

Irish Lung Fibrosis Association

2000 Steps More

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Introduction

The Irish Lung Fibrosis Association (ILFA) is a national organisation dedicated to supporting individuals and families affected by lung fibrosis in Ireland. Founded in 2002, ILFA provides resources, advocacy, and education to improve the quality of life for those living with lung fibrosis. Lung fibrosis is an umbrella term for several chronic and progressive lung disease characterised by scarring of the lung tissue and in some cases, leading to severe breathing difficulties. These conditions frequently pose a substantial burden due to the progressive nature and lack of curative treatments.

Management of lung fibrosis focuses on symptom relief, slowing disease progression, and improving the quality of life. Important components include pharmacotherapy, lifestyle support, and pulmonary rehabilitation. Addressing the biopsychosocial wellness of people with lung fibrosis is key.

To this end, ILFA developed the "2000 Steps More" initiative which encourages participants to increase their daily physical activity by adding an extra 2,000 steps to their routine, promoting better physical health and overall well-being.

Following a 2012 pilot study, the "2000 Steps More" initiative has been successfully delivered to patients across Ireland. This report is the first evaluation of the programme since that time.



Lung with extensive fibrosis (Image credit: Yale Rosen).



Lung Fibrosis in Ireland

In Ireland, idiopathic pulmonary fibrosis (IPF) and other forms of interstitial lung diseases (ILDs) pose significant health challenges. IPF, the most common form of ILD, affects approximately 2-20 people per 100,000 globally, with similar prevalence expected in Ireland. The median age of diagnosis for IPF is 65 years of age, with a higher prevalence in males and former smokers.¹

Up to date knowledge about the scale and burden of IPF in Ireland is constrained by the lack of an appropriate patient registry, and a dedicated national clinical programme. Both of these important avenues are being actively pursued by ILFA.

1. Richeldi L et. al, Idiopathic pulmonary fibrosis, *Lancet*. 2017. 389:10082: 1941-1952, [https://doi.org/10.1016/S0140-6736\(17\)30866-8](https://doi.org/10.1016/S0140-6736(17)30866-8).



The 2000 Steps More Initiative

The 2000 Steps a Day Challenge was based on an idea by Ms. Irene Byrne, Senior Physiotherapist with the Heart and Lung Transplant Unit at the Mater University Hospital Dublin and developed in collaboration with ILFA and patients in 2012/2013.

It is a simple concept suited to patients of all exercise levels because an individual's exercise goal is determined by their baseline step count. This ensures that the exercise programme can be used by those with mild or limited disease who are active and able to engage in exercise, and those with more advanced disease who may be struggling with reduced physical ability.

Patients begin the programme by recording their step count for a few days using their pedometer and then aim to add an extra 2000 steps a day to reach a new baseline over the following days or weeks depending on their ability. 2000 steps reflect the average number of steps required to walk one mile. Furthermore, research has shown multiple health benefits associated with 2000 steps per day and greater effects with more steps.² A walking pack and information are provided to the participant to support their engagement with the initiative.

In 2014, ILFA's 2000 Steps A Day Challenge won the Irish Healthcare Award for the Best Patient Organisation Project of the Year.

² Ahmadi MN et.al. Do the associations of daily steps with mortality and incident cardiovascular disease differ by sedentary time levels? A device-based cohort study. *Br J Sports Med.* 2024 Mar 8;58(5):261-268. doi: 10.1136/bjsports-2023-107221. PMID: 38442950; PMCID: PMC10958308.

Reviewing the 2000 Steps More Initiative

The 2000 Steps More initiative has been successfully up and running for over a decade. The need to review the efficacy of the programme was identified by ILFA Board member, Nicola Cassidy, with support from the ILFA Patient and Public Involvement (PPI) advisory group.

Working with authors of this report from the University of Limerick (UL), a successful application was made to the Irish Research Council, who are funding this and related work.

Recent past participants of the 2000 Steps More initiative (within the last 24 months) were invited to complete an online survey (Appendix 1) and engage in a focus group, to offer feedback and opinion on their experience of the 2000 Steps More initiative.

The recruitment of potential participants was led by the ILFA administrator and using diverse social media, patient events and networks of clinical colleagues. The survey was disseminated in Spring of 2024, and reports on various facets of the initiative. This research aims to enhance further iterations of the 2000 Steps More initiative and other ILFA endeavours for people with lung fibrosis and their families.



Results

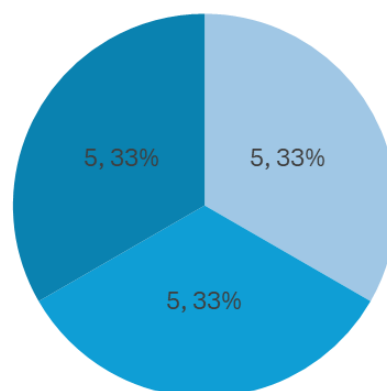
A total of 15 participants completed the survey, of whom 5 participated in a focus group and one individual interview. All participants reported some form of ILD as their chief respiratory diagnosis. The demographic details of participants are as follows:

Gender and age



Male: 9 (60%) Female: 6 (40%)
Average age: 67.5 years (43-79)

Setting: Urban, suburban, rural: 5(33% each)



■ Rural ■ Suburban ■ Urban



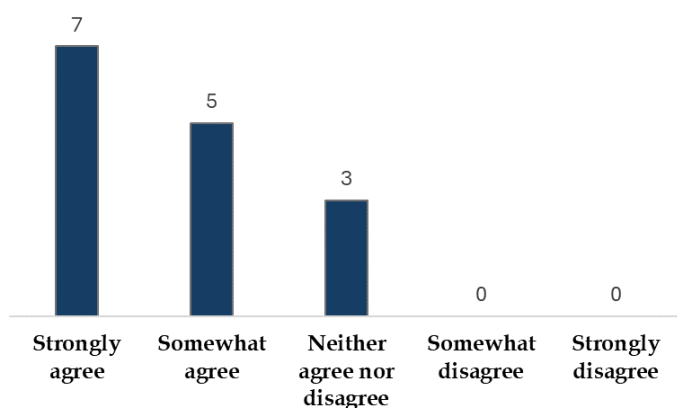
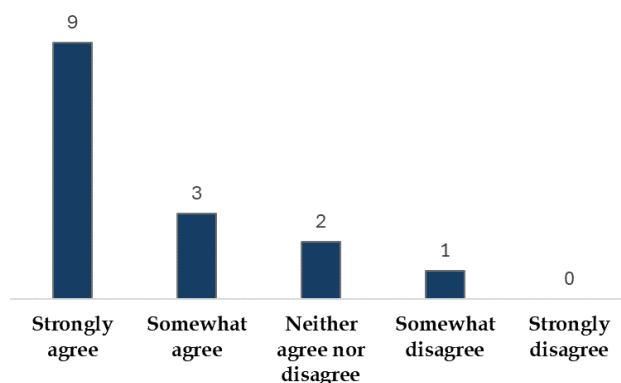
Geographic spread:

Dublin: 7 (46.7%)
Kerry: 2 (13.3%)
Clare: 1 (6.7%)
Kildare: 1 (6.7%)
Monaghan: 1 (6.7%)
Tipperary: 1 (6.7%)
Wexford: 1 (6.7%)
Wicklow: 1 (6.7%)

Results

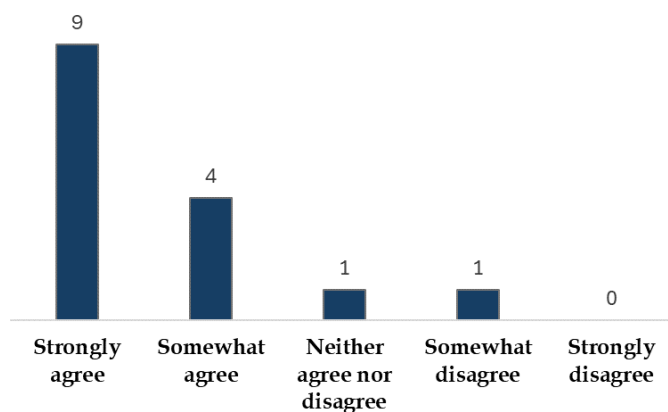
Participants were invited to rate certain aspects of the programme on a 1-5 Likert Scale (1: Strongly agree; 2: Somewhat agree; 3: Neither agree nor disagree; Somewhat disagree; Strongly disagree.). The statements posed are as follows:

The material provided was clear understandable to you

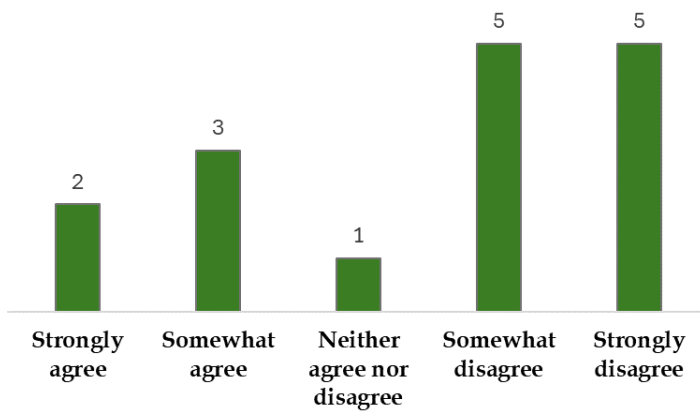


The pedometer that was provided motivated you to reach your target.

The ILFA 2000 Steps More challenge motivated you to exercise every day.

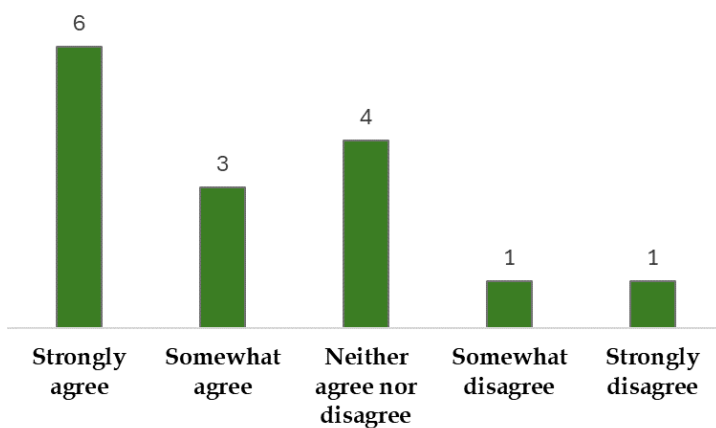
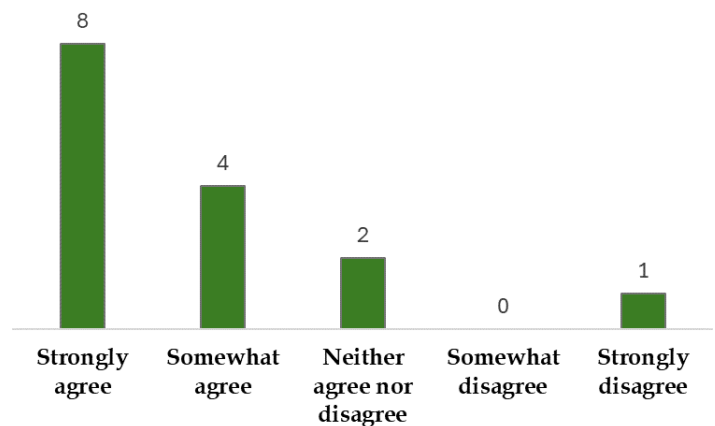


Results



The 2000 Steps challenge was difficult to incorporate into your daily routine.

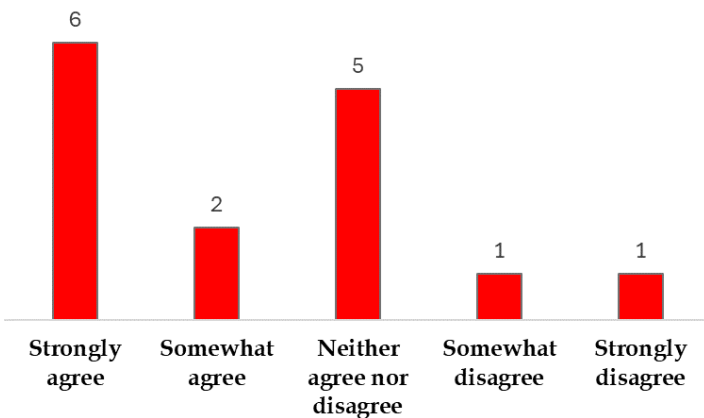
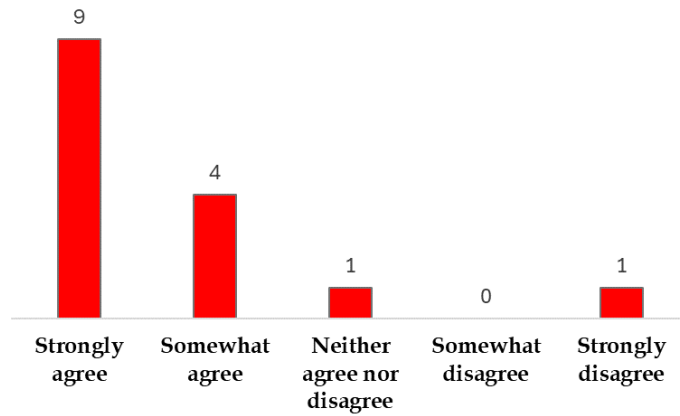
The language used in the material was suitable.



The walking programme helped improve your confidence.

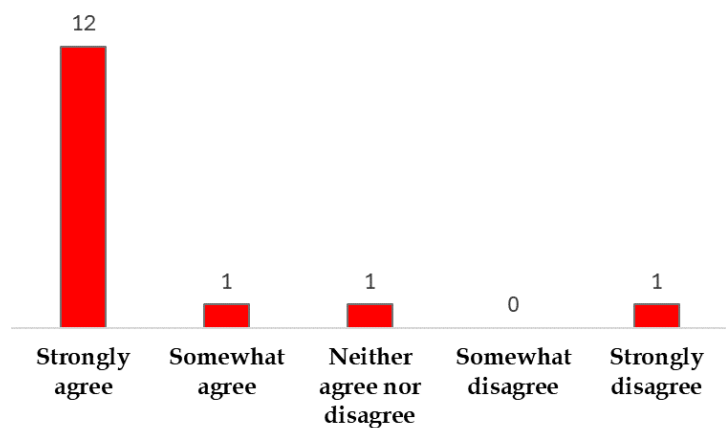
Results

You felt a sense of achievement after reaching your target.



The diary to record your steps, distance, calories and level of exertion was useful.

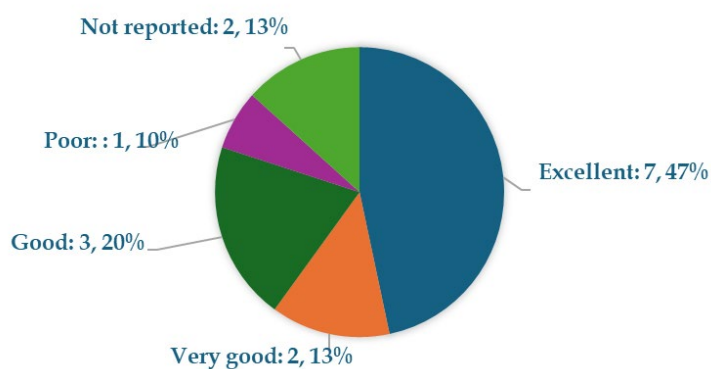
I would recommend this exercise programme to another patient.



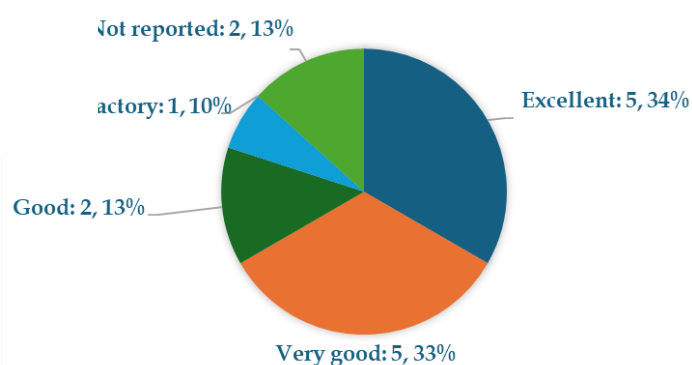
Results

Participants were invited to rate the usefulness of the resources supplied as part of the programme, including the pedometer, the information leaflet, the motivating poem and contract for success and the steps diary. Resources were provided on a continuum from excellent to poor, where this information was reported by participants.

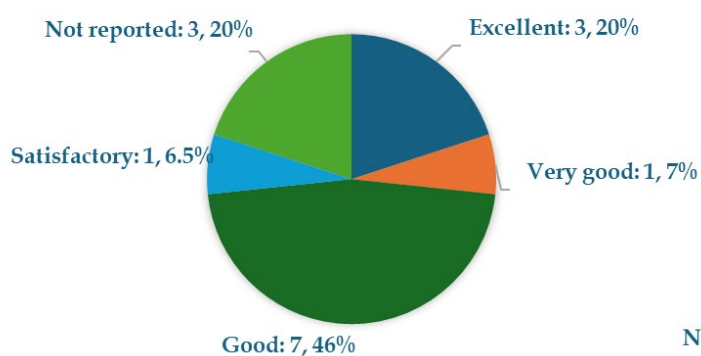
PEDOMETER



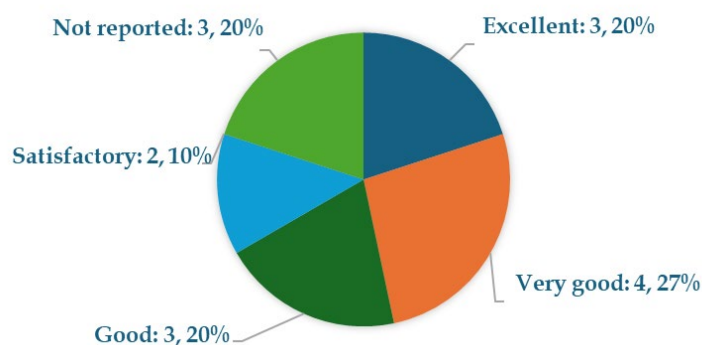
INFORMATION LEAFLET



POEM & CONTRACT FOR SUCCESS



STEPS DIARY



Results

Survey participants were also asked to comment on the best and worst features of the 2000 Steps More programme. The majority of participants were positive in their feedback, citing the ease of use and motivational nature of the initiative.

“It’s easy to do – you just need determination”.

“The pedometer was the biggest motivator for me. When I checked it and the step count was low that was my incentive to put on the coat and get out.”

“It helped me to focus on doing some exercise.”

Participants also commented on the impact it had on their sense of health and wellbeing.

“I felt better when I improved my step

numbers.” “Gaining confidence to get out”.

“I enjoyed getting the family out with me”

Regarding suggestions for improvement, most participants did not feel any enhancements were required. However, there was some feedback about the solitary nature of the programme.

“I would have liked more involvement/support from ILFA or other Association members. To me it was a solitary exercise.”

There were also recommendations about the use of Smart phones in place of the pedometer, although this did not reflect the views of all participants.

Focus Group Discussions

Five participants with experience of the 2000 Steps More initiative participated in a focus group (4 participants) and individual interview (1 participant) to further explore themes identified in the survey. Three of these participants were female, and two were male. The average age was 62.5 years (43-77), with participants coming from a range of urban, suburban and rural settings. All participants had been diagnosed with some form of ILD.

The participants were asked to report where they had learned about the initiative. There was a variety of responses with 2 participants learning about 2000 Steps More initiative through their clinicians who referred participants to ILFA; 1 through family members; and 1 through independent internet searches.

As with the survey, themes of motivation and focus were highlighted as important benefits of the initiative. Furthermore, the information that was provided about IPF in the ILFA pack was invaluable to many of the participants. One commented that prior to receiving this information:

“I got very little information from anyone at all about supports (for IPF), including from my consultant.”

2000 Steps More Pack



There was a great deal of discussion about the 2000 Steps More resource pack that is provided to participants, and the utility of the elements therein.

For all of the participants, the utility of a pedometer was usurped by technology, with all participants preferentially using Smart phones to monitor their steps.

Focus Group Discussions

Similarly, these participants reported that they used their Smart phones to record their steps in favour of a less technical paper-based steps diary. They did acknowledge that not everyone has a Smart phone, and that paper-based diaries and pedometers still have a role in the 2000 Steps More initiative but recommended that these resources be issued by request rather than by default to patients. Furthermore, the 2000 Steps More initiative was developed at a time preceding the widespread use and availability of Smart phone technology.

While participants really valued the information provided by ILFA as part of the 2000 Steps More pack, they commented that the DVD provided was of limited use as this technology is largely redundant for most people. All five participants reported that they would be very happy to receive information from ILFA in electronic form. The caveat with this of course is that these participants are technologically savvy as evidenced by their engagement in a virtual focus group, and paper-based information still has an important role for other ILFA members.



The provision of a fan was welcomed by the participants who found it a useful tool in dealing with the symptoms of their condition. However, some participants noted that the pedometer was quite fragile and broke within weeks of use. This same comment regarding quality of the fan was also made. One participant noted:

“My fan was fantastic but stopped working after a few weeks”

Participants further remarked that it might be sufficient to inform people about the utility of fans (and where appropriate, pedometers), and advise that people buy their own equipment. It should be noted that the pedometer is an approved medical grade device that costs €10 each. ILFA provides all the materials free of charge to patients and replacement items are available free of charge if needed.

Going Forward

As stated, all participants in this focus group reported the 2000 Steps More initiative to be a valuable tool in highlighting the importance of exercise in the management of IPF and motivating people to get out and walk within the scope of their ability.



“The 2000 steps always got me focussed to walk and I always felt better after exercise”.

There were some recommendations made for improvements to the initiative and future plans for other ILFA initiatives.

Participants noted that some level of follow-up or monitoring of people engaging in the 2000 Steps More initiative would be welcomed.

“I felt that there could have been some sort of follow-up. I felt I was just sent the package and just told “do it”.

The frequency of checking in was recommended to be “once a week in an ideal world”, but there was recognition by participants that ILFA resources are stretched and that this might be impossible. However, participants noted that they would be happy to receive follow-up from a peer, and clinical expertise was not required.

On that note, participants responded favourably to suggestions around a proposed “buddy-walking” system, where they would be paired either virtually or in real life with a buddy of a similar physical capacity to walk with. They felt that such a system would provide motivation, accountability and support and would likely improve their exercise engagement. An initiative reflecting this ambition (ILFA BUILD 2K) is currently in development.

Conclusions

The ILFA 2000 Steps More initiative is a well received, successful programme that positively impacts the exercise engagement and holistic wellbeing of participants. It is viewed as easy to use, accessible and well-resourced. There were suggestions around upgrades to the pack that accompanies the initiative, in particular, using technological options available to participants and ILFA. This may be a cost-effective option for ILFA as well as providing more appropriate choices for recording steps and disseminating information. Recommendations around monitoring and peer support should be explored to optimise the 2000 Steps More and other ILFA initiatives.

Next Steps

Based upon this report, a meeting took place in June of 2024 between the author (RC) and several members of ILFA. The findings of the report were warmly welcomed and a firm commitment to consider and address recommendations was provided. ILFA remains dedicated to pursuing all possible measures to support optimal care for all ILD patients and their families.

Acknowledgements

The authors would like to thank all the participants who contributed to the generation of this report and to the Irish Research Council who funded this report through the “New Foundations” research call, 2023.

Appendix: Survey Instrument

BUILD 2K: Buddy Walking In Fibrotic Lung Disease – Developing the 2000 Steps a Day Challenge

What is this study about? This study which is being conducted by University of Limerick in conjunction with ILFA, will gather feedback from people who have participated in ILFA's 2000 Steps programme. This information will help ILFA to update and improve the service.

Who are we looking for? We are looking for people who took part in the ILFA 2000 steps programme over the last 2 years. We are looking for adults aged 18 years or older only.

What will I have to do? You will be asked to complete a brief (10 minutes) online questionnaire about the 2000 steps programme. You will also be invited to participate in a focus group at a later date with up to nine other people who have also completed the 2000 steps programme. The group discussion will be audio recorded and will take about one and a half hours in total. All responses will be treated as confidential.

Where will the focus group take place? The focus group will take place either online via video call, using Microsoft Teams, or in-person if that suits more people. If you do not have access to the technology required to participate in an online video call your focus group will be conducted with a telephone conference call.

If you are interested in participating, further details are provided in the information sheet linked here and the consent sheet here (link disabled).

You will be asked to provide your consent in the next section of this online questionnaire.

You can also view the research privacy notice which shows what will happen with your data here:

For further details or if you have any questions regarding the study, please contact: Roisin.Cahalan@ul.ie or Ciaran.Purcell@ul.ie

Many thanks!

Do you consent to participate in this short online questionnaire?

Yes No

What is your name?

Please provide your email address.

What is your age in years?

Gender: Do you identify as.. (male, female, other, prefer not to say).

What is your respiratory diagnosis?

In what county do you live? (32 county listed)

How best would you describe your home setting? (Rural, Suburban, Urban).

Experience of the 2000 Steps a Day Challenge When did you undertake the 2000 Steps Challenge? Please select a year

- 2020
 2021
 2022
 2023
 2024

How much of the programme did you complete? (An approximate answer is fine).

Considering the following scale, please rate the following questions:

| | Strongly disagree | Somewhat disagree | Neither agree nor disagree | Somewhat agree | Strongly agree |
|---|-------------------|-------------------|----------------------------|----------------|----------------|
| The material provided was clear / understandable to you | | | | | |
| The pedometer that was provided motivated you to reach your target. | | | | | |
| The ILFA Walking Challenge motivated you to exercise every day | | | | | |

| | | | | | |
|--|--|--|--|--|--|
| The 2000 Steps challenge was difficult to incorporate into your daily routine. | | | | | |
| The language used in the material was suitable. | | | | | |
| The walking programme helped improve your confidence. | | | | | |
| You felt a sense of achievement after reaching your target. | | | | | |
| The diary to record your steps, distance, calories and level of exertion was useful. | | | | | |
| I would recommend this exercise programme to another patient. | | | | | |

Please rate the usefulness of the materials in the ILFA 2000 Steps a

Day challenge.

| | Poor | Satisfactory | Good | Very Good | Excellent | Not applicable |
|-----------------------------|------|--------------|------|-----------|-----------|----------------|
| Pedometer | | | | | | |
| Poem & contract for success | | | | | | |
| Diary | | | | | | |
| Information Leaflet | | | | | | |

Do you have any comments or feedback on any of these resources?

What was the best part (s) about the 2000 Steps Walking Challenge?

Do you have any ideas or suggestions on how to improve the 2000 Steps Walking Challenge?

Would you be willing to participate in a brief focus group to further explore our thoughts and opinions about the 2000 Steps walking challenge?

- Yes
- Maybe
- No

