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CF Outcomes Initial survey

Please complete the survey below.

Thank you!

What is your postcode?

What is your gender?

- Male
 Female

Please identify which group you belong to?

- Adult with Cystic Fibrosis >25 years
 Young person with Cystic Fibrosis 18-25 years
 Young person with Cystic Fibrosis 13-18 years
 Carer of person aged 0-18 years living with CF
 I don't belong to any of these groups

Participant Information Sheet.
Please read before continuing.

[Attachment: "Cystic Fibrosis Health Outcomes Prioritisation Survey PIF.pdf"]

If you are aged 13-18 years, you will also require guardian consent to participate in this survey. Please enter the following information so an information sheet and consent form can be sent to your guardian to complete via email attachment. The consent form will also need to be signed by you

Your name

Your email address

Your guardian's name

Your guardian's email

If you do not belong to any of the above-mentioned groups, or if you would like further information, please contact Charlie McLeod on E: charlie.mcleod@health.wa.gov.au or M: +61 0428 899 886.

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Online Consent form (>18years)

Please complete the survey below.

Thank you!

Please read and complete the consent document below

Online Consent form >18 years Prioritisation of CF-related Health Outcomes Survey

Research Sites: Perth Children's Hospital and Telethon Kids Institute

Study team: Dr Charlie McLeod, Dr Tom Snelling, Prof Steve Webb, A/Prof Richard Norman, Dr Andre Schultz, A/Prof Julie Marsh, Steven Mascaro, Mitch Messer, Grace Currie, Jamie Woods, Dr Siobhain Mulrennan, Carly McCallum, Ms Kate Spaapen.

In giving my consent to participate in this survey, I agree/understand:

- I have read the participation information sheet and understand the purpose of this study and what is required of me
- Participation is voluntary and I don't have to take part
- I may choose to exit the survey prior to submitting my responses, but after this time it will not be possible to withdraw my responses
- All information collected will remain confidential, which means no one will be able to identify me and my health care will not be affected whether I take part or not.
- I understand my email will be stored securely on the survey database, will be accessible to study investigators only, and will remain confidential within this group.
- I understand there is a small possibility that being asked to think about outcomes relating to CF may result in some emotional distress. I have been advised to contact my GP, CF clinic, or crisis care support if this occurs.
- Results of this study, including my email account details, will be kept for 5 years or until I turn 25 years old, whichever takes longer (this is a legal requirement).
- I am happy for results of this study to be printed in medical journals and be given to relevant groups including CF research networks and consumer groups to pass onto interested parties, via electronic or hard-copy reports.
- I have been given the opportunity to ask questions about this study and am satisfied with the answers I have received.
- If I have further questions I can contact the study team via charlie.mcleod@health.wa.gov.au or Charlie McLeod on 0428 899 886. If I have concerns about the conduct of this study, I should contact the Executive Director of Medical Services at the Child and Adolescent Health Service on +61 8 6456 2222.

Do you consent to all of the above?

- Yes
 No

Name

Date consent signed

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Please click "Add signature" and sign here

Are you happy to be contacted by a member of our research team in the future to consider being involved in further CF-related research activity?

Yes

No

If yes, please provide your email address

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Online Consent form (13 to 18 years)

Please complete the consent form below together with your child.

Thank you!

Please read the attached participant information sheet, then complete the consent information below

[Attachment: "Cystic Fibrosis Health Outcomes Prioritisation Survey PIF 13 to 18yrs.pdf"]

Participant Information, please read carefully.



Participant and Guardian Consent for 13 - 18 year olds
Prioritisation of CF-related Health Outcomes Survey

Study team: Dr Charlie McLeod, Dr Tom Snelling, Prof Steve Webb, A/Prof Richard Norman, Dr Andre Schultz, A/Prof Julie Marsh, Steven Mascaro, Mitch Messer, Grace Currie, Jamie Woods, Dr Siobhain Mulrennan, Carly McCallum, Ms Kate Spaapen.

In giving our consent to participate in this survey, we agree/understand:

- We have read the participation information sheet and understand the reason for this survey and what I/the child I am legally responsible for is required to do
- Participation is voluntary and I/ the child I am legally responsible for doesn't have to take part
- I/the child I am legally responsible for may choose to exit the survey before I/they submit the answers, but after this time it will not be possible to withdraw my/their responses
- All information collected will remain confidential, which means no one will be able to identify me/the person I am legally responsible for and my/their health care will not be affected if I/they take part.
- I understand there is a small possibility that being asked to think about outcomes relating to CF may result in some emotional distress. I have been advised to contact my/their GP, CF clinic, or crisis care support if this occurs.
- The child I am legally responsible for will need to provide their email for the survey to be issued, and to link survey responses to the provided consent form. This information will be stored securely on the survey database, will be accessible to study investigators only, and will remain confidential within this group.
- Results of this study, including email details, will be kept for 5 years or until I/the person I am legally responsible for turns 25 years old, whichever takes longer (this is the law).
- I am happy for results of this study to be shared. This includes through medical journal publications and with CF groups, via electronic or hard-copy reports. I understand I/the child I am legally responsible for will not be personally identified in these reports.
- I have been given the opportunity to ask questions about this study and am happy with the answers I have received.
- If I have further questions I can contact Charlie McLeod via E: charlie.mcleod@health.wa.gov.au or M: +61 0428 899 886. If you have questions, concerns or complaints regarding your child's participation in this research study or if you have any questions about your child's rights as a research subject, you should speak with the Executive Director Medical Services at CAHS via the switchboard on +61 8 6456 2222.

Do you BOTH consent to all the above?

- Yes
 No

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Name of Parent/Legal guardian providing consent

Date of Parent/Legal guardian consent

Signature of Parent/Legal guardian providing consent

Name of Adolescent (13-18 years)

Date of adolescent consent

Signature of Adolescent

Are you BOTH happy to be contacted by a member of our research team in the future to consider being involved in further CF-related research activity?

- Yes
 No

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Health outcomes prioritisation survey for individuals >13 years with CF

Please complete the survey below.

Thank you!

Please consider the following health outcomes that may occur resulting from treatment received for management of a Cystic Fibrosis pulmonary exacerbation. We want to know which outcomes are more or less important to you, recognising all outcomes have been identified as being meaningful to people affected by CF. Please attempt to provide answers to all questions.

	Extremely important	Very important	Somewhat important	Not so important	Not at all important
22) Inability to clear/cough up sputum	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23) Shortness of breath/difficult breathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24) Sputum production (presence of, or worsening from baseline)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25) Chest tightness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26) Coughing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27) Coughing up blood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28) Feeling unwell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29) Poor gut health (diarrhoea/bloating/flatulence)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30) Presence of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31) Feeling fatigued/deconditioned (having no energy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32) Poor exercise tolerance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33) Presence of fevers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34) Reduced/static lung function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35) Pulmonary exacerbations (more per year/shorter time till next exacerbation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36) Acquiring resistant organisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37) Inability to eradicate (get rid of) specific lung organisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38) Acquisition of specific lung organisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39) Cross infection during treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Sadness/depressed mood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41) Anxiety/worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42) Poor weight gain/weight loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43) Death resulting from treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44) Development of antimicrobial resistance (bugs that are hard to treat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45) Side-effect of treatment affecting kidney function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46) Side-effect of treatment affecting liver function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47) Nausea/vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48) Tiredness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49) Presence & severity of chills/sweats	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50) Presence & severity of wheezing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51) Difficulty sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52) Being worried about your CF	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53) Irritable/feeling cranky	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54) Reduction of usual activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55) Amount of school/work missed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56) Inability to meet personal/school/work goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57) Reduced ability to concentrate/think clearly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58) High treatment burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Health outcomes prioritisation survey for carers of children 0-18 years with CF

Please complete the survey below.

Thank you!

Please consider the following health outcomes that may occur resulting from treatment received by your child for management of a Cystic Fibrosis pulmonary exacerbation. We want to know which outcomes are more or less important to you/your child, recognising all outcomes have been identified as being meaningful to people affected by CF. Please attempt to provide answers to all questions, considering the impact of these outcomes FOR YOUR CHILD.

	Extremely important	Very important	Somewhat important	Not so important	Not at all important
59) Shortness of breath/difficulty breathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
60) Coughing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
61) Coughing up blood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
62) Chest tightness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
63) Wheeze	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
64) Sputum production (presence of, or worsening from baseline)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
65) Lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
66) Not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
67) Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68) Reduced exercise tolerance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69) Presence of headaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70) Poor appetite/eating difficulty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71) Poor weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72) Poor BMI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73) Nausea/vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74) Difficulty sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75) Reduced activity levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76) Presence of sweats/chills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77) Presence of fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78) Death resulting from treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79) Feeling sad/depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80) Feeling anxious/worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Reduced ability to concentrate/think clearly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82) Side-effect of treatment affecting kidney function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83) Side-effect of treatment affecting liver function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84) Poor gut health (includes abdominal pain, diarrhoea, flatulence)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
85) Impaired hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
86) Reduced/static lung function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
87) Pulmonary exacerbations (more per year/shorter time till next exacerbation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88) Unable to clear (get rid of) specific lung organisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89) Acquiring resistant (hard to treat) organisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90) Acquiring a specific bacteria/virus/infection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91) Cross infection whilst being treated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92) Feeling unwell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93) Feeling irritable/grouchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94) Reduction of usual activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95) Amount of school/work missed by child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
96) Inability of child to meet personal/school/work goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
97) High treatment burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>