



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

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Shareable abstract (@ERSpublications)

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. <https://bit.ly/3CN9ad0>

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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 two-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 45 experts participated in Round 1 and 51 in Round 2. Both focus groups included six people with PF. 12 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; and 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.

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 USA 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 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, whilst focus groups are commonly used to provide validation [11]. 26 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 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* e-mail 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 people with PF. The study was advertised on patient e-newsletters and social media platforms *via* Lung Foundation Australia to recruit adults (≥ 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 and 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* e-mail. The same group of eligible individuals with PF were invited to participate in both rounds. Owing 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 (Supplementary file 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 ≥ 4 and IQR=0, where these items were deemed essential for a self-management package. Components with a median score ≤ 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, Chicago, IL, USA) 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 geographical 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 (supplementary file 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 sex, 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

41% (45 out of 111) of invited experts completed the Round 1 survey; 44% (51 out of 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, an oxygen clinic coordinator and a clinical psychologist. 68% 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 out of 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.

TABLE 1 Participant demographic information

	Round 1	Round 2
Experts in PF		
Subjects n	45	51
Sex		
Male	16 (36)	24 (47)
Female	29 (64)	27 (53)
Age years		
25–35	4 (9)	5 (10)
36–45	14 (31)	15 (29)
46–55	15 (33)	18 (35)
Over 55	12 (27)	13 (26)
Discipline [#]		
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)
Experience in PF care years		
<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)
Location		
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)		
Subjects n	6	6
Sex		
Male	4 (67)	4 (67)
Female	2 (33)	2 (33)
Age years	67.5 (36–72)	67.5 (36–76)
Diagnosis		
IPF	4 (67)	4 (67)
Non-IPF [†]	2 (33)	2 (33)
Time since diagnosis years	3.5 (1–5)	3.5 (1–10)
FVC % predicted	70.5 (39–94)	82.0 (39–94)
T _{LCO} % predicted	49.5 (19–84)	49.5 (32–84)
Therapy [§]		
Antifibrotic	3 (50)	4 (67)
Immunosuppressant ^f	2 (33)	2 (33)
Oxygen ^{##}	2 (33)	2 (33)
Location		
(state in Australia)		
Victoria	6 (100)	5 (83)
Western Australia	0 (0)	1 (17)

Data are presented as n, n (%) or median (range). PF: pulmonary fibrosis; IPF: idiopathic pulmonary fibrosis; FVC: forced vital capacity; T_{LCO}: 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, and in Round 2, two used both therapies; ^f: one participant with PF used mycophenolate mofetil and prednisolone, and the other participant used only mycophenolate mofetil; ^{##}: in Round 1, both participants with PF used oxygen continuously including on exertion, and 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	
Self-management components					
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
Items added by HCPs in Round 1					
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
Items added/modified by patient focus group					
35. Role and importance of pulmonary rehabilitation and regular physical activity					New item: 9 and 14 combined
36. Managing coexisting medical conditions					“Comorbid” changed to “coexisting”
Components that achieved a high level of consensus (<i>i.e.</i> , IQR=0) are highlighted in orange colour. PF: pulmonary fibrosis; HCP: healthcare professional; IQR: interquartile range; R1: Delphi Round 1; R2: Delphi Round 2.					

None of the eight statements regarding the format and delivery of a PF self-management package reached consensus in Round 1 (table 3). 28 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 out of 28) of components reached consensus and were endorsed by the focus group. These included managing fatigue; role and importance of pulmonary rehabilitation (PR); role

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

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

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), but 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 favourite TV show, that's no good for you.

Focus group participants also suggested using the term "coexisting" 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 coexisting 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

TABLE 4 Essential, desirable and optional components of self-management in PF**Essential components (median score ≥ 4 , IQR=0)**

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 coexisting 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

Desirable components (median score=5, IQR >0)

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

Optional components (median score=4, IQR >0)

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

PF: pulmonary fibrosis; IQR: interquartile range.

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 endeavour 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 programmes [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 programmes 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 programme 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 programmes have been identified as some of the barriers to being physically active [26, 33]. In COPD, participants who successfully completed a 12-month supervised maintenance programme reported that regular assessments were important to remain physically active [34]. Therefore, regular feedback regarding an individual's fitness and accessible exercise programmes may be key facilitators to remain physically active following a PR programme.

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 6 months following a web-based self-management programme that comprised 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 physical activity [33] and therefore being able to see achievements is important. Previous studies have shown that the use of activity trackers such as pedometers and an 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 programmes 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 a 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 geographical 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 <10 to hundreds [41, 42]. A similar study achieved consensus on the investigated topics with similar numbers to 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.

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