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What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?

Welcome to our survey

What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?

This was recently chosen by the CF community as one of the top 10 questions to be answered by research.

If you are a person with CF, a parent of children with CF or a Healthcare professional working with CF, please help us answer this by taking part in the following questionnaire as honestly as you can.

Please be assured that this survey remains completely anonymous. This means that you will not be identifiable from the answers you provide. If you leave your contact details for further involvement activities these will be separated from your survey answers before they are looked at.

Many thanks,

The Evidence Based Child Health Team at The University of Nottingham, UK

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Privacy notice

QuestionCF: Research participant privacy notice

Privacy information for Research Participants

For information about the University's obligations with respect to your data, who you can get in touch with and your rights as a data subject, please visit: <https://www.nottingham.ac.uk/utilities/privacy.aspx>

Why we collect your personal data

We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are to run a research project to identify areas for future research into cystic fibrosis.

Legal basis for processing your personal data under GDPR

The legal basis for processing your personal data on this occasion is Article 6(1a) consent of the data subject.

Special category personal data In addition to the legal basis for processing your personal data, the University must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

The basis for processing your sensitive personal data on this occasion is Article 9(2a) the data subject has given explicit consent to the processing,

How long we keep your data

The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research. Measures to safeguard your stored data include deleting all personally identifiable data e.g. name, address, contact phone numbers as soon as we no longer need to contact you in relation to the project. We will also separate this identifiable data from survey responses so that study results will be anonymous and non identifiable.

Who we share your data with

We will not share your identifiable contact data with anyone outside the study team.

* 1. Please read our privacy notice and then tick the box if you are happy to continue

I have seen and understood the privacy notice

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What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?

*** 2. Are you**

- A person with CF
- A parent of a child / children with CF
- Spouse or partner of a person with CF
- Other relative or friend of a person with CF
- A Healthcare professional looking after people with CF

Thank you so much for helping us by completing this questionnaire.

Please click below to submit your answers

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Treatment plan

We are aware that living with CF brings different kinds of challenges and there are times when things can be more difficult than others. These difficulties may or may not be related to CF but it can affect how well you/your child take(s) treatments. We are interested in hearing from you about what the challenges of sticking to treatments are, and about ways you have found that help you and your family keep to your treatment plans.

3. In our survey of treatment burden 70% of you said that you sometimes miss treatments if you are busy or tired. How often do you do all your/your child's treatments exactly as suggested by your CF team?

- Every day
- 4-5 days a week
- 2-3 days a week
- One day a week
- Never
- Other (please specify)

4. Are there things which make it more difficult to stick to your/your child's treatment plan (please tick all that apply)

- School/College/work commitments
- The amount and type of treatments you/your child are/is on
- When you/your child are feeling more unwell (e.g.when you have an exacerbation)
- When you/your child are feeling well
- When you don't feel the treatment regime is making you/your child feel better
- The amount of preparation/cleaning of equipment needed
- Side effects of treatments
- Other (please specify)

5. What is the biggest thing in your life that makes you not stick to your treatment plan?

6. Is there anything that would help you to stick to your treatment plan better?

- Yes
- No

If yes, what sort of things would make it easier?

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Motivation

7. What sort of things do you do to help motivate yourself / your child to carry out the treatment plan.

- Use of rewards / bribes
- Planning activities during treatment e.g. Xbox games, watching TV
- Setting long term goals / targets
- Setting short term goals / targets
- Use of electronic devices such as trackers and reminders
- Having a routine that treatment regimens are built around
- Writing lists an/or keeping journals to help remember treatments
- Having strong role models
- Being organised and premixing/preparing medications in advance

Please tell us about anything else you/your child do to keep you motivated to doing treatments.

8. What things make it difficult to stay motivated? Please tell us anything that comes to mind.

9. Do you have support with your/your child's CF from

- Your immediate family?
- Other relatives and friends?
- Your CF Team?
- Support on social media (e.g. Facebook, Instagram, Twitter etc)
- Support groups (online or in person)?
- Online forums e.g. Childline?

Please tell us any other forms of support you have

10. Do you get the support you need for your adherence to treatments from your CF team?

- Yes, I feel well supported by my CF Team
- Yes, I feel partly supported by my CF Team
- No, I don't feel supported by my CF Team
- Other (please specify)

11. How well do you understand what your/your child's different treatments are needed for?

- I know what everything is for
- I know what some of my/my child's treatments are for
- I don't know what any of my/my child's treatments are for
- Other (please specify)

12. Does it make it easier to stick to treatments when you know what they are for?

- Yes
- No

Please tell us more about this

13. Do you feel able to talk honestly with your CF team about how often you/your child do your treatments?

- Yes
- No

Please tell us more about this

14. Do you feel that your CF team understand the difficulties of completing a full treatment plan every day?

- Yes
- No
- Other (please specify)

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Technologies

15. Do you / your child use any form of technology to help you manage your / your child's treatment regimen?

	Suggested by a health professional	Found/bought yourself
Apps	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>
Monitoring e.g. smart watches, exercise trackers, inebts	<input type="checkbox"/>	<input type="checkbox"/>
Games e.g. XBox, playstation, videogames	<input type="checkbox"/>	<input type="checkbox"/>
Electronic reminders	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us more about the technology that you use to help you manage treatments

16. How do the technologies in the question above help you / your child to stick to your treatment plan? Tell us anything about how they help you (or not).

17. What happens to the information you get from such technologies?

- I use the information for myself to monitor my/my child's health
- I use the information to monitor my/my child's health and adjust my/my child's treatment plan
- I share my/my child's information with my CF Team e.g. lung function measurements
- I share my/my child's information with other people with CF

Please tell us anything else about the information you get from technologies

18. Do you / your child use any apps or activity trackers to monitor physical activity?

- Yes
- No

Please tell us more about what you use and whether you find it helpful.

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Research

19. Would you be happy for yourself or your child to take part in a trial of technology to help manage CF treatment?

20. Are you already taking part in a trial of a new or existing technology?

- Yes
- No

If yes, please tell us more about this

21. Which technology would you like to see introduced into CF care?

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Health Care Professionals

22. Which professional group are you a member of?

- Physiotherapist
- Respiratory Paediatrician
- Respiratory Physician
- Gastroenterologist
- General Practitioner
- Junior Doctor
- Nurse
- Dietitian
- Psychologist
- Pharmacist
- Researcher
- Social worker

Other (please specify)

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Adherence & motivation

23. Could you tell us what factors you think affect how well your patients adhere to their treatment plans?

24. What sort of things do you do to help motivate your patients to carry out their treatment plan?

- Use of rewards / bribes
- Suggesting activities during treatment e.g. Xbox games, watching TV
- Setting long term goals / targets (months and years)
- Setting short term goals / targets (days and weeks)
- Suggesting use of electronic devices such as trackers and reminders
- Suggesting a role model as an example to look up to
- Suggesting that treatment regimens are built around normal routines
- Suggesting writing lists and / or keeping journals to help remember treatments

Please tell us about anything else you do to keep your patients motivated to doing treatments.

25. Have you found any specific strategies to improve adherence in your patients?

26. In your clinical practice, do you do joint goal setting as a way to promote adherence?

- Yes
- No

Please tell us more about how you achieve this?

27. Do you talk to your patients about the barriers that make it hard for them to take their treatments?

- Yes
- No
- Other (please specify)

28. If yes, how often do you incorporate this into your reviews?

- Every time
- Sometimes
- Never

Please tell us more about this

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Technology

29. Do you promote the use of technologies to help improve adherence within your clinical practice?

- Yes
- No
- Other, please tell us more

30. If yes, please tick all that apply

- Websites
- Monitoring e.g. smart watches, exercise trackers, inebts
- Games e.g. XBox, playstation, videogames
- Electronic reminders

Please tell us about any other technology that you use to help your patients manage treatments

31. Which forms of technology are your patients using to help them manage their/their child's treatment regimen?

	Suggested by yourself or another health professional	Suggested/used by the pwCF
Apps	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>
Monitoring e.g. smart watches, exercise trackers, inebts	<input type="checkbox"/>	<input type="checkbox"/>
Games e.g. Xbox, playstation, videogames	<input type="checkbox"/>	<input type="checkbox"/>
Electronic reminders	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us more about the technology that you use to help you manage treatments

32. How do you see technology being used in the future to help promote adherence? Please tell us more about this

33. What happens to the information you get from such technologies?

- It is kept and used by the pwCF to monitor their/their child's health
- It is kept and used by the pwCF to monitor their/their child's health and adapt their treatment plan.
- The information is shared with the CF Team e.g. lung function measurements
- The information is shared with the CF Team in an interactive way to adapt the treatment plan

Please tell us anything else about how electronic information is used

34. Are you involved in or aware of any trials of technologies for managing CF treatment and improving adherence?

- Yes
- No

If yes, please tell us more

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Final page

Thank you for your help so far, please tell us a little bit about yourself and finally if you have any additional ideas about how we can answer this question.

35. Age in years of person filling in survey

36. Age in years of person with CF (if parent/family)

37. Which country do you live in?

38. Would you be interested in continuing to be a Question CF contributor by taking part in future surveys? If you agree to us contacting you again, please tick the yes option below to allow us to keep your contact details (as per GDPR, we will store your contact details separately from your survey responses and will not share your details with any other organisation).

Yes (please leave your email in the comment box below)

No thank you

39. Would you be interested in becoming a member of the Question CF advisory group for the opportunity to take part in more in depth discussions and designing of research trials? (via phone or internet). If you agree to us contacting you again, please tick the yes option below to allow us to keep your contact details (as per GDPR, we will store your contact details separately from your survey responses and will not share your details with any other organisation).

Yes (please leave your email in the comment box below)

No thank you

40. email address

41. If you would like to suggest an idea for a research trial to look into effective ways of motivation, support and technologies to help people with CF adhere to treatment, please feel free to write your suggestion here

Thank you for your contribution, it is very much appreciated

please click below to submit your answers