn't happen, then I would just tell the hospital myself to extend it by another week and see what happens. But I don't think I ever got... Like, after two weeks, if I said, I don't feel like I'm better. They didn't run any other tests, just said have another week of IVs and see what happens...

[Facilitator\_1] 28:20

Yeah. Just until you felt better, really. There was kind of something that you said earlier as well about, you know, if they've done a cough swab, sort of in a routine clinic, and it's shown pseudomonas, they wouldn't necessarily contact you because you kind of have pseudomonas anyway. And if you're feeling okay...

[pwCF\_4] 28:38

They might have when I first started, but I think probably they just learned what I was like, and just coughing up Pseudomonas to me, because I've had it since I was [young], and I was told that it would always be there. So say that there was a flare up, although it's there, but it's not flared up, in which case, I was happy. And I think I probably explained to them not long after joining the clinic that I'd come and tell them if I needed treatment myself. And I think I'm quite stubborn. So they probably just accepted it.

Yeah, so again, it sort of goes back to what I was saying, [pwCF\_3], there's a level of confidence that you've got and you've got that relationship with your team and that you know, that actually, while you're feeling okay, you're kind of almost happy to know that you're living with pseudomonas, because it's not affecting your kind of like daily function. Yeah. Yeah.

I mean, I'm the type, I don't like doing regular FEV tests at home. I mean, I've got a medical thing they gave us when the pandemic started. And I used it when I got it. If I woke up one day and felt a bit crap I'd do it, and I don't think it was doing mental health any good to be honest. Now. I'm quite happy. I think I never use it now. I only do it when I'm in clinic. And I think my mental health is better for it, I'm happy just to trust how I feel, and to be vaguely sensible, if I got ill and it didn't resolve itself in a week or so. Although it's kind of new ground with Kaftrio, but I'd be sensible enough to get in touch with them myself when I felt that I needed to. But I also think, for my mental health, I've got to give my own body a chance to recover on its own these days, because it does tend to do a little bit better than it did prior to Kaftrio.

[Facilitator\_1] 30:34

Yeah. So your spirometer really, Is there as a sense check if you want it rather than for a monitoring piece of equipment.

[pwCF\_4] 30:42

Yeah, and I'm kind of inclined to just not use it at all. Yeah. There's just something about that, personally, that I don't like. I work in data and my inclination is to do it once a day and put it on a graph in Excel, which is fine if it's going up. But if it's going down, It's not... Yeah. I mean, the other thing, since I got a [smart watch] five or six years ago, is I think [pwCF\_1] said, resting heart rate, I found really good indicator of getting an infection before you actually get any other symptoms. So I guess six years ago, I didn't have any monitor then. So I would pretty much know when I was gonna get ill as my heart rate, although it bumped about, it would like step up one every day for about a week before or so, 10 days before. So it would go up quite a bit. And I could pretty much guarantee after a few times, so that noticing that would mean that was coming down with something. So I could kind of either prepare myself mentally before going to the hospital, or try and preempt it and have some maybe orals rather than going on IVs.

[Facilitator\_1] 31:57

Yes, to catch it early?

[pwCF\_4] 31:58

But I still find that now with a cold rather than chest infection. It seems to be a very good indicator of just your body being a bit under stress with something.

[Facilitator\_1] 32:08

Yeah. So having that wearable tech, where it's kind of like an automated diagnostic doesn't require any effort to get that reading, or that piece of data?

[pwCF\_4] 32:19

Yeah, yeah. Yeah, for some reason, that doesn't stress me out like doing that FEV. I don't know if its just a lifetime of clinical visits I have a negative association with but I don't get stressed over the [smart watch] data, the way I would with FEV.

[Facilitator\_1] 32:35

I think like you say there's such an anticipation put on what your FEV is going to be when you go to clinic isn't there? It’s like, and that puts so much pressure on technique, as well doesn't it, you know, and I suppose almost like internal competition with yourself.

[pwCF\_4] 32:55

Yeah, well, the shame that we've got, I mean, up until about a year ago, [CF Clinic] was still using the kind of ancient ones with a pen attached to them that look like an elephant. And it was just last year, I think switched to like a handheld digital one. And it always tells us I've done a bad effort, no matter how hard I'm trying, until I'm purple in the face blowing so hard, and it still says poor effort. What can I do? ... it's quite annoying as the staff don't know what to do about it either. So we're kinda... I don't know, my lung function could have always been like, 10% better than its recording, because I'm just not doing it properly for whatever reason.

[Facilitator\_1] 33:38

So do you think that something that told you what your lung capacity or that same sort of general function was other than the spirometry? Do you think you'd be interested in that if you were confident that it was accurate? You just did it when you needed it , or perhaps as part of an annual review or something like that?

[pwCF\_4] 34:01

I think it probably depends what the long term effects of Kaftrio are, personally. So if, theoretically, I was to continue along, like I am now or something similar. Actually it isn’t something I really think about and my lung health isn't something I really think about... I just try to keep myself fit and wake up every day and don't feel too bad. I think if you're struggling more or, you know, if I started to get more infections or felt a bit more breathless or something like that, then I may become more interested. But right now, I feel like every eight weeks of clinic is enough for me, you know, whichever methods they use. I do find clinic quite stressful generally. It probably is centred around the FEV result, but I don't know, either way the test probably doesn't matter. It's just getting a green light that you're Okay for another two months is quite stressful... even when I'm feeling quite well, it's still very stressful.

[Facilitator\_1] 35:07

I think there's something in what you said earlier as well, that I kind of heard in some of the presentations that the recent CF conference, and that's kind of like around adherence, and those who say, you know, you're doing your best effort, whether that's your best blow, you know, to get your FEV1, whether it's your best effort of taking all your tablets at the right time, you know, in the right manner, whether it's doing your nebulizers, you know, every single day, your best effort to maintain a treatment, and then you go to clinic and somebody says, actually, you know, your numbers haven't improved... And you say it's a bit of a demotivator. And you might not want to keep doing it, adhering.

[pwCF\_4] 35:52

Yeah, I'm not sure if it's something clinic thinks about, I often think that they remind me of what my mum was like, when I was little, when I was little, I think my parents were told that I had to eat meals that were double the size of theirs ... just six, trying to force feed me, but never been told a good way to encourage me to eat more. And I don't feel like clinic has any psychological training to know the right things to say, to actually get people to adhere. It's just 'oh you know, you should really do more of this, more of that, don't stop this, don't stop that'. And that's it. And this is something that you probably make like 100 decisions about every day, what you take and what you dont take. There's not a lot of like subtlety in the way that the clinic tries to improve what you do, to me. It's like they haven't taken into account the psychology of it.

[Facilitator\_1] 36:56

Yeah. I know, you said obviously, your work is in data. But do you think then that if you have all sorts of like, automated packets of data, that means that you have, I suppose a greater oversight? I mean, you negotiate pretty well with your team anyway. But do you think that is something that would help people generally where you can say, well, actually, look, this is the package of my data results. I know that when I see this information, I feel okay. And actually, I don't want to introduce more treatment, I don't want to be told I've got to do more, or that I'm not doing, you know, as well as I should be or something.

[pwCF\_4] 37:36

I think if you're comfortable with it, I'm not sure. Like I wouldn't be comfortable about it collecting data form my point of view, I'm not sure how comfortable I would be that having access to that all the time would be good for my personal mental health, to kind of log in and look at it every day. But, you know, if it was something that was recorded and then clinic reviewed with us in person every six weeks or something like that, I don't think I'd have an issue with that. And I think yeah, in that context, I suppose the more evidence you have to back you up at clinic, the better... if you feel like you need it. Yeah. But that totally depends on the person, you know, but even if I had a packet of data that was actually saying that was really ill, but I felt fine. Whether I would go with it and do what clinic wanted. I'm not too sure.

[Facilitator\_1] 38:30

No, but it gives you some information to negotiate.

[pwCF\_4] 38:34

Certainly. Yeah.

[Facilitator\_1] 38:39

I feel that I've given you a bit of a grilling. [pwCF\_6], I'll just welcome you. Thanks for joining the call. I'll come on and chat to you in a moment. I was just going to move to [pwCF\_5]. [pwCF\_5], [pwCF\_4] mentioned there about the role of their mum and I think, you know, it's a different angle when you're a parent and monitoring the health of somebody else, and you can't feel and sense what they're feeling. And I just wonder whether you had any thoughts around, you know, I guess your confidence levels in how [child]'s health is monitored?

[pwCF\_5] 39:22

Yeah, I suppose. What's been a revelation so far is the fact that obviously we're really, really early in the journey. They turned six a couple of weeks ago. They will start Kaftrio later this month hopefully. Everything so far has been cough-swab lead basically. They're pretty, pretty quick to cough-swab when needed, always cough-swab after treatment. They have only ever had oral antibiotics or nebulizers, never had IVs yet, but just as a parent, you just kind of know. So there's been quite... the usual thing that goes is that they have a bit of a sniffle. It almost always starts with a sniffle, dribbling nose, tickling cough at bedtime, and it either progresses, or it doesn't. And there's always this kind of watch and wait for three to five days. So we can have a bit of a personal joke, which is if they’re going to start starting to sniffle, lets hope it’s on a weekend, because then they will at least have a cough-swab before the weekend, and then we'll usually then just go straight down to [CF Clinic] in some form. Because if they have a sniffle on a Tuesday or Wednesday, we ring them on a Friday, and they say we'll see how you are Monday, by the time we get to Monday, they’ve had two nights of not sleeping. And at that point, they’re poorly. So as a parent, all you're trying to do is nip it in the bud. And you start you start to pick up some of the signs in terms of when they’re feeling a bit worse. Lower on energy. They’ve got celiac as well. So diets a difficult thing, you know, to kind of go alongside it. So yeah, just kind of gut instinct. You kind of know, but it's always waiting on a cough-swab. We've got some cough-swabs to do at home. But then you post them, you don't hear back for it's gonna be 10 days really, which is understandable. But what often happens is, if you get to the stage of a cough swab, they usually prescribe something before you've even heard it back, which is understandable. But yes, something that can speed that process up. Yeah, whatever that is, whatever that is. And [child]'s never really produced anything. So as a baby and young child, it was cough-swab, shoving it to the back of the throat. You do what you need to do to get something out, basically... we do what we have to do. They’re amazing. They put up with it. But if it can be simplified, and it can be sped up. Yeah... For [child], nasal drip is the first thing... Absolutely first thing in terms of a physical thing. So waiting for it to be on the lungs is kind of a bit too late.

[Facilitator\_1] 42:11

Yeah. So if you had a way of capturing that at home, and as you say, and the turnaround, I think it's really interesting what you've brought up about the speed of return of results as well. And that sort of like period of uncertainty or indecision, or potentially, as you say, starting with a course of treatment that may or may not be the right one.

[pwCF\_5] 42:30

Yeah. Yeah. And it's and it's yeah, our clinicians are amazing. I mean, they're known [child] since birth, could never fault them. But you can just feel... a number of times there's an element of "we might as well treat" and as a parent, we're very early in the journey. Hearing all you guys, all your experiences, it's kind of it's eye opening. And you'd think, if you can get rid of some of that, "what if?" Yeah, as they grow older, they'll know their own body. We know them, you can see their energy levels dip. You know, the physical stuff when they start to become poorly, you wouldn't wish it upon anybody. You're trying to shorten that period of "do we, don't we?" And "what are we fighting?" So they, they’ve had quite a high number of oral antibiotics over the last 18 months. To the point where they are saying "right. We've had that for the last two infections, let’s try something else". And you trust them, you have to trust them. But it might not necessarily be the right treatment.

And they're obviously only working with the results that they've got from those tests. Yeah.

[Facilitator\_1] 43:47

Exactly.

[pwCF\_5] 43:48

Exactly. So yeah. And so invariably, it's hospital visits for cough-swabs and things. So the last infection they had, which was laid on top of another infection, they was on orals, nebulizers, then another set of orals. It was in hospital every week, for four weeks, more cough-swabs, more observations, physical observations, not scans or X-rays or anything. So there's the time, which I know I appreciate for everyone else on the call, they've gone through a lot worse than that. But that kind of stuff with the new generation of CF patient... the mundaneness of hospital appointments for things that surely nowadays could be done at home. Yeah. That would be my thing, minimising the time, the effort, the disruption... you do what you have to do, everyone does what they have to do. I was interested in what you guys are saying about kind of measuring things and having kind of data and stuff. I've never even contemplated that level of information... it's kind of been black or white, infection or not. And you kind of have a cough-swab and think, let's hope its negative. Yeah, if there if there was some kind of "it might be, might not be" or "it's going that way or that way", I'm not sure I'd want to know. So, and the only kind of real comparison is [child]’s celiac, so they got diagnosed at 18 months. So as they were weaning, they were very poorly, hospitalised. They thought they had leukaemia, it was that bad. And their blood levels, which had been monitored since, have been coming down, but they haven't come down enough. So every time we go have a blood test, it's like, [sigh] "what's the number?" Yeah, and just as you guys were talking about kind of that level of information, my personal thoughts are "how much information do I need?" But you guys have been saying, I know when I'm poorly. Yeah. Yeah, obviously other things are picked up. And from a parenting point of view, and this is just my personal experience ... I've read certain things, I try not to read too much other stuff, is, you just fit everything into your life. You don't want to know, you don't really want to focus on it. That's my experience, you just want to get on, and live your life, and the stuff becomes routine... How much do I want to know? Because if I obsess with it [sigh]... it becomes burdensome.

[Facilitator\_1] 46:32

I think that's really mirroring what [pwCF\_4] was saying about, you know, using this spirometer. And I can see [pwCF\_2] nodding. You just want to, you want to be living and let the monitoring of CF just sit in the background, and...[Researcher\_1]'s put something in the chat about passive monitoring. And yeah...

[pwCF\_5] 46:50

It's almost like the passive monitoring provides an opportunity when you have a review, or a routine to go, "how have you been?" You go, "I feel like I've been alright, what do my stats show?" ... but on a daily basis? It could be just kind of, yeah, overwhelming... People choose what they want to know. But I kind of like to keep fit, I've got a [smart watch] and you suddenly go through a period of being obsessed. Then you go, "Oh, my God, what am I doing?" I'm just... Yeah. "Am I running? Or am I not running? Do I feel good? Or do I not feel good?", I think it can be quite easy to get drawn into the "what does the number mean?" So for example, on [child]’s celiac, so to be negative, a certain blood thing, a count had to be below eight. And that's changed to below 10. So they might now be negative and you go, "Well, what's actually changed?" Yeah, what does the data actually mean? And the think that from a parenting point of view is, "give me useful information, but don't overwhelm".

[Facilitator\_1] 47:57

Yeah. Yeah. So not information necessarily to make decisions on anything. But you know, like to say it's just, it's there almost as I suppose, sort of like in the background, if something changed drastically. "Okay, look, we need to take an action". So it's more there as a kind of prompt?

[pwCF\_5] 48:16

Yeah, "What might be going on", not on a kind of a routine where clinic says "We expect people with CF to monitor these things, so when it comes to clinic, we're going to have a conversation about the stats"... It's like, I think people will just turn off.

[Facilitator\_1] 48:28

Yeah. Yeah. Do you think it would have helped you though, you were saying about [child] having different courses of antibiotics? Well, we tried them. And then they tried something, you tried a couple of courses and they tried something else? If there was a much quicker return or at turnaround on the results, do you think it would have been of interest to you to say, after the first week, see if there has been a bit of a reduction, see if that medication was working? And take a decision to change earlier or not?

[pwCF\_5] 48:58

I think yeah, that becomes useful. When you know something's going on. So with [child], so aside from the last three months, every time they’ve gone on oral antibiotics, within 48 hours, things have improved, visibly, physically, they’re back to sleeping better, you know, there's obvious physical things that are happening... you can see it making a difference. Over the last three months where they’ve had different infections... So they had one course of colomycin, it got extended, because they hadn't got better the same way. So it was obvious, it was just obvious, they just hadn't become normal again, if that makes sense in loose terms. So having the ability to maybe monitor that as you're going through a little bit of treatment would be useful to know "Right. We're on the right course". Especially if maybe other things are being prescribed quicker. You want to know "you've got that, this is what we suggest". "Is it working? Yes or no?" Because my understanding of antibiotics, my simple understanding of antibiotics is, you don't want to have too much. And you certainly don't want too much of one thing in short space of time. So if you don't need it, and should be on something else. Change. Yeah. I think that's where data and information should work, and should be useful. Yeah.

[Facilitator\_1] 50:22

And their tolerability, you say, they’re really good. They puts up with everything, which, you know, obviously is amazing in doing that... If say for instance, you're having like your nebulizers and they’re feeling better after the first week. Yeah, nebulizers are a pain... do you stick to the length of course?

[pwCF\_5] 50:47

Everyone's different. We are still new to it. But it's going to have some benefit, you do it... [child] is amazing, a mobile phone can bribe a six year old very quickly. They’re amazing. But yeah, in the last three months where they’ve been on four nebulizers a day plus other stuff, you go [sigh], It's nothing compared to what the other four have gone through. But you know, that kind of that regimentation, if it then becomes overwhelming, I can quite easily see... I'm talking to one of the CF psychologists at the moment, "They’re six years old, at some point, they’re gonna start asking the, what is it? Why me?" questions, and then when they’re 12-13, they’re gonna go "stuff you", all that kind of stuff. That's part of the next part of the journey. I think if anything's too burdensome, too soon. We're human beings, we just go, "No".

[Facilitator\_1] 51:47

That's it, we're in it for the long haul with CF aren't we? As you say you don't want to make it worse than it needs to be particularly while children are young, and build it up, because you want them to still be in that position of being accepting of things.

[pwCF\_5] 52:05

[child] has blood tests every year, every three months, because celiac, for certain reasons, but the idea of finger prick tests, some of those kinds of things that are used for other illnesses, or even just measuring kind of nutrient levels in bodies and also stuff... that's the things you can do at home, that can take out the onerous elements of going to the hospital. Like [pwCF\_4] was saying, you find hospital visits stressful. At the moment [child] is kind of just quiet, just goes in, but at some point, they’re just going to turn off and just not want to be there. If you can reduce the amount of stuff you have to go into hospital for which is mundane, that can only make things better?

[Facilitator\_1] 52:46

Yeah. I agree.

[pwCF\_5] 52:49

Home tests, results come in quicker..., I don't know.

[Facilitator\_1] 52:54

what about something like cough monitoring, as well, you know, if that was through something like your [smart watch]? Do you think that would help? Do you think that as parents, your ears are sufficient?

[pwCF\_5] 53:06

I think as a parent, I just want to get on with life. Although, you know, there's a requirement that we have done everything, everything has been asked for us because, you do, you're a parent. I think if there was a level of monitoring that was acquired on a daily basis, I think I'd start to feel a little bit overwhelmed with the requirement. It's hard enough having alarms on the phone to make sure I do a nebulizer when the girls are over having a playdate... Yeah. So, the idea of monitoring stuff when things are being treated, yes. I'm not quite sure how a lot of parents would respond to having to monitor that much on a daily basis. It's hard enough being a parent, It's then hard to be parents of someone with CF, where the kid just wants to get on with their day. You know, I'm a single parent as well. So the end of the day is not easy. Yeah. So if you then having to recall stuff... with apps and things it can be done very quickly, but if it means a few missed bits of data means it's invalid, then I'd rather not bother.

[Facilitator\_1] 54:23

Yeah. Yeah. And as you say, you can't be with them 24/7. Do you feel like you've got a kind of heightened level of sort of like, scrutiny is not the right word, but you're kind of on a heightened level of watching out?

[pwCF\_5] 54:40

All the time. [child]'s been invited to a birthday party next weekend and your bells go "Ding ding ding ding ding" Yeah. "What is there?" "They've got a ball pit, they've got a bouncy castle..." And I'm going "Right that's not great , a ball pit, they'll have to stay out of that...", yeah, and then you add in all the other stuff ... everything becomes [hard]... Every 18 months now there's something new. So we're starting school, right, CF team are going to do all that, they moves up class, CF team go back in again. School Trip... They're going to a blooming farm yard, with hay bales! ... "Oh, yeah". All that sort of stuff. There's a level of anxiety as a parent that is just ringing all the time. So yeah, trying to normalise life is all we're ever trying to do. Because primarily, and this is what i'm talking to psychologists about, is how you navigate it with a child when they start going, "Why me?". I'm very grateful that [child]'s young when all this stuff, the new medications, are happening, and very fortunate in that sort of sense. But you're just trying to normalise it, and try to make it not overwhelming. And everyone, every single thing that's happening now is new, new, new, new, they are all... planning for everything is just too much. Yeah.

[Facilitator\_1] 56:00

Yeah, there's a lot to take in, isn't there? A lot to consider. I can remember when my [child], I think they was about eight, so a similar sort of age, and I went to a talk that was called 'teens, trials and tribulations' because I thought I need to know what's coming my way. And thankfully, it wasn't quite as bad as they had indicated it could be. So yeah, I hope you get a smooth run. Thanks, [pwCF\_5]. [pwCF\_4], did you want to just comment on something?

[pwCF\_4] 56:28

Yeah, just something that came to mind about... this isn't really about a test. It's about treatment. And it might be project breathe or some other thing. But I've got a, I agreed to start using a connected nebulizer a couple of years ago, where it gets uploaded to some website, and they can see what percentage of DNS treatments I do every month and stuff like that. And it's a bit of a double edged sword, especially if any tests that I was asked to do are potentially manual where we have to take an action every day or something like that, where it's definitely increased my adherence. But I would say at the expense of a little bit of happiness, and a little bit of freedom, because I know they'll be watching. So if I've been out with friends, and I come home, I'm really just want to go to bed and sleep. And it would probably just be actually better to go to sleep and to do the DNS that you kind of have to force yourself to make it up and do it and all that kind of stuff. And I think it's not a big thing. But it has a little bit of a drag on your happiness sometimes where before I sort of felt the freedom to just go "I'd probably be better if I just went to bed". Yeah. And now I dont. I stand there thinking "its bit of crap this" for like 10 minutes while I'm doing it, and I'm not sure whether it's good or bad. It's good that I do it a bit more than I did before because of it. But just knowing that you're being watched all the time is an odd feeling to get used to, and I don't think I've actually quite got used to that feeling even after two years. [The clinic] act a bit like your parents sometimes, it’s not that they nag me about it, but if they saw a drop off one month, they might do. Yeah, it is motivation to do it. I've got some reservations about it I think... and I think if any tests are going to be brought in, that included regular data where you felt obliged to do it, or potentially force your child to have a test, when you know that really it would be better for them if they were doing something else. So just asleep or something like that. That might be good for clinic and potentially good long term for your health. But that's not the be all and end all, all of the time I think.

[Facilitator\_1] 59:05

So actually, that prompts the question of with some data capture, would you prefer some data capture to just be for your eyes only, and not share with your team or not automatically share with your team?

[pwCF\_4] 59:26

Probably, yeah, I think it would be nice if you had a choice. Yeah, to share it if there was something in it that worried you, or that you thought would be useful, but it would certainly make you feel like you had more control, which is often the thing with CF. And certainly, I had a lot of mental health problems when I was a teenager up until the mid 20s. And I think a lot of that was around a lack ... or feeling like I had a lack of control. So anything that's even gives you the 'fake' feeling that you're in control is probably a good thing. I've never really thought like that. But yeah, that would probably be quite good.

[Facilitator\_1] 1:00:03

Yeah. Sort of like an on-off switch. So it can only go when I put that on? Thanks [pwCF\_4]. [pwCF\_2], did you want to go next?

[pwCF\_2] 1:00:16

I actually feel I'm slightly different. There's a lot of people saying in the chat that they like monitoring themselves. And [pwCF\_4] said it made them more adherent. I was on the precursor to project breathe, which is, it was called Smart-something, and every day, you had to do all these things. And I took myself off after six weeks, because I'm actually quite compliant. And it panned my compliance. That's I, I don't I've, I've taken twelve [...] this week, and I've not gained a pound, i'm not taking anymore. And things like that. And actually, after six weeks, I had to say, I'm sorry, but no, never again, like I've seen no improvement. And I've actually just taken myself off things. And then if I've skipped calorie shakes, I won't lose weight. And I see it as definitely, it's gonna sound strange, but it's a job, having a job, and I do my treatment. And I go and see my ‘colleagues’ at clinic. And don't think about it any other time. It's just habitual. But then it's the personal life. And if you're being involved in your personal life, by putting all of this stuff into data all the time and having someone watch you, it's no longer something you can separate from you. To me, I know that a lot of people disagree, but I just thought I'd offer the other side.

[Facilitator\_1] 1:01:32

Yeah, no, that's really interesting. I think, again, you kind of really touched on "its choice", isn't it? So it's choice, if you want that information, and you want that information for you, or you want that information to share with your team, because you want to make a joint decision, or, you know, sort of like jointly consider what the diagnosis is, wherever you have got an infection, or, or whatever. So yeah, it's kind of building in that option for choice, isn't it? I think we're all the same. You know, if you're told to do something, a lot of us probably dig our heels in, and go "you're not telling me what to do". But if you're doing it out of choice, you want to do it is a bit like going to the gym and things like that, isn't it? You know, if you want to do it, and you feel the benefit from it. As Joe Wicks, says, you know, exercise is not about losing weight, it's about feeling good afterwards. Yeah. I'll come to you, [pwCF\_1]. And then [pwCF\_6], I will come to you. You're on mute, [pwCF\_1].

[pwCF\_1] 1:02:40

There we go. And I just wanted to actually echo what [pwCF\_2] said, because I know often I probably because some of my monitoring data has been the only way that I've had quite serious infections recognised. And I have equally been in the same situations, [pwCF\_2], where I'm like, "why am I doing this?", and I've turned down opportunities to do it. I've done it because I've been in like a medical trial. And I had to monitor daily. And I've done, I did some of the early stages of project breathe, I think the same smart one that you're referring to [pwCF\_2]. But equally, I've turned down some because it's a burden that, like a time burden to add to my day, and a mental burden that I sometimes just can't tolerate. And it does make me think that, I noticed what [pwCF\_4] put in the chat about we need to be customised to us, I think maybe we need an assessment before we ever agreed to do that, whether it's part of a study, a trial, whether a doctor is just prompting us to. And we need an assessment to figure out if we are someone who would benefit from it, or if it could actually be detrimental. And that probably needs to happen each time we're asked to do it, not just "that person is or isn't suitable". But it depends where you're at, in your journey as well. Because like I said, sometimes I could, and it was the only information I had, sometimes it was too much. And I just also wanted to drop it in a couple of things I just thought of, which is with the monitoring. I think I echo what a lot of people are saying about FEV1 as well. And I only tend to do it if I'm grasping at straws, because I don't know what's going on, but I feel a bit off. In which case if I'm only doing those instances, and I can't keep it up daily, I actually don't really have a baseline to compare to anyway, so it kind of sends my mind spiralling... and the other thing I hadn't mentioned for diagnostics was bronchoscopy. That's often been the case for me when I was especially less productive and after having NTm treatment, where people really didn't know if that was clear or not. They didn't know what to do, whether to keep treating. Every time I had a really awful reaction. It always caused an exacerbation even if I was feeling otherwise fine. So now I just point blank refuse, which is tricky and it might cause bit of contention, but I just have to make the right choice for me on that one. And, and speaking of NTm, the diagnostics for that is so long, if I do a sputum sample, I might get a smear result in like a month or two, and I probably won't get a full culture for six months or so. Which is really hard to deal with when you don't know what's going on. And so if anything can be done to speed that up, or to catch it sooner, maybe by sinus sampling, rather than waiting for the chest even, I don't know. NTm is a really tricky one, it takes a really long time.

[Facilitator\_1] 1:05:38

That's brilliant. Thanks, [pwCF\_1]. And yeah, and NTm is notoriously difficult. And as you say, you know, being able to produce a sample or give a sample that is, first of all, sufficient, I guess, to get a good result. And then the kind of almost like lack of competence, like say around that first stage, like you say, you just get a slide smear, don't you? It's like, oh, yes, there's something there. But a bit. There's some uncertainty around it always isn't there until you get that kind of like, say that full culture? And if there is a way of speeding that up? I'm not sure that there is a way of speeding up growing bugs. But if it could be, it would be great. [pwCF\_6], I'll come to you. I'm sorry. It's taking me a while to get round to you. I hope you're still there. I can't see you. Yeah. Oh, there you are. Lovely to see you. Thanks for joining us.

[pwCF\_6] 1:06:36

You've had some decorating done.

[Facilitator\_1] 1:06:43

It's good to see you. I just wonder whether you had any thoughts on what everyone's been talking about? Because, obviously you're quite into your sport as well. So you obviously do some probably monitoring around that? How does that reflect in your CF care and sort of looking at when you're getting infections and things as well?

[pwCF\_6] 1:06:59

Yeah, so that's good. Like, everybody's obviously got their own background and their own pathway and their own experiences. And it's really interesting to see that there's, there's a bit of variation amongst everybody. There's also some similarities. What I'd say is [pwCF\_4], you mentioned about using the lung function device, I think that's when I joined the call, that's what you were talking about. And I got one as well. And when O first got it, I thought, great, i'll use this all the time, keep track, keep a graph and everything else, did it a couple of times and then didn't blow very well. And I thought, that's actually demotivated me. So kinda stopped using it. So it didn't last very long. So it's like that, that's like you said that that trend where if it’s all going well, then great, you want to see the results day after day. But if you start to go down the slope, it kind of puts you off a bit, and then your mind starts to race and everything else. So I think in terms of... you do know how you're feeling yourself... I think that's the key thing. Actually, it was an example where one time I was at clinic, five, six years ago, maybe and used the lung function machine that was the new modern one at that time. And I told the nurse that I didn't feel great, but it was okay. And I blew into that. And then the reading came out. Like really low. So they came back into me and said, Look, you're coming in, tomorrow. I was like, Well, hold on. I don't feel good, but it's not that bad. And then they says, right. Okay, then we went to use a different machine. So we went use the bellows and the bellows showed me to be absolutely fine. So it's just showing you the data isn't always correct. And if you don't, I mean, so I think we need to be wary of that as well. If, if you're wearing something on your wrist, you know, a [smart watch] or whatever, whatever it may be. And you can get obsessed with it. So its about that balance. Where, you know, it's good to have info when you need it, but you don't want to get burdened with that, trying to monitor it every day. Like [pwCF\_1] said, if I was feeling well, I'd probably be more reluctant. I wouldn't bother to monitor, and its only when I become unwell, I think "I need to check that", but then you don't know what your normal sort of baseline is. So that that's definitely that's a big factor for me. I don't know unless it's been monitored for you automatically, and you don't have to physically do it. I think it'd be very difficult to maintain compliance in that way. I mean, medication isn't a problem in terms of compliance, you know, I'd be quite happy to do that day in, day out. But it's, it's like people have said in the call its that extra burden. As much as it's going to help you, if you don't feel like you need the help at the time, it's easy to forget to actually do it. So, yeah. It's a real balancing act.

If we can, if we can get something out of it, in terms of the study, I think it's gonna be really useful. And I think for younger people, was it [pwCF\_5], who was on about having children, I think, in that instance, its going to be useful. But, you know, keeping us in that realm of normality is obviously, the key. Yeah, that's a difficult one.

[Facilitator\_1] 1:10:59

And how do you feel about what people just said about monitoring, effects of medication on an infection? So like, on infection levels? So if you'd been told that you have an infection, say you've got Pseudomonas or NTm, and you've started the course of treatment. Would you be interested in knowing the level of infection, whether the level of infection is being affected by the medication, so that you know that it's working, and you're on the right thing? Or, actually, this doesn't look like it's working after a week? So maybe we should switch to something else?

[pwCF\_6] 1:11:37

Yeah, that would be good. What I don't want is to know that you're on a scale of 1 in 1 to 100, and you're in the worst position you could possibly be because that's not going to help you. But to see an improvement, you know, is definitely going to, you know, bring your spirits up, it's going to make you feel better as you go through it. So yes, I think, some sort of monitoring, and being able to see that improvement, because you do feel better. But then, you know, as you're going through treatment. But I think sometimes you have a bit of a niggle, it's like a sports injury, you think you're better? You're not sure. And then, you know, if I think you'd have something to definitively say that you were better, probably would be helpful.

[Facilitator\_1] 1:12:31

And what do you think your preference be? I think we've sort of talked about cough swabs, sputum samples, blood tests, you know, other indicators, as [pwCF\_1] and [pwCF\_4] was saying about resting heart rate and things like that. Then thinking about the ease, perhaps of collecting those samples, and we don't, you know, sputum is not available on demand for a lot of people, wether you're on Kaftrio or pre-Kaftrio, you know, not necessarily being able to produce a sputum sample on demand is hard. And hence the reason that you know, why obviously, [pwCF\_1]'s had bronchoscopies as well to try and get those samples from further down in the lungs as well. So yeah, kind of what would your preference be?

[pwCF\_6] 1:13:18

Well, I think we've all had enough of swabs going down the throat and up the nose recently, so that's...another thing that people with CF were ahead of.

Heart rate? Obviously, I wear a watch every day. So that's probably a good indicator. For me, personally. Blood tests? I don't like needles, but I'll get a blood test done. But I wouldn't get a blood test done every day. I wouldn't want that or every week, I wouldn't be interested in that if I could help it.

[Facilitator\_1] 1:13:55

If something could be done with a really small like bloodspot, from a finger prick or something like that at home?

[pwCF\_6] 1:14:02

Yeah, that is an option, you know what, at the end of the day it whatever’s going to be most reliable. If you told me that the swab was the most reliable, if you told me the blood was most reliable, most accurate, i'd probably go with it.

[Facilitator\_1] 1:14:16

Yeah, I think that comes back to that confidence again, isn't it? You know, if you're going to spend time getting a sample or giving a sample or having to go to clinic to get a sample, or to collect some data, you want confidence that it's giving the right result, don't you? it's giving a good result? A firm result, I suppose? Yeah.

[pwCF\_6] 1:14:38

Yeah. So when you're in that situation where you aren't feeling good, I think whatever you can get to help improve that, you would probably do at the time. But as I say, that aside, you're not going to do it every day if you don't feel like you have to. So yeah, during that period of illness definitely just the most reliable, most accurate method.

[Facilitator\_1] 1:14:38

There's some talk around possibility of being able to use urine samples as well for pseudomonas. It's not something that's, that's proven yet, but I was just wondering what people's thoughts are around that, you know, sort of almost like a dipstick test at home that could say indicate either indicate an infection or indicate a level of infection.

[pwCF\_6] 1:15:29

Yeah, absolutely. I mean, it's simple, it's painless, and for me, easily done. Yeah. Yeah, I think that would be a good indicator.

[Facilitator\_1] 1:15:44

I think we're all used to collecting various samples and having them in pots. And I've had conversations with people about how happy they are or not to keep samples in the fridge, if they're taking it off to hospital or getting into the post and, and things like that. But just that, you know, perhaps something that offers almost like that instantaneous feedback. And going back to what [pwCF\_5] was saying about, you know, the speed of return of results as well. And then, as we were saying, also, you know, the sharing of information with your team and having the choices around that. Yeah. I'm watching the time where we're almost at the end, we've covered so much, and it's been absolutely brilliant. As always, I'm so grateful for you all joining the call and just being so open and honest. And with all your experiences and insights. It's such valuable information. And I'm sure, you know, for [Researcher\_3] and [Researcher\_1] and [Reseacher\_2], you know, it's really, you know, say valuable for them to hear. [Researcher\_1], I'll come to you.. Is there any questions that you feel like we haven't covered? Is there anything any information that you need us before we let everybody go?

[Researcher\_1] 1:16:53

Oh, my, it's been fascinating, by the way, and I don't want to take up all the time... I'd be definitely be very, very interested in speaking to you guys again, because I'm sure there's plenty more we can get out of your experiences. It's been fantastic getting to know you. And I think we can learn a lot more about your experiences. I did pop in the chat there a little bit about personalised medicine and how long it took for you to get into routines. I think there are a few answers there that were quite good. So thank you very much for that. I think [pwCF\_1] at the start, you said something about having chest X-rays and a CT and it took three months to get anything done about it. And then I think it might have been you who mentioned the nasal swab that you put in the post. Obviously, that's a huge difference in the turnaround time, what were the factors?

And more generally, open to everybody, what are the kinds of factors that influence how long it takes to get the results? And what's the kind of impact of that on you?

[pwCF\_1] 1:18:08

Yes, so the X-ray and MRI that I had where it was three months after they think the infection started. It wasn't that it took three months to get the result it was that I was asymptomatic for three months, while it got really, really severe. To the point where when they actually saw the scan, they couldn't believe that there was no indication sooner. So that was kind of alarming. And that means that we now have regular MRIs in place again to avoid radiation. That's kind of the go to, but I now have those scheduled for about every six months. And honestly, sometimes I feel like I need them more often because I feel like things can change really quickly without me realising until it's bad. And I don't know why that is, I just generally am quite positive and energetic. And so I don't always notice the small things or if I just don't have signs. And the sinus thing that was a quick turnaround, I think because it was pretty evident quite quickly that it was Pseudomonas. And that cultured really quickly. And I also have access to I don't know if this is a widely used programme, but MyChart which I only actually get not because my clinic offers it, but because I've had an appointment at a sort of a partner hospital that uses it and then gave me access for something else. And because of that I can see my results and I would pick up on them long before my team would actually let me know what the results were. So if I wasn't seeing them on my phone and getting the email notification to say hey, you've got a new test result. I don't know if they would ever told me... Sometimes they haven't in the past because they've thought "oh they's cultured Pseudomonas a couple of times", but it's not really a regular bug for me. It's not a constant thing. And sometimes I think they think in their heads that it is and kind of forget to told me that it's there. They just think that's my normal... And so I have to kind of remind them every time like this isn't normal for me, like how long have you known? Yeah, hope that answers your question.

[Researcher\_1] 1:20:08

That's great. Thank you very much. Sorry, [pwCF\_2]?

[pwCF\_2] 1:20:15

No, sorry my Team's does this sometimes my hands just go up and down ignore.

[Facilitator\_1] 1:20:18

I was just catching up with your comment [pwCF\_2] in the chat about your lips and knuckles bleeding as well.

[pwCF\_2] 1:20:30

Oh, yeah. So that's how I know. So when I have an exacerbation, my knuckles literally start to bleed and my lips split open. And that is the first sign and I've I have only connected that really in the last 12 months, but it's been going on for about six years. And then I have I have suddenly get high temperature about two or three days later. And then I've normally by that point already contacted them and said I need to receive orals. And then if I'm able to get my orals in to me fast enough, it just stays a high temp and I move on to IVs. If I don't get them in fast enough, I start having night sweats. But yeah, the first sign is bleeding. Which is Yeah, I don't know. I don't know why. And it never used to be the case. It's been probably four or five years. So I don't know, the team just accept it and go, that's fine. Just tell us when you knuckles bleed.

[Facilitator\_1] 1:21:28

you have any other signs of sort of like a reduction in hydration or anything like that?

pwCF\_2 1:21:34

No, no, I do. I know it's not that type of cracking. They literally, they just bleed. There are two other patients at my hospital where they said they've had it. They don't understand the mechanism. It's not like dry skin. And my lips. They split open. But it's not dehydration, either. It's very strange. But it's I'm not the only person they've seen it in. Yeah. But obviously I don't know anything about what those other patients have, or whether they're male or female, or anything ... So yeah, that's it. I know, it's a bit weird.

[Facilitator\_1] 1:22:13

As one of our other involvement group members regularly says to me, they says, CF is the condition that just keeps on giving. Yeah, you never quite know what's coming to you. Sorry, [Researcher\_1], were you going to ask something else?

[Researcher\_1] 1:22:36

Yeah, there's probably a few bits. But we're at time now. So I didn't want to keep anyone here beyond time.

[pwCF\_2] 1:22:47

Sorry, if you have more questions, I'm happy to stay longer.

[Facilitator\_1] 1:22:52

Oh, yeah. Sorry. I was gonna say. I should know by now. Yeah, if you want to ask, that's fine. If anybody needs to leave, then obviously, that's fine as well. And, yeah, we can just we can follow up. If anybody's got any ideas and thoughts afterwards, then please do feel free to get in touch. But yeah. Go ahead, [Researcher\_1].

[Researcher\_1] 1:23:13

All right. Thank you very much. So I think [pwCF\_5], you mentioned you are going in to the clinic for swabs. Is that right? [pwCF\_1], you had some at home?

[pwCF\_5] 1:23:24

Yes. Yeah, predominantly in clinic, we've been given some to take away, which usually is a case of if we really can't make it to clinic, or if it's a weekend so on. So for example, [child]'s gonna have been coming down during the week. And just you kind of just get a sense you can have to do one anyway. But yeah, it's it's in clinic pretty much, pretty much.

[Researcher\_1] 1:23:48

And do you think you're happy with that? Are you confident in what you do with it, or not?

[pwCF\_5] 1:23:59

I think we're still in such early days in the whole journey that you get on with it, but I think as life moves on, something like that, which is just a mundane test, and it is not, it's not a case you pop in, you're done within 30 seconds. It's a particular time that the nurse or the physios free the following day, they make as much time as possible. You're told 2:30, you get there and they're usually running late. You're in hospital for 45 minutes, because you wait for a bit, then they want to see you, they do weights, they do heights, they do cough-swab, then the physical check. They do other bits and pieces, it turns into a mini review because you're there for a reason. Where when its that kind of stage, For [child], as a six year old, it's like "have they got something yes or no?" Not we need to go through the kind of a mini kind of appointment again, it's like "just get this thing done. Then tell me as quick as possible, what we're doing". Its kind of just "get to the next stage as quickly as possible and allow us to get on with our day". Which sounds a bit mean, but like, it shouldn't take three hours to get a cough-swab done and then waiting. Usually, say its a Thursday, Friday, it's usually the Monday, 10 days later you get them back, by which time they've already had to make a decision. It seems a little bit in the in my naive view of the medical world, it seems a little bit unnecessary to take that long, and be that cumbersome when it is just "Infection - yes or no". So that's just it's gonna get more and more frustrating I imagine.

[Researcher\_1] 1:25:40

Is there any like anxiety or concerns about going into the clinic specifically, because there are other people there?

[pwCF\_5] 1:25:48

Not at the moment, we're just very lucky, [child]'s conformed to what they has to do. As a personality. They does what they have to do. So we haven't had battles with anything in particular. Yeah, whenever they have something new, they’re like, "Oh, I don't like that". But within the day they get used to it. The hospital visits become routine. They're just a bit of a pain in the backside. They’re missing school. They’re missing stuff. So yeah, no, no anxieties yet, but they’re six, it is going to change.

[Researcher\_1] 1:26:20

Yeah, yeah. Sure. In terms of confidence, between say, this is open again, to everyone, between you, your team and whatever tests you've had done. What do you think the kind of percentage split is? What sort of outcomes do you ge, based on you what you think, what the team thinks, and what the test says?

[pwCF\_2] 1:26:50

I find it a very even split. With if I've got something new, they will call me and say, How are you feeling? Do you want to treat it? Because I also have to send samples every four weeks. A cough, like a sputum. And usually it's just the same bug. So they'll just be like, you know, contact us if you're feeling unwell. Don't wait on our results. But if it is something new, they'll say that how are you feeling? And do you want to treat or not? And then I'll make a sort of, we'll make a vague decision, and we'll sort of negotiate and then it goes from there. So it is very much like a partnership rather than they're just telling me.

[pwCF\_1] 1:27:44

I'm at the same clinic because [pwCF\_2] and I think my experience is pretty similar. They do really ask my thoughts. And often I will be the one to tell them, hey, I really do need an MRI or something before they would ever pick up on it. So they're pretty reliant on that. What I will say is my last MRI, they told me it was fine. It was stable, but they actually didn't tell me the full extent of it. Like it was stable from their perspective. They were like, ah, everything's mild, you don't worry about it. But someone else in the team told me it said mild, new infection indicated. And I would have liked to know if it was something new. Yeah, I guess you just do want to know, don't you? So the main thing for me is, it is an even split. And I generally really trust their judgement. But I also will trust it less if I ever feel like I'm not being given the full information.

[Researcher\_1] 1:28:39

That's very interesting. And just to pick up on that more, so I presume the team didn't quite tell you exactly what it was that they saw, for whatever reason, and how did that impact you or your confidence in that going forward?

[pwCF\_1] 1:28:54

I'm still kind of in this the phase now, where I'm still not sure what's happening. And my last clinic appointment that was scheduled, hadn't I hadn't had one for like the last six months because I was in a medical trial. And so I think they sort of assumed I was taken care of. But the last one, I always expect see a consultant when I have a clinic. And this time, I just saw one of the specialist nurses and so everything I asked, they’re like, "Oh, I have to ask the consultant and get back to you". And in that situation, I actually don't trust that things aren't lost in translation. Especially because I know how busy they are. And I know the characteristics of different people and how they communicate and this particular nurse doesn't communicate in the same way that I do. I do worry about the message getting lost. So yeah, I'm still in the phase now where I actually do have that uncertainty. I don't know what's happening because it was and still is unclear and I think it will be until I actually get an appointment and see a consultant which might be a few months now.

[Facilitator\_1] 1:30:00

Thank you for that. Go ahead [pwCF\_4].

[pwCF\_4] 1:30:03

I think for me, it's probably like 75% me, 25% clinic... I think it's gonna depend what it is. So if it's something I've had before, that I'm confident I know what the symptoms are and what I need, then it's probably all me. And whatever clinic said, I would probably ignore them and just go with my gut feeling. If they came to me after a clinic, I think it's happened once, in the last few years, where it was something completely new, that I didn't have any experience of, I kind of went with what they said. Because I think, you know, after 33 years of having pseudomonas, i'm pretty good at knowing what my limits are and how to deal with it. Whereas something completely new, I would want to learn more before I become more arrogant about it. I thought it was interesting what [pwCF\_1] said there, which I hadn't thought about, It kind of depends who you see in clinic as well. And I've got a main consultant who I probably see 60-65% of the time, I think that I'm seeing them less now that I have Kaftrio, as the consultant feels like it's less important that you see them if you're generally quite healthy, but quite often get, I can't remember their official name, but whether they in between being a student and a full doctor, and they'll start off and you'll have like 10 of them in a room with with the consultant. And then eventually, they'll just see you on their own. And quite often, you know a hell of a lot more about CF than they do. And if I come across somebody like that, I wouldn't listen to them at all. I would definitely go with my gut, or just request, them to ask [consultant] about it. Because yeah, I think after having CF long time, you know, apart from those top consultants, you'd know more than almost anybody else I would say.

[Researcher\_1] 1:32:09

That's a really great insight. Thank you very much. I just popped a question in the comments along that. If anyone has any more bits to add. [pwCF\_5], you got your hand up as well. Have you?

[pwCF\_5] 1:32:17

Yeah, just gonna say just because we're dealing with paediatrics. So its a different kind of thing. It's consultative, but it is consultant led, just because I've put it up in the chat we're/they're learning about [child], What we got told at the outset of this is that no CF patients are the same and it's almost like I could understand if a consultant doesn't communicate in the best way it can almost probably sound like a bit of a 'Get Out of Jail Free' card. But as a parent you understand, you're gonna go "Yeah, because you've read so much about it". And no two experiences are the same. And each time [child]'s got an infection is not the same as last time. So what do we do this time? But it is, Yeah, the team is amazing. We always see a consultant when we have an appointment. If it's a non-scheduled appointment, so if you've got an infection, it might just be a nurse or the physio, but we do see a consultant once every eight weeks, which I think is important as a parent when you go through paediatrics, just like [pwCF\_4] said, you start to become more informed than other people. And I think as we're learning about [child]'s journey with the consultant and the nurses and the physio is really important, really important, because they need that, they're growing to understand them. So just by, almost just by looking at them, they can go, Okay, this sniffles a bit more than something else. So it's consultative, but it's definitely, quite rightly led by them. And sometimes you just sit there and go, "Yeah, fine". Because, you know, it's going to be [child]'s experience where they starts to have a say. And I think invariably that'll come in, they becomes a teenager, they'll start to know their own body. They'll know what they want to do or not do. So that'd be an interesting transition. But yeah, as a paediatrics, we found we were, you know, led very nicely and informed and communicated in the right way and always ask the right questions. "Are you happy with that?" and, you know, that they give you the time, which I appreciate paediatrics is different when you move out of that kind of that age group, but our experience has been very positive. I will have to quickly apologise and disappear. So thank you.

[Facilitator\_1] 1:34:45

Thanks so much for joining us. I hope you've enjoyed it.

[pwCF\_5] 1:34:48

It's pretty good. Yeah, pretty good. Excellent. See you all soon.

[Facilitator\_1] 1:34:55

Go ahead, [pwCF\_4].

[pwCF\_4] 1:34:55

Just answered the question from the chat. For me, it's quite important. I actually switched consultant at [CF clinic] about 10 years ago, I really didn't get on with that other person though, the main consultant who's still there, because he was quite old school and really wasn't interested in, you know, negotiating with the patient on what the best course of action was. He just wanted to tell people. But I prefer to attend in person still. So I still go and make an effort to go up to the clinic. And it's now every eight weeks rather than every four weeks, because I seem to be doing pretty well on Kaftrio. And I think because I go up [there] a lot less now I'm even more inclined to want to see the consultant, I've got a good, what I would say is a good relationship with them where they talk, honestly, and they actually listen to us. And when you get the kind of trainee doctors and stuff on their own, you just don't get the same, but you haven't gotten the relationship with them. And it takes a long time, I think with CF, to learn about you and for you to learn how they work, and how best to get on... so it's become even more important, the less I see them that I actually see my consultant. And I'd rather change appointment, then, you know, if they actually told us in advance that he was on holiday, I'm gonna get somebody else, I would rather change the appointment to see him rather than see somebody else.

[Researcher\_1] 1:36:31

It sounds like everyone sort of had their own experiences, especially very early symptoms. I would imagine that if it's not your regular team, they probably aren't going to know those particular symtoms, and probably aren't gonna think, ‘oh, yeah, you know, this is classic’. Do you think something like a checklist of your personal symptoms would be a useful thing or not?

[pwCF\_2] 1:37:15

No, I. So I, I've occasionally had been had this lips thing and gone straight to high temperature. And I've come in unless it just comes straight in. And then I turn up for whatever reason, all the consultants are busy and I see the registrar, they looks at me and goes, your temperature is like, maybe slightly high, let's give you some fluids and out you go. Just speak to Dr. so-and-so, tell them and they just sort it. And I think CF patients we know how to handle doctors who aren't listening to us. It's just an ongoing thing. I don't think it would be beneficial to anybody. It's not that it's a bad idea. But I just think we all know how to say, yeah.

[Researcher\_1] 1:38:00

All right. Okay.

[pwCF\_4] 1:38:01

It might be a good idea from a research perspective. Because I suspect there's a hell of a lot of symptoms that people say that the clinic never asks about or writes down or anything like that, that we could tell you. So from that perspective useful. I'm the same as [pwCF\_2], I will just ask to see a higher doctor if I didn't get my ordinary one.

[Researcher\_1] 1:38:31

Again, well, thank you very much for that as well, that's, that's really good. That's a good idea with the spin on the research side of things as well.

Thinking about the characteristics of tests, the diagnostics, going back to, you know, the accuracy of them, the speed, the time it takes, the kind of sample that you have to do, the location it can be done, whether it's at home or in the clinic, the kind of cost implications or any other things that you can think of… If you were to rank them in order, what are the most important sort of characteristics of a test for you?

[pwCF\_2] 1:39:21

Speed of result is top, definitely.

[Researcher\_1] 1:39:26

Why is that?

[pwCF\_2] 1:39:30

so I'm free flowing with my mucus, so I just always give a sputum sample. And then I get my results in stages because I have an NTm. But it's not a bad one. It's like a minor, nothing, waste of time one, but that takes a whole eight weeks to come back as a minimum. So I just get lots of information. So I turn up and within the first week they'll go oh, it's whatever common cold. And then by the end of that, they say, Oh, I know, Burkholderia as we anticipated, but then the other things, all the other things sort of pop up slowly over time, I just think at some point, it's actually going to be important one of those, that's the really late one, and we're going to started treating everything else. So speed is yeah…

[Researcher\_1] 1:40:21

This is culture is it? And it's the time it's taking the culture to grow?

pwCF\_2 1:40:27

Yeah, to grow on the plate. Yeah. And often, particularly, for the NTm, this shouldn't be possible. But my Burkholderia grows over it, which is, which is completely ridiculous. And so then they have to restart, they have to go back to the freezer and swipe it again. And then it's like, we've reset the clock. And I know that actually, I don't have an NTm, otherwise, I would have more symptoms, but it's just the principle of like knowing.

[pwCF\_4] 1:40:59

I think, for me, I would probably say the accuracy, and then convenience, and then unpleasantness because some tests pretty horrible, and I would have to be pretty ill to agree to have them. Well, I mean, I'm incredibly like sensitive with sinuses and stuff. So like getting a covid test in my nose is excruciating. So anything that involves putting stuff in my nose, I hate. And I've like not gone into clinical trials, because they've had a test like that, and stuff. So yeah, the main thing is accuracy, I suppose. Because what's the point in doing the test, it doesn't give you a good result. And, you know, I work full time and do this and other voluntary stuff. And, you know, a test that doesn't take three hours to do or you can do at home rather than go to the hospital is really useful. Because, you know, a lot of CF people now do work full time and have kids and all sorts of stuff, everybody's got a busy life. I think sometimes not necessarily clinic, but people or companies in general that do things with CF just assume that we're all stuck at home being ill all the time. And that is not the case anymore.

[Facilitator\_1] 1:42:19

I was just going to mention on the point of convenience, would you consider using either like GP services or localised services for the collection or to for giving some samples?

[Researcher\_1] 1:42:34

Just to add on to that, what about like Boots, or you know, your high street pharmacies, something like that.

[pwCF\_2] 1:42:39

I do all my bloods through the GP, already, unless I happen to be in clinic, because they keep a routine on my liver. And I just go two minutes down the road.

[Facilitator\_1] 1:42:49

Do you find it quite easy to get an appointment? That you're kind of booked in regularly. Yeah?

[pwCF\_2] 1:42:54

Yeah. My GP is excellent. I know not everybody's is, but my GP is just like "rock up. You're fine".

[Facilitator\_1] 1:42:59

And how did you manage that through COVID as well? Did it just carry on?

[pwCF\_2] 1:43:03

I gotta be honest. COVID didn't impact me in that respect. I still went to face to face clinic. Our hospital shut down. But I was having some problems. So I still did face to face clinics. The GP still saw me. Actually the GP started doing home visits. So like, Yeah, it was fine.

[Facilitator\_1] 1:43:22

That's good. It's really good to hear that you've got that support as well. Yeah. They we're good.

[pwCF\_4] 1:43:28

Yeah. My preference is to have it done at home, when I was in paediatrics, and I managed to cling on paediatrics for as long as humanly possible because it was in [previous city], rather than [current city] and their paediatrics was amazing. They had home visit nurses, and you were assigned a single nurse. So I had the same CF nurse from like the age of seven to about 19. And they did everything at home. So you needed a blood test, they'd just come to your house, you tell them what time. I went to [CF clinic] adults where, I mean, it's a lot better now. But it was really quite a bad clinic when I started, it was quite a shock to the system. So my experience of having your own nurse that comes your own house, I would say that that is my preference for everything. You're much more relaxed. If a nurse comes to my house and does FEV, I blow higher at home because I'm more relaxed than I ever do in hospital and stuff. It's the way to go, but it got cut becuase of the money basically. But that would be my ideal world.

[Researcher\_1] 1:44:37

That is fascinating. Thank you [pwCF\_4]. You also mentioned that you thought the [current CF clinic] clinic wasn't great but now it's improved, what was it that improved?

[pwCF\_4] 1:44:49

I'm guessing staff change but they were just... The person who ran it at the time, he's still there actually, and he's a lot more relaxed now. But he was incredibly inflexible. The there was no safety protocols or clinic it was you're in this ancient bit the hospital sitting next to, you know, 50 other CF patients on the seat next to you. Their attitude was terrible, and they offered no ... the services that I was used to at [previous CF clinic] just didn't exist. They were quite open, that when you requested something that you were going to cost too much money, and they wouldn't do it. And that was it. Kind of it was one of those places in the NHS where you only got something if you fought for it. So like everybody had this nebulizer. I can't remember what was called it was supposed to be a really advanced nebulizer. But it took me about 50 minutes to do [...]. I mean, I was getting up at half five in the morning to get to uni for 10 o'clock, the treatments took that long. And then the e-flow got released. And the clinic, they knew it was out there, but they didn't want to pay for it. So they never told any of the patients and I found out about it. And I kind of demanded it, and got it ... and my treatment went out in like five minutes. So that kind of massively changed my life. Because I think it was 400 quid at the time I didn't want to spend, we talked to other people in the clinic and have never even heard about it, the clinic hadn't advertised the fact that they could get it. They just wern't proactive, there was no clinical trials, just nothing, just crap in general. Absolutely hated going there. But they have gradually improved over the years and I'm really happy with the care that I get from them now. You know, there's some things which could be better. But I think it's out of their control... , which, for example, means I can't get medication from my local pharmacy, which I also have a good relationship with. I've got to get through [other pharmacy] or [private healthcare pharmacy] or whoever they are, who were also crap, and it must have cost them a fortune too. So that flexibility was taken away. But overall, they are good. They listen to what patient's say, you know, that sort of thing. I do feel like they're on my side, whereas I didn't 20 odd years ago.

[Researcher\_1] 1:47:13

Sorry to hear about that. But I'm glad that it sounds like it's getting there at least.

[pwCF\_4] 1:47:17

I suspect it might be a common story for lots of people who were older. And through old school clinic, you know?

[Researcher\_1] 1:47:26

Do you think that this change is, as you say, you know, it's old school clinicians, the patient never knows what's right. “I'm clearly right, because I've done the education”, or do you think it's do you think that's changing now, where people you know, the new clinicians coming in are a bit more responsive and understand that the patients probably know more than they do about the condition?

[pwCF\_4] 1:47:47

Yeah, I think it definitely partly that and the younger doctor I've got now is maybe 20 years younger than the person who still runs the clinic, but I think he's kind of moved on with a times bit now too. Attitudes have changed. I mean, you know, I've got a degree, I've got a decent job, I consider myself an equal to my doctor, which I think kind of shocked the first one, who definitely didn't look at me isn't an equal and like a partnership sort of thing. That's definitely changed. And the environments changed. So the move to a new bit of the hospital and actually a lot of things improved then as well. So I guess maybe they were constrained in what they could do because of where they've been shoehorned into. I also think people have changed, so patients are probably more aware of their rights, and less respectful of authorities than they were 30 years ago. So better both sides.

[Facilitator\_1] 1:48:54

I wonder whether there's some impact there from as we've been talking about monitoring and data, that perhaps centres are monitored more closely as well. Reporting and auditing has definitely improved a lot of services. I don't know about CF personally, but in a number of other cases, prostate cancer, for example, that's definitely one of the things that they are working towards because they know it's, it's audited, and it's nationally available. I imagine it'll be the similar here?

[Facilitator\_1] 1:49:36

And I think CF is a pretty well connected network as well. You know, obviously with the development of social media, you know, people can talk and discuss the CF centres, which perhaps wasn't available before, you know, perhaps there's a little bit more pressure there to match up.

[pwCF\_4] 1:49:56

The internet probably, because the internet enabled me to research things that were going on in America that I doubt they would have mentioned, if I hadn't gotten there first... before the internet, I would never have been able to get that information. I think [pwCF\_2] was waving their hand when I was speaking by the way.

[pwCF\_2] 1:50:13

I just wanted to say that the difference between CF centres even now is great. When I speak to patients, some of the things that patients experience, just think my goodness, and actually I moved adult CF centre. And I don't... I moved from [town], which has changed a lot since I've moved. So I don't want you to think that it is a bad CF centre now, because it's been a long time and the staff have all changed. Because like, I've kind of like kept an eye [on them]... My family are all in [city]. So if we could ever move back, like I would. So, and they have changed, but I'm very happy where I am. But I think it is an attitude that you could never get rid of because it is a personality of a doctor or a nurse. So I was at a paediatric unit in [town] where the doctor really believed the patient is going to be an adult, they need to be responsible from the beginning and really was very, very good. And then I moved to the adults. And they were like, "No, you do this", and would just talk at me. And I couldn't cope with that. Whereas I knew, and I moved away, and I asked around and looked at various things. And this was where I found I was happier. And actually, it was a good move for me. And I'm sure it has changed. But I don't know that you can change the personality. And if there's a few strong lead personalities, then the whole of the clinic follows that.

[Researcher\_1] 1:51:40

Thank you very much for that. [pwCF\_6], I think we skipped over your rankings of the characteristics. I know that's going back a while now. But do you have any input on that?

[pwCF\_6] 1:51:49

Not really, to be honest. And what I mean is, at the time, when you aren't well, you'll basically take whatever is available, and I do get that there are things that are uncomfortable. I dare not ask [pwCF\_4] what you've been offered in the past in terms of samples, but yeah, yeah, there's probably a limit to certain things. But I think generally speaking, if, if you're in that bad condition, you know, you'll really let them do whatever is necessary. So I don't have a preference. Bloods, as I say, I'm not a big fan for bloods. But I think bloods are one way or another fairly essential. So there's nothing you can really do.

[Researcher\_1] 1:52:42

That's fair enough. Thanks.

[Facilitator\_1] 1:52:42

I think one of the examples that I've mentioned, [Researcher\_1] and [Reseacher\_3] to you, when we were sort of like having our pre-chat that I can remember always finding really frustrating was, and this demonstrates the need for well, accuracy, as [pwCF\_4] says, you know, if it's not going to be accurate, what's the point in doing it speed, like [pwCF\_2] was saying, but it was when having a course of [tobymycin], and you have to have that 24 hour, and then the day eight levels checked, to make sure that it's kind of clear in your system, you're not getting that build-up of toxicity. And the amount of times that they either couldn't get enough blood from [childs]'s finger, and they'd be sort of squeezing and squeezing, squeezing, and they’d be absolutely distressed. And then think, Okay, think that's just about enough, and then send it off. And then we'd get a call saying, it wasn't enough, you're gonna have to come back, and we can't give you next IV treatment until we've got the result back. So then you're in that distress cycle of, oh, God, we've got to get this done. It's got to go off to the lab, we need the results back really, really quickly. Because otherwise, we're going to fall behind on this IV treatment that they've told us we've got to come in and start in 24 hours, because they’re growing pseudomonas, we've got to react as quickly as possible. And then all of a sudden, the reacting quickly as possible, seems to go off the scale while you're waiting for the return of a blood result. And then you have to go through it again on day eight, as I say that, for us was one of the most distressing parts of having a course of treatment was meeting those tests points to check, say for toxicity level. So it wasn't even monitoring the infection or checking that the treatment was working as such it was making sure that it wasn't causing some additional problems.

[Researcher\_1] 1:52:50

That's a really great insight. So monitoring, response to treatment. That's a whole other thing that I think would be interesting to get into. Sorry, [pwCF\_6].

[pwCF\_6] 1:54:55

So I have just got to say I have to apologise on joining late, but I do have to Jump off.

[Facilitator\_1] 1:55:01

Just okay. Yeah, it's been lovely to see you, [pwCF\_6], thanks so much for joining. We'll catch up soon. Thank you. Bye. Bye. Was there anything else that you wanted to cover? [Researcher\_1]?

[Facilitator\_1] 1:55:29

You know if anybody has any thoughts afterwards, and you want to send them through me, but likewise, [Researcher\_1], you know, if you have any additional questions, I can circulate them to everybody. You know, and, and I'm sure as you say, there's going to be plenty more opportunity for us to all chat as the project progresses as well, you know, what works really well with the target product profiles that [Resercher\_3] mentioned before that when we were, you know, building the checklist for companies to consider when they're developing antimicrobial treatments, you know, with the kind of constant input from the community. And it really helped inform that works. So yeah, I'm sure going forward, we're going to have plenty more opportunities to do that.

[Researcher\_1] 1:56:17

So that's great. One of the questions that we always do end up throwing in, just to close up is, is there anything that you thought? ‘Why haven't asked about this?’ ‘Or I really wish they asked about this? Because it'd be really good insight?’, So is there anything that you feel it be useful to tell us that maybe we haven't touched on?

[pwCF\_2] 1:56:52

I think maybe breadth of what you're looking for, needs to maybe always be considered and widened as much as possible, especially now, Kaftrio, for those who are on it, is making some slightly strange situations. Or, you know, there's always kind of a focus on the most common and the easier to grow and the most prevalent, but being broad. Now, you know, there's, there's lots and lots of bacteria. I know, sorry, I'm sorry, that sounds patronising. I think I said that very badly. But breadth is just something I think we'll we would all like.

[Researcher\_1] 1:57:32

No, absolutely. That's great, thank you.

[pwCF\_4] 1:57:37

I feel like it's talking about almost everything really. I think probably just to reiterate, this isn't just a CF thing. I think this is just the NHS in general, that personalised medical, like personalised treatments, diagnosis, everything, is probably the key because not just in terms of, because some people get certain symptoms at all, but the level of treatment everybody's willing to take, and the outcomes and all different patients want are probably quite different. And there'll be a middle ground for everybody, which is different, where you're not necessarily having the best treatment. But if you're happy and able to get on with your life as you like, then that is fine. And it needs to be personal to the individual rather than I guess the way it's structured now, which is we've identified bug X, this is the perfect treatment, you must have it, or we recommend you should have it, it needs to be coming down somewhere in the middle.

[Researcher\_1] 1:58:41

Absolutely, that's a great insight. And I think a few people touched on that earlier as wel, refusing to take part in in a trial because it was too invasive or because it took too much of the time and I think that flexibility is very important going forward. Definitely. Thank you for that [pwCF\_4].

[Facilitator\_1] 1:58:57

That's kind of the point that I was gonna say is that alignment and [pwCF\_4] you kind of mentioned it earlier as well. The alignment between care and research. And you know, I think you know, if what is being asked for in research is very familiar as part of care and if you know what is part of care is actually really useful to research so it doesn't have to be duplicated for research. I think some really important points to consider because like we've said people with CF are busy you know, they're busy with standard life, they're busy as [pwCF\_2] said with you know, having CF as an extra job as well. And I think you know if you can align as I say what is standard of care and research actually will make people's lives a lot easier. Absolutely.

[Researcher\_1] 1:59:52

That's probably a good place to wrap up is it [Facilitator\_1]?

[Facilitator\_1] 1:59:55

Yeah, unless anybody wants to chip in with anything but say you know, if you have any thoughts afterwards, let us know and you know, say we'll definitely keep in touch as the project progresses. And just to say thank you. Thank you so much for joining. Thank you for staying longer.

[Researcher\_1] 2:00:11

Absolutely. Thank you very much.

[Facilitator\_1] 2:00:13

And I hope you enjoyed it.

[pwCF\_4] 2:00:16

I'll see you all soon. Thank you. Bye, everybody. Bye bye.