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### Appendix I: Questionnaire

- 1. Do you consent to participate in this study? Yes/No
- 2. Are you over the age of 18? Yes/No

Note: This survey is only for people aged 18 and over.

- 3. Male \_\_\_ Female \_\_\_\_
- 4. How many natural teeth do you have? No natural teeth / 1-9 teeth /10-19 teeth/ 20 or more teeth
- 5. During the past 12 months, did your teeth or mouth cause any pain or discomfort?

  Y/N/Don't know
- 6. Are you a regular attender? If so how regular- every 3, 6 or 12 months?
- 7. What was the reason for your last visit to the dentist? Routine exam/pain/treatment etc.
- 8. Are you happy with the appearance of your teeth? Yes/No/Don't know

  If no, please explain \_\_\_\_\_\_
- 9. In relation to CF, are you anxious/ worried attending your dentist? Yes/No/Don't know. If yes, why?
- 10. Do you make the dental receptionist aware of your CF status when scheduling an appointment? Yes/No/Don't know
- 11. Are there any precautions you take when attending your dentist? E.g schedule appointment for first thing in the morning/ minimise contact with other patients? Yes/No/Don't know
- 12. Do you believe that CF has impacted on your oral health in any way?e.g. too tired to brush your teeth during bouts of illness etc.

In relation to CF, are you anxious/ worried attending your dentist?

Why do you feel this way regarding attending the dentist?

What do you feel is important for dentists to know about the condition?

- 13. Are you employed? Full Time employment or part time employment?
- 14. Are you in receipt of a social welfare benefit? If so, what one- Disability Allowance, Illness Benefit etc.
- 15. What level of education have you completed? No formal schooling/Less than primary school/Primary school completed/ Secondary school completed/High school completed /College or university completed/Postgraduate degree

Appendix II: Do you believe CF has an impact on your oral health? If yes, what impact has it had?

Medication	Caused vomiting
	some treatments cause vomiting, cannot
	brush due to vomiting
	when on some meds-nausea due to tb
	meds causing discolouration
	meds causing discolouration
	after IVs-more plaque
	dry mouth from meds
	dicolouration
	staining and discolouration
	inhaled meds weakened my teeth
	tired-need energy, go for sugar snack
	tablets and nebs causing problems
A/bs	Cause staining
	Eroding teeth
	Cause discolouration
	Caused needing many fillings
	Cause lost enamel

	sugary diet, sugary meds
Tiredness	Tired
	too tired
	tiredness, less energy at night
	on IVs weakness and ill-no energy
	when sick, too much energy to brush
	no energy to brush teeth, "I remember
	having to ask my mum to brush them for
	me."
	too tired
	tiredness and depression
	too tired to brush and floss
	too tired
Diet	dicolouration
	eat a lot of sweet to get calories in
	addicted to sugar
	poor taste so eat strong flavours with high
	fat and sugar
	eating jellies and OJ to treat hypos since
	developing CFRD

CF	tummy issues causing bad breath and
	erosion
	missed appts due to being unwell
	unable to brush teeth when unwell

# Appendix III

Thematic analysis: Are you anxious regarding attending the dentist? If yes, why?

## <u>Theme</u>

Dentist-related issues	"I have previously been treated with lack of
	understanding from dentists/hygienists"
	"fear I will be judged by the dentist"
	"fear of dentists"
	"I am always in trouble when I attend"
Cross-infection concerns	'Cross-infection due to sink at dentist chair"
	"risk of infection- I did not feel this way
	before but I do now in light of Covid-19"
Concerns regarding dental treatment	"I find it difficult to be in a flat position as it
	affects my breathing. It's also very difficult
	not to cough"
	"Chair tilted back, might induce a cough
	when dentist working closely"
	"fear of extractions and the injections
	required into gums"
Problems with teeth	<u>"embarrassed about my teeth"</u>

	"I feel my teeth are going to break soon
	sometimes"
CF related problems	
	another thing wrong with my teeth"

Appendix IV: What do you think is important for the dentist to know about CF?

Theme	Select Quotations
Practicalities of dental	That it is often difficult for people with cf to lie down and not
tx	cough for long periods of time.
	that we need to be in an upright condition.
	It would be great to do the treatment upright and have multiple
	breaks
	When i need to cough he stops, not lying too flat back in chair
	Possible breathing difficulty when in chair if patient has
	infection.
	My dentist is very good and tilts chair upright and also pauses
	when I indicate I need to cough. It slows process but get us very
	understanding and allows time
	That I can't lie flat or sometimes breathe through my nose quick
	enough
	Extra breaks may be needed, my dentist/hygienist are good
	when it come to that!
	Difficult to lie in one position for a long period of time, may need
	breaks for coughing
	Sometimes it is hard for people with cf to sit in the dental chair
	in the drainage position as it can cause coughing fits

	Would have liked option to sit more upright during prolonged
	treatment, felt this was where I was exposed to risk of
	aspiration
	In case I cough during the procedure.
	Position of chair. Breaks needed for coughing.
	Lying back can induce bronchospasm
Impact of	All the nebs we inhale we take could definitely have a part in
medication/tx/diet	destroying our teeth
	Affects from antibiotics / diet
	The full extent of the treatment required that may impact the
	teeth, gums and tongue. That some medication is delivered via
	inhaler and nebuliser.
	before lecture on oral hygiene sweets etc CF patients need to
	maintain weight.
	More about the impact of our long term medication has had on
	our teeth and about cf in general
	CF dietary requirements,
	Impacts of antibiotics on tooth heath
	discolouration from medication
	The effect different meds have on oral hygiene
Impact of CF	About cf in general and how cf has impacted out oral health

Antibiotic use in CF, dietary requirement in CF, cross-infection risks in CF and CF vulnerability to pseudomonas especially

How badly it affects your teeth

Yes due to calcium deficiency

To have an understanding really would be a good start.

All of it and the impact it has on our health and mental health and how that could relate to our dental hygiene/care/condition Infection ,low immune system

### **Cleanliness/sterility**

of dental surgery

Cross-infection of patients with CF

pre and post transplant care.

Going forward the importance of ppe when a cf patient is

undergoing treatment

Clean lines, cross-infection

That of a member of staff has a cold, cough or flu I will not

attend.

cross-infection risks, especially infection risk from pseudomonas

### <u>Abbreviations</u>

**CF- Cystic Fibrosis** 

DDE- Developmental Defects of Enamel

PWCF- People with CF