

# A paradigm shift in cystic fibrosis nutritional care: Clinicians' views on the management of patients who have overweight and obesity<sup>1</sup>

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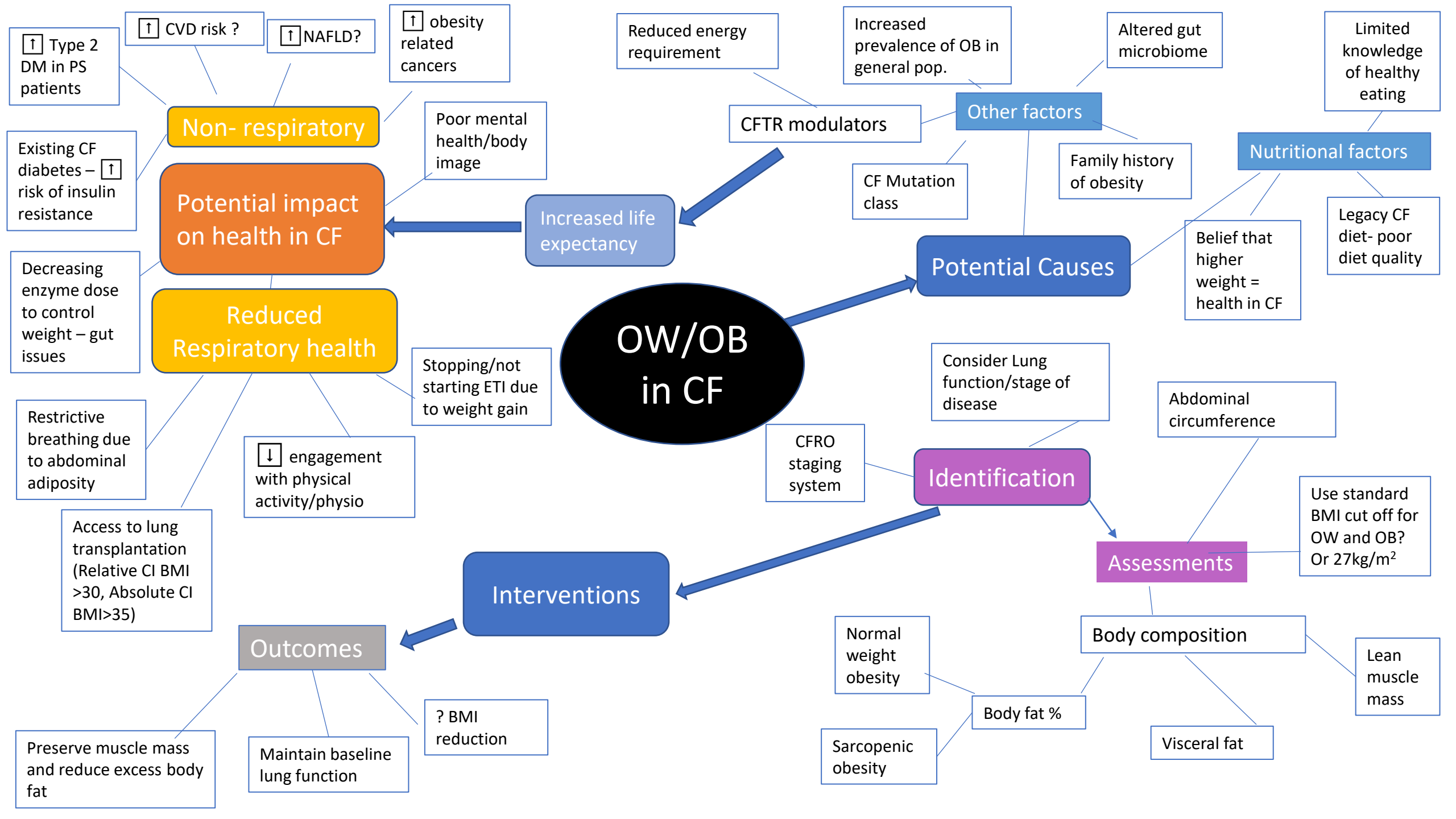
2001  
15% BMI  $\geq$  25kg/m<sup>2</sup>

2021  
36% - 40%  $\geq$  BMI  
25kg/m<sup>2</sup>

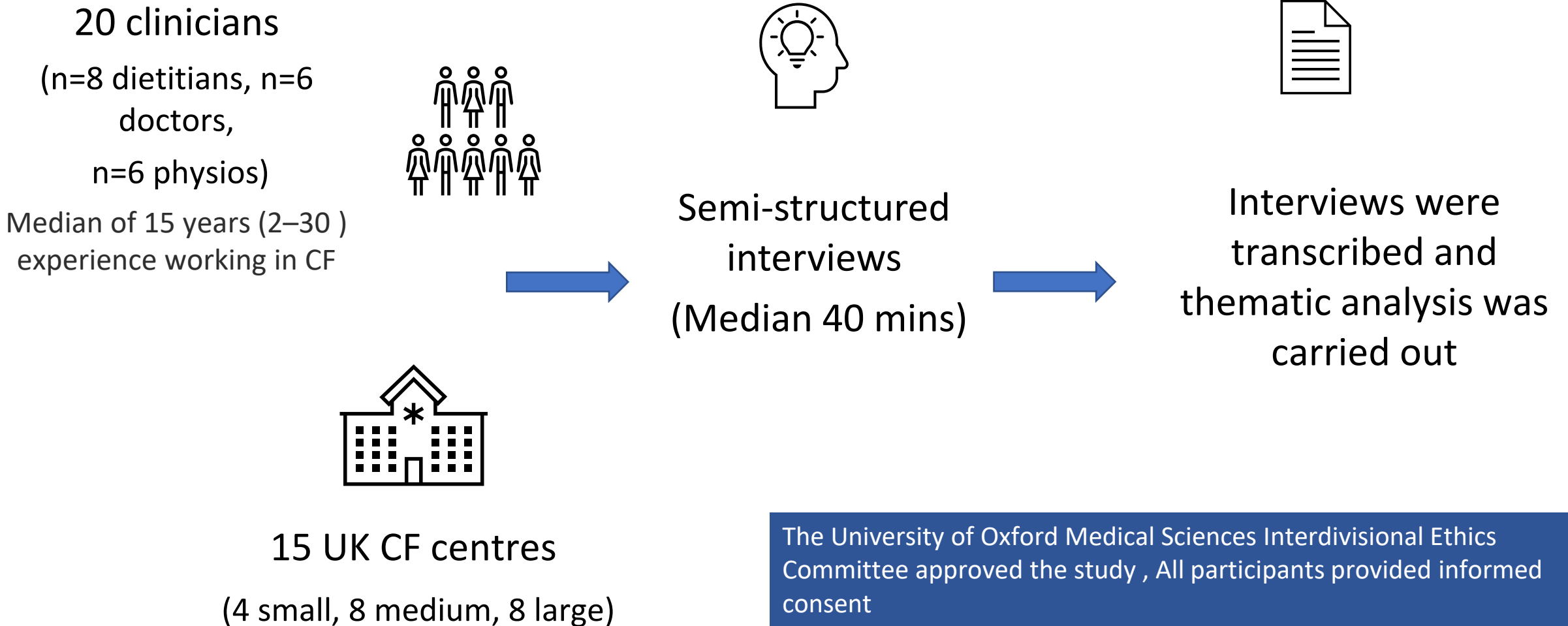
2019  
CFTR modulators

Survival = 32  
years

Survival = 53  
years

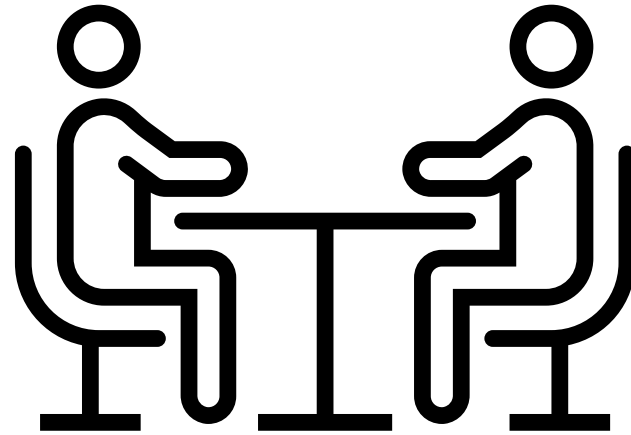


# Methods



The University of Oxford Medical Sciences Interdivisional Ethics Committee approved the study, All participants provided informed consent

# Challenges of raising the topic of overweight and obesity in the CF clinic



Existing clinician–patient rapport guided the initiation, tone and content of the discussion around excess weight

*I'd say some pwCF very confident if I have a really good rapport with them anyway. I know what their response is going to be and then other times I feel really not confident because I don't want to cause problems. (Dietitian 5)*

*I've been on one particular ward round where the consultant has brought up somebody's weight [...] once we left, we had to go in and apologise because she was really upset about it and was like 'I know I'm overweight, I don't need someone to tell me that' (Physio 3)*

# Concern about weight stigma and negative mental health effects led some clinicians to wait for patient-initiated conversations

*I mean, it always depends on the patient, doesn't it? And there's those that are forthright and open and absolutely, "oh my God, look at the size of me?" You know, that's easy, isn't it? (Physio 6).*

*Some people don't like it even when you bring it up ...they find it really hard, I find it really hard to talk to people I've known them for such a long time.... the overweight ones just do not want to talk about losing weight. (Dietitian 8)*

*I tend to avoid obese because that comes with a stigma, so we try and even if they're obese, I guess talk around that they're overweight and branching it into the next category (Dietitian 3)*

# Ways of raising the topic of excess weight differed among professional groups

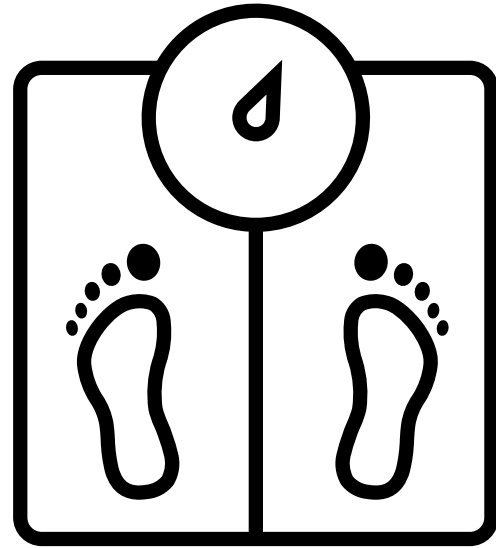
*They say “Oh I'm too breathless for physical activity, I can't do it, I can't climb a flight of stairs” etc.... I might say well I noticed that you've put on a couple of extra kilos, perhaps sometimes if we think about how we can reduce some of that weight, then that might make it a bit easier for you to do those tasks. (Physio 1)*

*We're really focused on lots of other things but actually the weight thing may end up becoming much more relevant and it may be on the top priority of the patient, we need to get a bit better at presenting patients some data about what are some of the risks about having a BMI over this etc. (Medic 3)*

*I would use the BMI categories and I would say that you're going towards that category now... you've got to be careful, and you need to be watching your calories. (Dietitian 7)*



# The changing landscape of assessment due to CF-specific causes of weight gain



# Importance of understanding the historical context of how pwCF think about diet and realisation that CFTR modulators are changing CF nutritional care

*I think for some of these people there's going to be an element of actually giving them permission to eat less. If you're in your late 20's and your doctor has for the last 20 years been badgering you to eat more... and then a switch within a year when they are telling you the exact opposite, that's going to be one hell of a habit to break I suspect (Medic 1)*

*One of the things that they say is "I never had to think about food, before it was like the silver lining of CF is that I could eat whatever I wanted and suddenly I've got all these benefits [of ETI] but I'm having to restrict my diet." (Physio 4)*

*Everything that's happened in the last two years with the modulators and lockdown it feels that every patient I'm seeing now has gained 10 kg. (Dietitian 2)*

# Complementing BMI with body composition and weight trajectory assessments was considered useful

*We look at it over trends, so if somebody is just gaining a kilo since the last time, we'd seen them 3 months ago.... I wouldn't even raise an eyebrow.... if they've been gaining a kilo every six weeks and it was now up to about 10 kg, then that's clearly very different. (Dietitian 2)*

*We have got the facility to do bioimpedance testing and that's really helpful because it allows them to see “Oh look actually my percentage of fat is actually X above what would be considered healthy” then it gives them a different perspective to think about rather than just weight. (Medic 2)*

# Assessment of overweight and obesity was perceived as a team effort, but management was currently perceived as dietitian led

*It's a three-pronged approach, isn't it. If the dietitians are modifying their dietary intake, as the physio is encouraging them to do more exercise, and the doctor supporting both of those two colleagues[...] So, it's a three-way dialogue and I don't really mind who starts it. (Medic 1)*

*The doctor has got the overarching responsibility, so I don't think it should just be dietitians who are thinking about it [weight management] otherwise it seems like they are the 'food police' in the corner... (Dietitian 1)*

*I think it needs to come from the whole of the team so that you're all saying the same thing. But it doesn't always happen. (Dietitian 8)*

*I probably don't think it's my responsibility. It would be more I would say our dietetic colleagues who would be weighing them ... because I don't want to encroach on other people's roles (Physio 5)*

# Clinicians reported that pwCF may avoid dietetic review due to weight management discussions

*There are times there are some patients that have come to clinic and maybe it is with the weight gain, I don't know, but they don't want to see the dietitian at clinic (Physio 5)*

*Sometimes I think some patients choose the physios to have those conversations with and they can be selective about who they talk to [about weight issues], so if they don't want to talk to the dieticians about it but seem to want to talk to us about it (Physio 4)*

Presence of clinical equipoise for weight management due to the lack of CF-specific evidence on the consequences of obesity and intentional weight loss



# Tension between negative aspects of rapid weight gain and weight gain traditionally representing good health for people with CF

*Some people, without doubt you know, it [CFTR modulator] puts them into an unhealthy weight category... and they just really struggle, and we've had a small number that have had to stop it because they just can't cope with that anymore... which is obviously quite a big deal considering the potential benefits for all other aspects of CF. (Medic 5)*

*A big notice point with our patients is they're often quite reluctant to lose weight because of wanting that insurance weight in case they get unwell (Dietitian 3)*

*We do ask everyone in clinic 'how you feel about your weight'? just to kind of get their perspective on it and to be honest with you [...]. if they turn round and say "Oh yes, it's great, you know... where they've got a BMI of 27 and it's still rising, you know you don't want to burst their bubble. (Dietitian 2)*

# Unclear impact of excess weight on respiratory outcomes and development of co-morbidities in CF

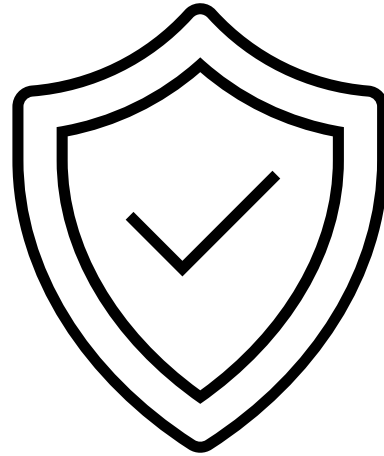
*We clearly know that people who are obese in the general population have much worse respiratory outcomes, obviously there's no study yet in CF saying what's going to happen to people with a BMI of 30 plus with CF, versus those with a BMI of 25. (Medic 4)*

*Rush forwards the 10-15 years... I do think it's [weight management] is going to be ... One of the main problems we deal with in CF potentially. (Medic 3)*

*There's definitely an increasing proportion of patients with fatty liver syndromes and I don't think that's just CF liver disease, some of it I truly believe is a second hit from diet and lifestyle. And in the general population up to 25% of people with fatty liver develop Cirrhosis[...].and there's all these the well-known complications of obesity in the general population, cancers, there's been a lot of discussion about the risk of cancer in Cystic Fibrosis, particularly gastrointestinal. (Medic 5)*



# Opportunities for a safe, effective, and acceptable weight management approach for pwCF



CF teams have the required professionals to deliver weight management interventions but may lack knowledge, skills, and time

*The CF patients already have an established relationship with us as a team... And sometimes it's easier to talk to the people that you know, than branch out and go to another group of people who you've got to explain everything to...(Physio 1)*

*We're starting to approach it with patients but it's quite difficult because I don't have a lot of experience in weight management. (Dietitian 5)*

*I don't know if clinics the right place because sometimes you only have a very short time and if somebody's desperate to see a doctor, you know whatever you say they've probably forgotten it by the time the doctor comes in. So, I think we might need to think about how we deliver our care in future going forward (Dietitian 2)*

# Lack of consensus around potential dietary approaches for weight management in CF due to minimal evidence base but CF specific adaptations should be explored

*We've quite a few pwCF have had a real success with [group-based commercial weight management programme] ... if it's something that's a balanced healthy approach and it's offering the results that the patient wants to achieve then we try and support them with that and make sure that they come to us if they've got any questions about any aspect of it as well. (Dietitian 4)*

*In past years we've always just encouraged our patients to sort of just eat... All the time so extra snacks, extra high calorie drinks, often their appetite is really, really poor. So, they're kind of overriding cues when they're not hungry and they're forcing themselves to eat constantly.... so probably some of them are out of sync. I'm keen to go on courses particularly around intuitive eating and mindful eating and non-weight approaches to healthy eating (Dietitian 5)*

# Strengths and Limitations

## Strengths

- First exploration of clinician views on this emerging topic
- In-depth semi structured interviews
- Wide perspective from different experience , size of centre, professions – most were experienced but this is typical in UK CF clinical community.

## Limitations

- Findings are not generalisable but provide insight
- UK only – no international perspective
- No psychologists or specialist nurses included

# Conclusions and next steps

- Approaching weight management in CF is complex – may require more time than available in routine appointments.
- Need to conduct further qualitative research to explore the perspectives of pwCF regarding management of OW/OB – help to develop interventions.
- Identifying high-risk individuals (including those with milder CF mutations and/or family history of obesity) should be explored to allow early intervention perhaps in paediatrics.
- Need to develop safe, acceptable, and effective interventions that are sustainable within the CF care model to support people with CF who are living with overweight or obesity

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