

## Early View

Original research article

# Developing a self-management package for pulmonary fibrosis: An international Delphi study

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## Title Page

### Developing a self-management package for pulmonary fibrosis: An international Delphi study

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**Take home message**

This study identified 12 components deemed essential for self-management in PF. People with PF emphasised the importance of physical activity and managing mood. Individualisation, goal setting and feedback were important for effective self-management.

## **Abstract**

**Rationale:** Self-management is considered as an important part of disease management for people with pulmonary fibrosis (PF) but there is a lack of consensus regarding what components should be included. This study aimed to attain consensus from experts in PF and people living with the disease on the essential components and format of a PF self-management package.

**Methods:** A 2-round Delphi process was conducted. In each round, a panel of experts completed an online survey to rate a range of components, formats and delivery methods, followed by an online patient focus group to integrate patient perspectives. Consensus was defined a priori.

**Results:** Forty-five experts participated in round one and 51 in round two. Both focus groups included six people with PF. Twelve components were considered essential for self-management in PF: 1) understanding treatment options; 2) understanding and accessing clinical trials; 3) managing medications; 4) role of oxygen therapy; 5) role and importance of pulmonary rehabilitation and regular physical activity; 6) managing shortness of breath; 7) managing fatigue; 8) managing mood; 9) managing comorbidities; 10) smoking cessation advice and support; 11) accessing community support; 12) how to communicate with others when living with PF. Both groups agreed that self-management in PF required individualisation, goal setting and feedback.

**Conclusion:** This study identified 12 essential components and highlighted individualisation, goal setting and feedback in self-management of PF. The findings provide a basis for the development of PF self-management interventions.

**Keywords:** Interstitial lung disease, pulmonary fibrosis, self-management, self-care, Delphi, patient perspectives, healthcare professional perspectives

## Introduction

Interstitial lung diseases (ILDs) are a heterogeneous group of over 200 lung disorders [1]. Pulmonary fibrosis (PF) is a hallmark feature of many types of ILD with idiopathic pulmonary fibrosis (IPF) being the most common subtype [2]. Effective therapeutic options for PF are limited. Two antifibrotic treatments (pirfenidone and nintedanib) are currently available for people with IPF, with recent approval of nintedanib for other progressive fibrosing ILDs in the United States and Australia [3-5]. Whilst shown to be effective in slowing disease progression, people with PF still face a significant symptom burden over the disease trajectory.

A recent systematic review reported significantly better survival among those taking antifibrotics [6]. With longer survival comes the need to more effectively manage the disease. However, unmet needs for support and information have frequently been reported among people with PF [7].

Modern PF care requires a person-centred approach, shared-decision making with healthcare professionals (HCP) and optimal self-care [8,9]. Recent studies showed that HCPs welcomed a more proactive participation in clinical care by those with PF [10], whilst those with PF expressed interest in learning more about self-management [11,12].

Self-management interventions aim to promote a person's ability to adopt positive health behaviours and to manage symptoms, treatments, and other disease consequences [13]. Such interventions have been shown to improve health-related quality of life and reduce hospital admissions [14] and are highly recommended by clinical guidelines for other lung conditions such as chronic obstructive pulmonary disease (COPD) [15]. In our previous study, HCPs and people with PF identified a range of components considered important for self-management. These included disease knowledge, managing symptoms and treatments, support, and lifestyle changes [16]. However, there is a lack of consensus regarding which components are essential for self-management in PF and the optimal delivery method. This study aimed to gain consensus from an

expert panel of HCPs and people with PF on the essential components of a self-management package for PF, and its optimal format and delivery method.

## **Methods**

This study was conducted between February and June 2021 using a Delphi method. Ethics approval was received from Monash University Human Research Ethics Committee (project ID: 27139). The Delphi method involves an iterative process aimed at obtaining a consensus of expert opinion. A series of surveys are typically administered, while focus groups are commonly used to provide validation [11]. Twenty-six components identified in our previous study [16] were presented to the expert panel through an online survey. Two survey rounds were completed with each round being followed by a patient focus group that allowed integration of the perspectives of those with PF and validation of results.

The Delphi panel comprised of international experts in PF from the disciplines of medicine, nursing, allied health and clinical research. Healthcare professionals who specialised in providing care to people with PF and/or had an expertise in PF research were identified through peer reviewed literature, professional networks, and word of mouth. Eligible HCPs were invited via email with survey completion indicating consent. The same group of HCPs were invited to participate in both rounds. To account for possible attrition following Round-1 and to optimise our sample size, we extended an invitation to an additional five HCPs who then participated in Round-2.

Focus groups comprised of people with PF. The study was advertised on patient e-newsletters and social media platforms via Lung Foundation Australia to recruit adults ( $\geq 18$  years) with PF.

Participants from our previous study who expressed interest in future research were also contacted [16]. People with both IPF and non-IPF diagnoses, varying disease severity and treatment experiences were included. Non-English speakers were excluded given the focus group discussions

required communicating in English. Participants were required to have access to an internet connection and a device that allowed them to participate in the online focus group. Informed written consent was obtained via email. The same group of eligible individuals with PF were invited to participate in both rounds. Due to one participant from Round-1 passing away prior to Round-2 commencing, we identified another individual living with PF who was invited to participate in the Round-2 focus group.

The online surveys were created and distributed using the *Qualtrics* survey platform. Each survey was open for 4 weeks, with a reminder sent at 2 weeks.

In the Round-1 survey, the expert panel was asked to rate a range of self-management components by answering the question '*Do you agree that the following items are essential for a PF self-management package?*' and rate several format and delivery methods for a self-management package (*Supplement 1*). Participants were invited to nominate additional components and comment on each item.

A 5-point Likert scale was used for the rating, with 1 'strongly disagree', 2 'disagree', 3 'neutral', 4 'agree', and 5 'strongly agree' as anchors. An interquartile range (IQR) =0 is usually considered as having achieved a high level of consensus [11]. Therefore, in this study, consensus was defined as a median score  $\geq 4$  and interquartile range (IQR) =0, where these items were deemed essential for a self-management package. Components with a median score  $\leq 3$  and IQR =0 were eliminated and components without consensus (IQR >0) were retained for the Round-2 survey. The median scores and IQR were calculated using *SPSS (IBM)* statistical software.

Round-1 survey results were presented to the patient focus group using teleconference software (*Zoom*) and facilitated by two researchers. An online method was chosen to allow participants to take part from various geographic locations and provided a safe environment during the COVID-19 pandemic. Discussions were recorded and transcribed verbatim. Data analysis was performed using

a content analysis approach and representative quotes were extracted. Items that reached consensus in the survey and were endorsed by the focus groups were considered as essential components of self-management for PF. Focus group feedback on items not reaching consensus was included in the Round-2 survey for reconsideration (*Supplement 2*).

In the Round-2 survey, the expert panel was asked to rate the items not reaching consensus in Round-1 and any additional items nominated by the panel or focus group. Results from Round-1 (median score and IQR) along with representative quotes derived from the focus group were presented for consideration. Round-2 survey results were then presented to a second focus group for discussion and final approval of essential components and optimal delivery methods. In this final step, the voice of the focus group participants was decisive for the choice of components for inclusion in a self-management package even if the component did not reach consensus in the Round-2 survey.

Demographic information on Delphi participants including gender, age, discipline, location, and years of experience in PF were collected. Information on focus group participants including age, ILD diagnosis, lung function and current treatments were recorded.

## Results

Forty-one percent (45/111) of invited experts completed the Round-1 survey; 44% (51/116) completed the second round (**Table 1**). Across both rounds, the majority of HCPs were female (64% and 53% respectively), respiratory physicians (58% and 61% respectively), followed by clinical researchers (22% and 31% respectively) and allied health professionals (22% and 20% respectively) which included physiotherapists, exercise physiologists, oxygen clinic coordinator, and a clinical psychologist. Sixty-eight percent of HCPs had over a decade of experience in PF. Most were from Australia, New Zealand or North America.



Both focus groups included six people with PF who lived in Australia (**Table 1**). Five participated in both groups. Participants had a median age of 67.5 years and were predominantly male (67%). Four participants had IPF, two had connective tissue disease-associated ILD. The median time since diagnosis was 3.5 years. Forced vital capacity ranged from 39% to 94% predicted and transfer factor for carbon monoxide ranged from 19% to 84% predicted. Both focus groups included participants on antifibrotics, immunosuppressants and oxygen therapy.

**Table 2** summarises the results for all components considered in this study. In the Round-1 survey, 23% (6/26) of components reached our *a priori* defined consensus and were endorsed by the focus group. These included understanding treatment options for PF; understanding and accessing clinical trials; managing medications, shortness of breath and comorbidities; and accessing community support. Eight new components were suggested by the expert panel: preparation for a medical consultation; monitoring and assessing the disease; awareness of potential noxious exposures; managing pain; managing sexual problems; advice on travelling; how to communicate with others when living with PF; and support for carers and family.

Minor modifications were made to two components after Round-1. The first related to recognising exacerbations. Whilst experts generally agreed that people with PF could be trained to recognise an exacerbation, some disagreed on how these individuals should self-manage an exacerbation:

*“I strongly agree with the recognition, but not with managing. The patient should recognise and immediately consult with the specialist.”*

This component was subsequently modified to ‘recognising an exacerbation’ in the Round-2 survey.

The second component centred around vaccinations. Focus group participants expressed interest in broader aspects of vaccinations than had been presented, including safety, risks, and contraindications with medications and other vaccines. The conversation was mainly focused around COVID-19 vaccines:

*“Everyone says the importance of my pneumonia vaccine which I went and got, but no one has mentioned anything to me about the risk, potential risks due to my condition of the COVID vaccine.”*

This component was changed to ‘vaccinations (including role and importance, risks and contraindications)’ for the Round-2 survey.

None of the eight statements regarding the format and delivery of a PF self-management package reached consensus in Round-1 (**Table 3**). Twenty-eight components along with the eight statements regarding format and delivery methods were included for consideration in Round-2.

In the Round-2 survey, 18% (5/28) of components reached consensus and were endorsed by the focus group. These included managing fatigue; role and importance of pulmonary rehabilitation (PR); role of oxygen therapy; smoking cessation advice and support; and how to communicate with others when living with PF.

In the surveys, managing mood was considered very important to self-management in PF (median score =5), however, did not reach consensus (IQR=1). Participants with PF expressed their need for managing mood, and emphasised it was essential for self-management in PF:

*“Even things like seeking a counsellor or someone to help with, because the mental health decline is major... Something like that in a package, I think would be essential.”*

Managing mood was therefore listed as an essential component (**Table 4**).

In addition, participants with PF highlighted the importance of maintaining regular physical activities after PR:

*“One of the things I rate as incredibly important in a patient’s journey through PF is exercise... I mean what happens afterwards (when PR concludes), do you just give up and go and sit down and watch your favorite TV show, that’s no good for you.”*

Focus group participants also suggested using the term 'co-existing' rather than 'comorbid' medical conditions as it is more easily understood. Descriptors for the relevant components were altered to reflect these discussions.

Two statements regarding the format and delivery of a PF self-management package reached consensus in the Round-2 survey and were endorsed by the focus group: *'the self-management component/s delivered to the patient must be tailored to their specific needs'* and *'goal setting and feedback are essential for effective self-management in PF'*.

Consensus was not achieved for 21 components (IQR >0). Components with a median score of 5 were classified as 'desirable', whilst components with a median score of 4 were classified as 'optional'. **(Table 4).**

## Discussion

Experts in PF and people with PF identified 12 components essential for self-management in PF. These covered areas relating to understanding of treatment options and clinical trials; managing medications and co-existing medical conditions; managing mood, shortness of breath and fatigue; understanding the role of oxygen therapy; the importance of PR and regular physical activity; accessing community support; smoking cessation advice and support; and how to communicate with others when living with PF. All participants agreed that a PF self-management package should be individualised and involve goal setting and feedback.

Self-management has been identified as an important aspect of living with PF [10-12]. Emerging studies have investigated the impact of various self-management interventions such as patient education, action planning, home monitoring and support groups on people with IPF [17,18]. Improvements in psychological well-being [19,20], self-efficacy [18], disease knowledge [21],

adherence and management of medication [22], and completion of advance care planning [21] have been reported following these interventions. However, this is the first study to gain consensus between HCPs and people with PF regarding essential components for the self-management of PF.

Clinical guidelines recommend the use of both pharmacological and non-pharmacological approaches to manage PF including medications, lung transplantation, oxygen therapy, PR, psychosocial support, and smoking cessation [23,24]. Individualised supportive care is also recommended in conjunction with disease-specific treatments to focus on symptom relief, improving quality of life, and end-of-life planning [23,24]. In this study, most components identified as being essential for PF self-management were also recommended in the guidelines. An exception was advance care planning which although did not reach consensus, was rated by experts as highly important and highlighted in patient focus groups as being important to know '*what happens towards the end and what options do you have*'. Therefore, information and discussions related to planning end-of-life affairs should be considered. Although the term "palliative care", was seldomly used by participants in this study, some components such as managing medication side effects, shortness of breath, fatigue and mood may be considered as part of palliative care [23]. Future research should endeavor to further explore the palliative care needs of people with PF. The importance of lung transplantation as a treatment option was also not highlighted in this study although it remains an important life-extending treatment option that should be considered by people living with PF.

Managing mood was identified as essential for self-management by people with PF. The negative impact of PF on psychosocial and emotional aspects of life are frequently reported [7]. Anxiety and depression are prevalent in 31% and 23% of people with ILD, respectively [25]. Whilst medications are available to treat anxiety or low mood, coping strategies [26] and mindfulness practices [27] can also help with acceptance of the disease and improve mood and stress. In addition, PR [28], support groups [20] and disease management programs [29] can relieve feelings of isolation, anxiety and

depression. People who have a lack of disease knowledge, low level of activation for self-management, worse physical symptoms and more comorbidities are at higher risk of anxiety and depression [25,26,30]. Therefore, it is important for HCPs to provide support especially to those at risk and refer them to suitable programs to learn more about their condition and adopt coping and disease management skills.

Maintaining physical activity after PR was also highlighted by people with PF. Many studies have demonstrated short-term benefits of PR on exercise capacity, symptoms and health-related quality of life. However, evidence for long-term benefits is limited [31]. In this study, people with PF emphasised the need of maintaining regular physical activity after completing PR. In an observational study, only 39% of participants continued home exercise and only 11% maintained an exercise program 12 months after completing PR [32]. A lack of feedback regarding exercise capacity and a lack of access and social support to attend local exercise programs have been identified as some of the barriers of being physically active [26,33]. In COPD, participants who successfully completed a 12-month supervised maintenance program reported that regular assessments were important to remain physically active [34]. Therefore, regular feedback regarding an individual's fitness and accessible exercise programs may be key facilitators to remain physically active following a PR program.

Goal setting and feedback were considered essential for effective self-management in this study. Goal setting is a behaviour change technique frequently used with self-monitoring and patient education in self-management interventions to promote positive health behaviours and better management of chronic illnesses [35]. In COPD, improvements in exercise performance, anxiety, uptake of smoking cessation support and success in quitting smoking were seen six months following a web-based self-management program that comprised of goal setting and feedback, self-monitoring and patient education, in conjunction with support from HCPs and an online patient forum [36]. An example of goal setting and feedback that might be relevant to people with PF is

undertaking regular physical activity. Staying motivated to exercise was a significant challenge highlighted by participants in this study and previous studies [11,37]. Good self-efficacy is a facilitator to maintaining physically active [33] and therefore being able to see achievements is important. Previous studies have shown that the use of activity trackers such as pedometers and exercise diary can improve daily steps when used with goal setting and motivational counselling [38].

Participants in this study agreed that individualisation was essential for self-management in PF. Self-management interventions have been defined as *'structured but individualised interventions that often consist of several components aimed at motivating and supporting people to adopt positive health behaviours and develop skills to manage their disease'* [39]. Whilst programs with a structured education component were informative [29], the disease experience, care goals and personal circumstances vary between different individuals [10,16,26] and are likely to change over time. Therefore, easy access to information that is tailored to an individual's situation is critical. The role of HCPs in providing relevant information, tailoring and support for self-management remains unclear. Findings from our study suggest it was not seen as essential, however, other studies have reported that easy access to HCPs allowed them to reach out for assistance when required [16,22]. Given the low degree of activation for self-management reported in previous study [30] and a lack of awareness of available support being identified as a barrier to accessing self-management support [40], encouragement and support provided by HCPs may be important in self-management.

To our knowledge, this is the first study that gained consensus from both people living with PF and an international, multidisciplinary expert panel of HCPs regarding the essential components for self-management in PF. The Delphi approach allowed for anonymity and participation of individuals from various geographic locations. This study included participants with both IPF and non-IPF diagnoses, with a broad range of lung function, functional capacity, and treatment experiences. However, several limitations should be considered. Although we attempted to include a broad range of participants, the experiences and views represented may not reflect those of all people with PF or PF

experts. Our virtual focus groups may have led to the exclusion of those not familiar or confident with using technology. However, many of the topics covered in this study have also been discussed by participants with PF in studies that did not involve using technology [11,12]. In addition, whilst we were able to provide a more in-depth explanation of components to focus group participants, it is possible that HCPs from different countries had different understanding of the components provided in the surveys. However, we did provide HCPs with the option of adding comments on all items, including the possibility of requesting more information on the meaning of items. Lastly, although our study may have benefited from including more participants, there are no established recommendations regarding an optimal sample size for a Delphi process. In previous studies, the number of participants included in an expert panel varied considerably ranging from less than 10 to hundreds [41, 42]. A similar study achieved consensus on the investigated topics with similar numbers as this study (37 to 43 expert participants and 10 participants in the focus groups) [11]. In addition, having six participants in a focus group does align with some recommendations [43] but more importantly both groups of participants covered a range of expert areas, disease stages, symptoms, and treatment experiences.

In conclusion, this study identified 12 components essential for a self-management package in PF and emphasised the importance of individualisation, goal setting and feedback for effective self-management in PF. A range of desirable components were also identified, which may be important for some people living with PF and may be delivered if resources are available. The study findings provide guidance on the design of future PF self-management interventions.

## **Informed consent and participant details**

I confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

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## **Declaration of interest:**

Joanna Y. T. Lee, Gabriella Tikellis and Anne E. Holland have no relevant conflict of interests to disclose. Yet H. Khor reports fellowship support from NHMRC Investigator Grant, and grants from Boehringer Ingelheim, during the conduct of the study.

## **CRediT authorship contribution statement**

**Joanna Y. T. Lee:** Conceptualisation, Methodology, Formal analysis, Investigation, Writing –original draft, Project administration, Funding acquisition. **Gabriella Tikellis:** Conceptualisation, Methodology, Formal analysis, Investigation, Writing –review & editing. **Yet H. Khor:** Resources, Methodology, Writing –review & editing. **Anne E. Holland:** Conceptualisation, Methodology, Formal analysis, Investigation, Writing –review & editing, Supervision.



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**Table 1. Participant demographic information**

| Experts in PF                                    |                                    | Round 1<br>n=45 | Round 2<br>n=51 |
|--|------------------------------------|-----------------|-----------------|
| <b>Gender</b>                                    | Male                               | 16 (36)         | 24 (47)         |
|  | Female                             | 29 (64)         | 27 (53)         |
| <b>Age (years)</b>                               | 25-35                              | 4 (9)           | 5 (10)          |
|  | 36-45                              | 14 (31)         | 15 (29)         |
|  | 46-55                              | 15 (33)         | 18 (35)         |
|  | Over 55                            | 12 (27)         | 13 (26)         |
|  |                                    |                 |                 |
| <b>Discipline *</b>                              | Physician                          | 26 (58)         | 31 (61)         |
|  | Nurse                              | 8 (18)          | 8 (16)          |
|  | Researcher                         | 10 (22)         | 16 (31)         |
|  | Allied health †                    | 10 (22)         | 10 (20)         |
|  | Other                              | 0 (0)           | 0 (0)           |
|  | Multiple disciplines               | 9 (20)          | 14 (28)         |
| <b>Experience in PF care (years)</b>             | < 5                                | 4 (9)           | 5 (10)          |
|  | 6-10                               | 11 (24)         | 8 (15)          |
|  | 11-25                              | 21 (47)         | 26 (51)         |
|  | > 25                               | 8 (18)          | 10 (20)         |
|  | Do not provide direct patient care | 1 (2)           | 2 (4)           |
|  |                                    |                 |                 |
| <b>Location</b>                                  | Asia                               | 5 (11)          | 7 (14)          |
|  | Australia/New Zealand              | 15 (33)         | 16 (31)         |
|  | Europe                             | 8 (18)          | 12 (23)         |
|  | North America                      | 16 (36)         | 13 (26)         |
|  | South America                      | 1 (2)           | 3 (6)           |
|  |                                    |                 |                 |
| Focus group participants (people living with PF) |                                    | Round 1<br>n=6  | Round 2<br>n=6  |
| <b>Gender</b>                                    | Male                               | 4 (67)          | 4 (67)          |
|  | Female                             | 2 (33)          | 2 (33)          |
| <b>Age (years)</b>                               |                                    | 67.5 (36-72)    | 67.5 (36-76)    |
| <b>Diagnosis</b>                                 | IPF                                | 4 (67)          | 4 (67)          |
|  | Non-IPF ‡                          | 2 (33)          | 2 (33)          |
| <b>Time since diagnosis (years)</b>              |                                    | 3.5 (1-5)       | 3.5 (1-10)      |
| <b>FVC (% predicted)</b>                         |                                    | 70.5 (39-94)    | 82.0 (39-94)    |
| <b>TLCO (% predicted)</b>                        |                                    | 49.5 (19-84)    | 49.5 (32-84)    |
| <b>Therapy §</b>                                 | Antifibrotic                       | 3 (50)          | 4 (67)          |
|  | Immunosuppressant                  | 2 (33)          | 2 (33)          |
|  | Oxygen ¶                           | 2 (33)          | 2 (33)          |
| <b>Location<br/>(state in Australia)</b>         | Victoria                           | 6 (100)         | 5 (83)          |
|  | Western Australia                  | 0 (0)           | 1 (17)          |

Data are presented as n (%) or median (range).

PF: pulmonary fibrosis; IPF: idiopathic pulmonary fibrosis; FVC: forced vital capacity; TLCO: transfer factor for carbon monoxide.

\* Healthcare professional participants were allowed to choose multiple disciplines.

† Allied health professionals included physiotherapist, exercise physiologist and oxygen clinic coordinator and clinical psychologist.

‡ Non-IPF diagnoses included connective tissue disease-associated interstitial lung disease (n=2)

§ In round 1, one participant with PF used both antifibrotic therapy and oxygen therapy; in round 2, two used both therapies.

|| One participant with PF used mycophenolate mofetil and prednisolone; the other participant used only mycophenolate mofetil.

¶ In round 1, both participants with PF used oxygen continuously including on exertion. In round 2, one used oxygen continuously and one used it only on exertion.

**Table 2. Summary of results from Delphi surveys: components of self-management in pulmonary fibrosis**

|   | Round 1 |     | Round 2 |     | Consensus status and changes made      |
|---|---------|-----|---------|-----|--|
|   | Median  | IQR | Median  | IQR |  |
| 1. Understanding PF   | 5       | 1   | 5       | 1   | No consensus                           |
| 2. Understanding expected disease course and prognosis                            | 5       | 1   | 5       | 1   | No consensus                           |
| 3. Understanding treatment options for PF   | 5       | 0   |         |     | Consensus achieved in R1               |
| 4. Understanding and accessing clinical trials                                    | 4       | 0   |         |     | Consensus achieved in R1               |
| 5. Managing medications (including side effects)                                  | 5       | 0   |         |     | Consensus achieved in R1               |
| 6. Managing cough   | 5       | 1   | 4       | 1   | No consensus                           |
| 7. Managing shortness of breath   | 5       | 0   |         |     | Consensus achieved in R1               |
| 8. Managing fatigue   | 4       | 1   | 4       | 0   | Consensus achieved in R2               |
| 9. Role and importance of pulmonary rehabilitation                                | 5       | 1   | 5       | 0   | Consensus achieved in R2               |
| 10. Role of oxygen therapy  | 5       | 1   | 5       | 0   | Consensus achieved in R2               |
| 11. Managing oxygen therapy   | 5       | 1   | 5       | 1   | No consensus                           |
| 12. Reducing the risk of an exacerbation  | 4       | 1   | 4       | 1   | No consensus                           |
| 13. Using an action plan  | 4       | 2   | 4       | 1   | No consensus                           |
| 14. Role and importance of regular physical activity                              | 5       | 1   | 5       | 1   | No consensus                           |
| 15. Nutrition and dietary advice  | 4       | 1   | 4       | 1   | No consensus                           |
| 16. Smoking cessation advice and support  | 5       | 1   | 5       | 0   | Consensus achieved in R2               |
| 17. Managing activities of daily living   | 4       | 1   | 4       | 1   | No consensus                           |
| 18. Managing comorbid medical conditions  | 4       | 0   |         |     | Consensus achieved in R1               |
| 19. Managing mood   | 5       | 1   | 5       | 1   | No consensus                           |
| 20. Role and importance of social support   | 4       | 1   | 4       | 1   | No consensus                           |
| 21. Accessing peer support  | 4       | 1   | 4       | 1   | No consensus                           |
| 22. Accessing community support   | 4       | 0   |         |     | Consensus achieved in R1               |
| 23. Advance care planning and advance directives                                  | 4       | 1   | 5       | 1   | No consensus                           |
| 24. Accessing reliable information about PF                                       | 5       | 1   | 4       | 1   | No consensus                           |
| 25. Vaccinations  | 4       | 1   | 4       | 1   | 'Role and importance' removed after R1 |
| 26. Recognising an exacerbation   | 5       | 1   | 5       | 1   | 'Managing' removed after R1            |
| <b>Items added by HCPs in round 1</b>   |         |     |         |     |  |
| 27. Preparation for a medical consultation  |         |     | 4       | 1   | No consensus                           |
| 28. Monitoring and assessment of the disease                                      |         |     | 4       | 1   | No consensus                           |
| 29. Awareness of potential noxious exposures                                      |         |     | 4       | 1   | No consensus                           |
| 30. Managing pain   |         |     | 3       | 1   | No consensus                           |
| 31. Managing sexual problems  |         |     | 4       | 1   | No consensus                           |
| 32. Advice on travelling  |         |     | 4       | 1   | No consensus                           |
| 33. How to communicate with others when living with PF                            |         |     | 4       | 0   | Consensus achieved in R2               |
| 34. Support for carers and family   |         |     | 4       | 1   | No consensus                           |
| <b>Items added/modified by patient focus group</b>                                |         |     |         |     |  |
| 35. Role and importance of pulmonary rehabilitation and regular physical activity |         |     |         |     | New item: 9 and 14 combined            |
| 36. Managing co-existing medical conditions                                       |         |     |         |     | 'Comorbid' changed to 'co-existing'    |

PF: pulmonary fibrosis; HCP: healthcare professional; IQR: interquartile range; R1: Delphi round 1; R2: Delphi round 2. Components that achieved a high level of consensus (i.e., IQR =0) are highlighted in orange colour.

**Table 3. Summary of results from Delphi surveys: format and delivery of a self-management package in pulmonary fibrosis**

|   | Round 1 |     | Round 2 |     | Consensus status        |
|---|---------|-----|---------|-----|-------------------------|
|   | Median  | IQR | Median  | IQR |                         |
| 1. Components tailored to specific diagnosis                  | 4       | 2   | 4       | 1   | No consensus            |
| 2. Components tailored to patient's specific needs            | 4       | 2   | 4       | 0   | Consensus reached in R2 |
| 3. Delivered with support from HCPs                           | 4       | 1   | 4       | 1   | No consensus            |
| 4. Delivered by a multidisciplinary team                      | 4       | 2   | 4       | 1   | No consensus            |
| 5. Delivered using independent and self-paced learning        | 4       | 1   | 4       | 1   | No consensus            |
| 6. Delivered remotely   | 4       | 1   | 4       | 1   | No consensus            |
| 7. Goal setting and feedback are essential                    | 4       | 1   | 4       | 0   | Consensus reached in R2 |
| 8. Patient access to personal health information is essential | 4       | 2   | 4       | 1   | No consensus            |

HCP: healthcare professional; IQR: interquartile range; R2: Delphi round 2. Components that achieved a high level of consensus (i.e., IQR =0) are highlighted in orange colour.

**Table 4. Essential, desirable and optional components of self-management in PF**

|   |   |
|---|---|
| <b>Essential components (median score <math>\geq 4</math>, IQR = 0)</b> |   |
| 1.  | Understanding treatment options for PF  |
| 2.  | Understanding and accessing clinical trials                                   |
| 3.  | Managing medications (including side effects)                                 |
| 4.  | Role of oxygen therapy  |
| 5.  | Managing shortness of breath  |
| 6.  | Managing fatigue  |
| 7.  | Managing co-existing medical conditions                                       |
| 8.  | Managing mood   |
| 9.  | Role and importance of pulmonary rehabilitation and regular physical activity |
| 10.   | Smoking cessation advice and support  |
| 11.   | Accessing community support   |
| 12.   | How to communicate with others when living with PF                            |
|   |   |
| <b>Desirable components (median score = 5, IQR &gt; 0)</b>              |   |
| 1.  | Understanding PF  |
| 2.  | Understanding expected disease course and prognosis                           |
| 3.  | Managing oxygen therapy   |
| 4.  | Advance care planning and advance directives                                  |
| 5.  | Recognising an exacerbation   |
|   |   |
| <b>Optional components (median score = 4, IQR &gt; 0)</b>               |   |
| 1.  | Managing cough  |
| 2.  | Reducing the risk of an exacerbation  |
| 3.  | Vaccinations  |
| 4.  | Using an action plan  |
| 5.  | Nutrition and dietary advice  |
| 6.  | Managing activities of daily living   |
| 7.  | Managing sexual problems  |
| 8.  | Role and importance of social support   |
| 9.  | Accessing peer support  |
| 10.   | Support for carers and family   |
| 11.   | Accessing reliable information about PF                                       |
| 12.   | Preparation for a medical consultation  |
| 13.   | Monitoring and assessment of the disease                                      |
| 14.   | Awareness of potential noxious exposures                                      |
| 15.   | Advice on travelling  |

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## 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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## Introduction

### Introduction

Thank you for participating in this Delphi study, which aims to achieve consensus regarding the components for inclusion in a self-management package to support people with pulmonary fibrosis (PF).

The first round of survey was completed by 45 health professionals from a range of disciplines including respiratory physicians, nurses, physiotherapists, exercise physiologist, psychologists, and researchers. The responses came from North and South America, Europe, Australia, New Zealand and Asia.

**Six components reached consensus in Round 1** and will be included when we develop a PF self-management package. They were:

- 1. Understanding treatment options for PF**
- 2. Understanding and accessing clinical trials**
- 3. Managing medications (including side effects)**
- 4. Managing shortness of breath**
- 5. Managing comorbid medical conditions**
- 6. Accessing community support**

### What does Round 2 involve?

In this survey, we present:

- Items that did not reach consensus in Round 1 along with the scores rated by health professionals
- Additional items recommended by health professionals
- Perspectives of people with PF on each item including representative quotes from a patient focus group.

**In this round, we would like to ask you to re-evaluate these items for inclusion in a PF self-management package taking into account the patient perspectives.**

### **This survey includes 3 sections**

**Section 1** relates to self-management topics that did not reach consensus in Round 1.

**Section 2** relates to additional self-management topics suggested by health professionals.

**Section 3** relates to the format and delivery of a self-management package.

### **Intro block**

### **Ethical considerations**

Your responses are anonymous and confidential. We will only report aggregate 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 program 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 research study, which includes reporting of non-identifiable results in a thesis and any publications arising from the study.

### **Section 1 intro**

## **Section 1**

Please indicate how strongly do 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.

### **Section 1 - Items with no consensus**

#### **1.1 Understanding PF – causes, pathophysiology and symptoms**

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“I had no real understanding, I still don’t really, except as to what can be done at my stage now to make my breathing better.”*

*“Understanding PF is number one!”*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree      Disagree      Neutral      Agree      Strongly agree

☐      ☐      ☐      ☐      ☐

**Comments:**

## Section 1 - Items with no consensus

### 1.2 Understanding expected disease course and prognosis

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"If it's explained well and say 'hey it sounds bad but it's not as bad as it really sounds, because there are treatments now, they can't cure it, but they can hopefully stop the progression of it', which I'm lucky as I said, it has for me, but at the first instance, that's where the problem is."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.3 Managing cough

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.4 Managing fatigue

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus



## 1.5 Role and importance of pulmonary rehabilitation

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"I think to me, that is probably the most important part of all these PF self-management, that community support through pulmonary rehabilitation."*

*"I can be very lazy and without the expectation to be somewhere, it's very easy to just not [do exercise]. It's been great!"*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree



Disagree



Neutral



Agree



Strongly agree



Comments:

## Section 1 - Items with no consensus

### 1.6 Role of oxygen therapy

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"Well I think it's not knowing enough about it... I think the role of oxygen is so important."*

*"I don't actually know when to get oxygen, I mean I'm aware of oxygen, I'm not aware of if I need it and whether I'm eligible for it."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.7 Managing oxygen therapy

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients made minimal comments regarding this item but did not disagree that it was important for self-management of PF:**

*"... all the IPF or PF patients, all gonna need oxygen eventually."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.8 Vaccinations (including role and importance, risks, contraindications)

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"I just find it interesting, everyone pushed the conversation with pneumonia vaccine but wondering why there's been no talks about Covid vaccine and other vaccines, and whether it's something that's even safe for us or something that we should absolutely be doing."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree



Disagree



Neutral



Agree



Strongly agree



Comments:

## Section 1 - Items with no consensus

### 1.9 Recognising an exacerbation

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"I think different people may experience different exacerbations, so a definition of what constitutes an exacerbation or what can constitute an exacerbation, so that you actually recognise it for what it is."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.10 Reducing the risk of an exacerbation (e.g. by preventing infections)

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.11 Using an action plan (e.g. for exacerbation, symptom and treatment management, disease monitoring)

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"I mean not everyone will have the same symptoms of a decline, so having a list, if you're experiencing any [of the symptoms on the list]... then that constitutes an exacerbation, you should probably contact whoever it is that you should contact, whether it's your GP or your specialist."*

*"They tell you things verbally but they hardly ever write the damn thing down, by the time I got home I've forgotten the thing they told me."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree      Disagree      Neutral      Agree      Strongly agree

☐      ☐      ☐      ☐      ☐

**Comments:**

## Section 1 - Items with no consensus

## 1.12 Role and importance of regular physical activity

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients made minimal comments regarding this item but did not disagree that it was important for self-management of PF:**

*"I was encouraged to continue sort of sporting activities, I used to do gym and a lot of walking so I continue those for as long as I could."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree



Disagree



Neutral



Agree



Strongly agree



Comments:

## Section 1 - Items with no consensus

### 1.13 Nutrition and dietary advice

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"I think nutrition, you gotta start looking at food as medicine. And may be at least a specific session with a nutritionist who looks at what you're eating and how you're eating, and to write up a rough plan, a guideline."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.14 Smoking cessation advice and support

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

## 1.15 Managing activities of daily living

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.16 Managing mood (e.g. anxiety, depression, grief, fears, etc.)

**In Round 1, the health professional scores were:**

Median score = 5 (strongly agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“Even things like seeking a counsellor or someone to help with, because the mental health decline is major... Something like that in a package, I think would be essential.”*

*“The depressed feelings, so when that was the thing, I would really have appreciated help when I was first diagnosed, because I did wake up a few times at 3am thinking ‘oh geez I’m gonna die.’”*



**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.17 Role and importance of social support

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“At this point in my life I couldn’t manage without it [family support], so it’s definitely something that needs to be focused on.”*

*“She’s [patient’s wife] the one who’s running around most of the time, looking after me, so as long as I have her, I don’t feel too bad.”*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.18 Accessing peer support

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, the patient responses varied:**

*"I mean I did a lot of googling but it would have been rather helpful I think, to have a longer conversation like in a group situation as to what are other people's suggestions in handling this information [about diagnosis and treatment options]."*

*"I haven't thought too much about social support or peer support and so forth."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.19 Advance care planning and advance directives

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“To me, this is about what happens towards the end and what options do you have... talking about your close family and so forth, what options do you have to make life more comfortable for them.”*

*“I haven’t been told anything about this at all, I’m not sure what it is, but I did ask about euthanasia...”*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 1 - Items with no consensus

### 1.20 Accessing reliable information about PF

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 4 (agree) to 5 (strongly agree)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“I mean I don’t trust Google doctor [laugh], ‘cause you Google the symptoms and Google doctor, and invariably you’re gonna die in the next hour and a half so...”*

*“I went there with my two boys and they just said ‘Dad that’s what you’ve got’, I Googled it and said ‘aw... I got 2 years plus to live’, so then I kept Googling, Googling, and Googling, I found*

*out it's bad but it's not as bad as I thought it was."*

**Considering these responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree



Disagree



Neutral



Agree



Strongly agree



Comments:

## Section 2 - New items

### Section 2

In the first round of survey, health professionals made a number of suggestions about additional components for inclusion in a PF self-management package.

We asked the patients in the focus group about these items and have provided their responses.

We would like you to tell us how strongly do you agree that these new components are **essential** in a self-management package for people with PF.

## Section 2 - New items

### 2.1 Preparation for a medical consultation

**In the focus group, patients agreed that this item was important for self-management of PF:**

*"You don't know what questions to ask, I think as part of a package handed to someone that has been diagnosed with this, may be from the Lung Foundation or someone like that, you should have a list of questions to ask your specialists."*

**Considering the patient responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.2 Monitoring and assessment of the disease

In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.

**Considering the patient responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.3 Awareness of potential noxious exposures (e.g. inhalational and medical exposures)

**In the focus group, patients agreed that this item was important for self-management of PF:**

*“Just a checklist, because a lot of the time, everyone is different, it may not apply to you at all, but if you’ve got a list, you can sort of go, ‘well that’s me, right there, I can see all of these things that apply to me’, and then you can move on from there, you can ask the questions that you need to ask, to reassure yourself about what it is that’s happening.”*

**Considering the patient responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.4 Managing pain

**In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.**

**Considering the patient responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.5 Managing sexual problems

In the focus group, patients made no comments regarding this item but did not disagree that it was important for self-management of PF.

Considering the patient responses, do you agree that this item is essential for a PF self-management package?

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.6 Advice on travelling

In the focus group, patients made minimal comments regarding this item but did not disagree that it was important for self-management of PF:

*"I had tried the portable oxygen unit but it's only when we're flying overseas that I would hire the unit, that's the only time I have tried it so..."*

Considering the patient responses, do you agree that this item is essential for a PF self-management package?

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 2 - New items

### 2.7 How to communicate with others when living with PF

In the focus group, patients agreed that this item was important for self-management of PF:

*“And the other big one would be how to communicate with others about what’s happening to you because I don’t communicate with anyone other than my wife about what’s happening to me, my Mum doesn’t know that I also have IPF...”*

*“I’d seen previously where people worked with an illness and how it suddenly affected their relationships with everybody. The first question would always be ‘how are you?’, you know that sort of thing, so you always start to get treated differently.”*

Considering the patient responses, do you agree that this item is essential for a PF self-management package?

Strongly disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly agree

☐

Comments:

## Section 2 - New items

### 2.8 Support for carers and family

In the focus group, patients agreed that this item was important for self-management of PF:



*"We need to remember it's the people closest to us who assist us the most who need support too."*

*"My coping mechanism is just to ignore it, pretend I don't have anything, but my wife is the one who worries about it more than I do."*

**Considering the patient responses, do you agree that this item is essential for a PF self-management package?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 3 - Format and Delivery

### Section 3

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

We would like you to tell us how strongly do you agree with the following statements.

### Section 3 - Items with no consensus

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

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients disagree with this statement to some extent:**

*"I mean a lot of the specifics would be the same for all of those different types of ILDs... I think it's how different the information is delivered to the patient that is the difference... We probably need the same sort of information, but people can consume it differently."*

**Considering these responses, do you agree with this statement?**Strongly disagree  
☐Disagree  
☐Neutral  
☐Agree  
☐Strongly agree  
☐

Comments:

**Section 3 - Items with no consensus****3.2 The self-management component/s delivered to the patient must be tailored to their specific needs****In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed with this statement:**

*"I think having an individualised self-management plan would be fantastic!"*

*"I think if that's specifically tailored to you, you could take that to each one of your appointments so that everyone is on the same page."*

**Considering these responses, do you agree with this statement?**Strongly disagree  
☐Disagree  
☐Neutral  
☐Agree  
☐Strongly agree  
☐

Comments:

## Section 3 - Items with no consensus

### 3.3 A self-management package must be delivered with support from healthcare professionals (e.g. using telehealth or face-to-face consultations)

In Round 1, the health professional scores were:

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

In the focus group, patients made no comments regarding this statement but did not disagree.

Considering these responses, do you agree with this statement?

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

## Section 3 - Items with no consensus

### 3.4 A self-management package must be delivered by a multidisciplinary team

In Round 1, the health professional scores were:

Median score = 4 (agree)

Range 1 (strongly disagree) to 5 (strongly agree)

**In the focus group, patients agreed with this statement:**

*“100%! There’s no point having it organised just by one of your health professionals, when you see multiple people, you need everyone knowing what’s going on and working towards the plan.”*

*“100% that you need a multidisciplinary team, I agree with that, but a single point of contact to pull it all together for you... I mean you need appointments with endocrinologist and all sorts of things, and if you haven’t got a contact to push for that, for whatever available, for wherever you’re going, then it becomes difficult.”*

**Considering these responses, do you agree with this statement?**

Strongly disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly agree

☐

Comments:

**Section 3 - Items with no consensus****3.5 A self-management package for PF can be effectively delivered using independent and self-paced learning****In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 1 (strongly disagree) to 5 (strongly agree)

**In the focus group, patients' responses were neutral:**

*“That would depend on the person, I think that would work fine with me but I don’t think that would work for my brother [who also has IPF] at all.”*

**Considering these responses, do you agree with this statement?**

Strongly disagree  
☐Disagree  
☐Neutral  
☐Agree  
☐Strongly agree  
☐

Comments:

### Section 3 - Items with no consensus

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

In Round 1, the health professional scores were:

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

In the focus group, patients disagreed with this statement to some extent:

*"Yeah via Zoom is fine, if it is face-to-face and there's some interaction I think it's fine, but if it's delivered remotely just via an app or website I'm not sure that'd be all that effective."*

Considering these responses, do you agree with this statement?

Strongly disagree  
☐Disagree  
☐Neutral  
☐Agree  
☐Strongly agree  
☐

Comments:

### Section 3 - Items with no consensus

#### 3.7 Goal setting and feedback are essential for effective self-management in PF

**In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 3 (neutral) to 5 (strongly agree)

**In the focus group, patients agreed with this statement:**

*"I definitely like to get some feedback about where I'm at, whether I've moved up or down, that sort of feedback 100% I need to know."*

*"You know the biggest thing is not to decline, so anything that helps you minimise your decline, that's all I really care about. Like I don't have a goal to run a marathon, I don't have a goal to do anything specific, I just wanna do what I can to be of benefit."*

**Considering these responses, do you agree with this statement?**

Strongly disagree  
☐

Disagree  
☐

Neutral  
☐

Agree  
☐

Strongly agree  
☐

Comments:

**Section 3 - Items with no consensus****3.8 Patient access to personal health information (e.g. lung function results, step counts) is essential for effective self-management in PF****In Round 1, the health professional scores were:**

Median score = 4 (agree)

Range 2 (disagree) to 5 (strongly agree)

**In the focus group, patients agreed with this statement:**

*"Like the specific medical information, the bloods, I want that, because it means that I can carry it around, and if I speak to someone else or I move somewhere, I can then just pull it out and say 'well here it is, this is everything'. That's part of how I cope with it... or feel like I have some sort of control, is by having all of my stuff together that I can look at."*

**Considering these responses, do you agree with this statement?**Strongly disagree  
☐Disagree  
☐Neutral  
☐Agree  
☐Strongly agree  
☐

Comments:

**Section 3 - additional comments****3.9 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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