

Front page

DESIGNING A SELF-MANAGEMENT PACKAGE FOR PULMONARY FIBROSIS: WHAT ARE THE ESSENTIAL COMPONENTS?

Thank you for your interest in our research study, which aims to achieve consensus regarding which components should be included in a self-management package for pulmonary fibrosis (PF).

Your responses are anonymous and confidential. We will only report group results of the study and in such a way that you will not be identified. Your participation is voluntary, and you are free to withdraw from the study at any stage.

This study is part of a PhD project supported by the National Health and Medical Research Council (NHMRC), Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF). Ethics approval has been received from Monash University with project ID - 27139.

By completing this survey, you agree that:

- You have read the information provided to you in the invitation email
- You have had an opportunity to ask questions and are satisfied with the answers received
- You understand that you can withdraw from the study at any stage.

You hereby consent to:

- Take part in this research study
- The use of the information provided by you in this study, which includes reporting of non-identifiable results in a thesis and any publications arising from

the study.

Introduction

. INTRODUCTION

This survey includes 2 sections:

Section 1 relates to self-management topics.

Section 2 relates to the format and delivery of a self-management package.

Section 1 explanation

. SECTION 1

Please indicate how strongly you agree that the following items are essential in a self-management package for people with PF.

For each item, please respond using the following scale:

Strongly disagree Disagree Neutral Agree Strongly
agree

You are welcome to provide any comments or suggestions regarding each item in the 'Comments' box under each question.

Q1

. Do you agree that the following items are essential for a PF self-management package?

. 1. Understanding PF - causes, pathophysiology and symptoms

Strongly Disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q2

. Do you agree that the following items are essential for a PF self-management package?

. 2. Understanding expected disease course and prognosis

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q3

. Do you agree that the following items are essential for a PF self-management package?

.

3. Understanding treatment options for PF

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q4

. Do you agree that the following items are essential for a PF self-management package?

.

4. Understanding and accessing clinical trials

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q5

. Do you agree that the following items are essential for a PF self-management package?

.
5. Managing medications (including side effects)

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q6

. Do you agree that the following items are essential for a PF self-management package?

.
6. Managing cough

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q7

. Do you agree that the following items are essential for a PF self-management package?

7. Managing shortness of breath

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q8

. Do you agree that the following items are essential for a PF self-management package?

8. Managing fatigue

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q9

. Do you agree that the following items are essential for a PF self-management package?

9. Role and importance of pulmonary rehabilitation

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q10

. Do you agree that the following items are essential for a PF self-management package?

10. Role of oxygen therapy

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q11

. Do you agree that the following items are essential for a PF self-management package?

11. Managing oxygen therapy

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q12

. Do you agree that the following items are essential for a PF self-management package?

12. Role and importance of vaccinations

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q13

. Do you agree that the following items are essential for a PF self-management package?

.

13. Recognising and managing an exacerbation

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q14

. Do you agree that the following items are essential for a PF self-management package?

.

14. Reducing the risk of an exacerbation

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q15

. Do you agree that the following items are essential for a PF self-management package?

.

15. Using an action plan

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q16

. Do you agree that the following items are essential for a PF self-management package?

.

16. Role and importance of regular physical activity

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q17

. Do you agree that the following items are essential for a PF self-management package?

17. Nutrition and dietary advice

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q18

. Do you agree that the following items are essential for a PF self-management package?

18. Smoking cessation advice and support

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q19

. Do you agree that the following items are essential for a PF self-management package?

19. Managing activities of daily living

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q20

. Do you agree that the following items are essential for a PF self-management package?

20. Managing comorbid medical conditions

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q21

. Do you agree that the following items are essential for a PF self-management package?

21. Managing mood (e.g. anxious or depressed feelings)

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q22

. Do you agree that the following items are essential for a PF self-management package?

22. Role and importance of social support

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q23

. Do you agree that the following items are essential for a PF self-management package?

.

23. Accessing peer support

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q24

. Do you agree that the following items are essential for a PF self-management package?

.

24. Accessing community support

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q25

. Do you agree that the following items are essential for a PF self-management package?

.

25. Advance care planning and advance directives

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q26

. Do you agree that the following items are essential for a PF self-management package?

.

26. Accessing reliable information about PF

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q27

.
Are there any other components that you think should be included in a self-management package to support people with PF in managing their health?

Yes

No

.
If you answered 'yes', please provide some more details in the comments box below.

Section 2 explanation

. **SECTION 2**

The following questions relate to the format and delivery of a self-management package for people with PF.

Q1

. Do you agree with the following statements?

.
1. The components of a self-management package must be tailored to each specific PF diagnosis (e.g. IPF, HP, CT-ILD)

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q2

. Do you agree with the following statements?

. **2. The self-management component/s delivered to the patient must be tailored to their specific needs**

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q3

. Do you agree with the following statements?

.
3. A self-management package must be delivered with support from a healthcare professional (e.g. using telehealth or face-to-face consultations)

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q4

.
Do you agree with the following statements?

.
4. A self-management package must be delivered by a multidisciplinary team

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q5

. Do you agree with the following statements?

.
5. A self-management package for PF can be effectively delivered using independent and self-paced learning

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q6

.
Do you agree with the following statements?

.
6. A self-management package for PF can be effectively delivered remotely (e.g. via an app or website)

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q7

. Do you agree with the following statements?

7. Goal setting and feedback are essential for effective self-management in PF

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q8

. Do you agree with the following statements?

8. Patient access to personal health information (e.g. lung function results, step counts) is essential for effective self-management in PF

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

. Comments:

Q9

Do you have any other comments about the format or delivery of a self-management package for people with PF?

Yes

No

If you answered 'yes', please provide some more details in the comments box below.

Demographics**DEMOGRAPHICS**

Please answer the following questions about yourself.

1. Please indicate your gender

Male

Female

2. Please indicate your age

Less than 25 years

25 - 35 years

36 - 45 years

46 - 55 years

Greater than 55
years

3. Please indicate your work role/s (choose all that applies)

- Physician
- Nurse
- Researcher
- Allied Health Professional - please specify
- Other - please specify

4. Please indicate which area of the world that you practice in

- Australia / New Zealand Europe North America South America Asia Africa

5. What is your experience in providing care to people with PF?

- Less than 5 years 6 - 10 years 11 - 25 years More than 25 years I don't provide direct patient care

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