

ILFA Member Service Needs Analysis

Start of Block: ILFA Welcome text

Q1 Welcome

Thank you for agreeing to take part in this Irish Lung Fibrosis Association survey. This survey is being administered by Invisio Ltd on behalf of the Irish Lung Fibrosis Association (ILFA). The intended audience for this survey are lung fibrosis patients and post-transplant patients. The purpose of the survey is to assess your experience of accessing support services and various healthcare professionals.

This short survey should take about 5 minutes to complete. Your personal details will not be associated with your response, your response is completely anonymous.

Please click / touch "Next" below to begin...

Q2 Privacy The information collected on this survey is aggregated in all reporting and is used by the Irish Lung Fibrosis Association (ILFA) to help plan for the future for the benefit of its members. Information collected on this survey will not be used for any purpose other than this.

Identifiable or individual responses in their entirety will never be used in any reporting of survey results. The legal basis for the ILFA contacting you is the ILFA's legitimate interest in understanding the views and experiences of its members and other stakeholders. You may unsubscribe from further contact for this purpose at any time by emailing info@ilfa.ie with "unsubscribe surveys" in the subject line. ILFA survey responses are processed by our research partners Invisio Ltd and research consultant Daniel Sheahan using the Qualtrics technology platform. Any personally identifiable information supplied by you in responding to this survey is given voluntarily and is not part of a statutory or contractual requirement. There is no automated decision making associated with this survey. All data is held securely on servers in the European Union. All data is treated by the respective organisations in accordance with [Invisio's privacy statement](#) and [ILFA's privacy statement](#)

End of Block: ILFA Welcome text

Start of Block: ILFA demographics

Q3 Please choose your age group:

- Under 18
- 18 - 30
- 31 - 40
- 41 - 50
- 51 - 60
- 61 - 70
- 71 - 80
- 81 or older

Page Break

Q4 Do you identify as:

Male

Female

Other

Page Break

JS

Q5 Which county do you live in?

▼ Antrim ... Wicklow

End of Block: ILFA demographics

Start of Block: Patient type

Q6 Are you:

- A lung fibrosis patient
- A post-transplant patient

Page Break

Display This Question:

If Are you: = A post-transplant patient

Q7 When did you receive your lung transplant?

- In the last year
- Between 1 and 2 years ago
- Between 2 and 3 years ago
- Between 3 and 5 years ago
- More than 5 years ago

Page Break

Display This Question:

If Are you: = A lung fibrosis patient

Q8 When were you diagnosed with lung fibrosis?

- In the last year
- Between 1 and 2 years ago
- Between 2 and 3 years ago
- Between 3 and 5 years ago
- More than 5 years ago

Page Break

Q9 Did you receive your initial diagnosis:

- In the public healthcare system
- In the private healthcare system

End of Block: Patient type

Start of Block: Clinical nurse specialist

Q10 Do you have access to a clinical nurse specialist?

- Yes
- No

End of Block: Clinical nurse specialist

Start of Block: Services referred to

Q11 Have you ever been referred to any of the following (please select as many as apply or else "none of the above")

- Social worker
 - Dietitian
 - Clinical psychologist
 - Occupational therapist
 - Speech therapist
 - Physiotherapist (for a pulmonary rehab programme)
 - None of the above
-

Page Break

Display This Question:

If Have you ever been referred to any of the following (please select as many as apply or else "none... = Social worker

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Dietitian

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Clinical psychologist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Occupational therapist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Speech therapist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Physiotherapist (for a pulmonary rehab programme)

Carry Forward Selected Choices from "Have you ever been referred to any of the following (please select as many as apply or else "none of the above")"



Q12 How long after your initial diagnosis were you referred to your...

	Within a month of my diagnosis	Within 2 to 6 months of my diagnosis	Within 7 to 12 months of my diagnosis	More than 12 months after my diagnosis
Social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietitian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None of the above	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Services referred to

Start of Block: Rating services received

Display This Question:

If Have you ever been referred to any of the following (please select as many as apply or else "none... = Social worker

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Dietitian

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Clinical psychologist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Occupational therapist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Speech therapist

Or Have you ever been referred to any of the following (please select as many as apply or else "none... = Physiotherapist (for a pulmonary rehab programme)

Carry Forward Selected Choices from "Have you ever been referred to any of the following (please select as many as apply or else "none of the above")"



Q13 How would you rate the service you have received from your...

	Excellent	Good	Okay	Poor	Very poor
Social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietitian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input checked="" type="radio"/> None of the above	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Rating services received

Start of Block: Services would like or have liked

Q14 Thinking back to when you received your initial diagnosis, would you have benefitted from a referral to any of the following immediately after diagnosis?

	Yes, I would benefitted from this service	I had this service immediately after diagnosis	No, there would have been no benefit to me at that time
A social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A dietitian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A clinical psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A speech therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

Q15 Do you think you would benefit from any of the following now?

	Yes, I would benefit if I had this service now	I already have this service now	No, there would be no benefit for me right now
A social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A dietitian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A clinical psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A speech therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

Q16 Do you think you would benefit from any of the following in the future?

	Yes, I would benefit from this in the future	No, there would be no benefit for me in the future
A social worker	<input type="radio"/>	<input type="radio"/>
A dietitian	<input type="radio"/>	<input type="radio"/>
A clinical psychologist	<input type="radio"/>	<input type="radio"/>
An occupational therapist	<input type="radio"/>	<input type="radio"/>
A speech therapist	<input type="radio"/>	<input type="radio"/>
A physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>

End of Block: Services would like or have liked

Start of Block: Preferred mode for accessing services

Q17

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

A social worker

- Group setting
 - Face-to-face appointment
 - Virtually
 - Not at all / no interest
-

Q18

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

A dietitian

- Group setting
- Face-to-face appointment
- Virtually
- Not at all / no interest

Page Break

Q19

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

A clinical psychologist

- Group setting
- Face-to-face appointment
- Virtually
- Not at all / no interest

Page Break

Q20

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

An occupational therapist

- Group setting
- Face-to-face appointment
- Virtually
- Not at all / no interest

Page Break

Q21

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

A speech therapist

- Group setting
- Face-to-face appointment
- Virtually
- Not at all / no interest

Page Break

Q22

For the following service, please select your preferred ways of accessing it. You may select more than one way for accessing each service.

A physiotherapist (for a pulmonary rehab programme)

- Group setting
- Face-to-face appointment
- Virtually
- Not at all / no interest

End of Block: Preferred mode for accessing services

Start of Block: Appointment preferences

Q23 For the following services, what is your preference for appointment availability?

	Once-off following diagnosis	Annual appointment	An appointment as needed
A social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A dietitian	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A clinical psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A speech therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A physiotherapist (for a pulmonary rehab programme)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Appointment preferences

Start of Block: What would make life better now

Q24 What services would make your life better right now?

End of Block: What would make life better now
