

Stakeholder attitudes to a potential national registry for interstitial lung disease

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Abstract

Aim

This survey aimed to characterise patient and healthcare professional (HCP) attitudes to a potential national registry of interstitial lung disease (ILD).

Methods

The survey was co-developed with the Irish Lung Fibrosis Association (ILFA) Patient/Public Involvement Research Advisory Group and distributed electronically to ILFA members, specialist respiratory healthcare professionals (HCPs) and on ILFA's social media channels. Patients provided feedback on the acceptability of analysis of their medical data. HCPs provided feedback on the utility of a national registry. Responses were scored on a 4-point scale (1 = very low; 4 = very high acceptability/utility).

Results

Responses were collected from 6-26 November 2023. A high proportion of patients reported being "very comfortable" with collection of medical data [e.g. for time to diagnosis and care type: 89 patients (67%)] and with further analysis for research [106 (78%)]. HCPs reported high utility for data on patients' medical condition [32 HCPs (94%)] and disease impacts [31 (81%)]. Both groups stated concerns about data confidentiality, access and security. HCPs stated concerns about GDPR compliance and logistical aspects with long-term registry maintenance.

Discussion

The concept of a national ILD registry and further analysis of data is acceptable to patients and perceived as useful by HCPs.

Introduction

Interstitial lung disease (ILD) is an umbrella term describing a spectrum of diseases of progressive scarring of the lungs causing progressive breathlessness, limitation of physical activities and worsening quality of life¹. However, due to the diversity of ILD conditions, paucity of guidance and updates to diagnostic criteria over time, it has proven to be challenging to precisely determine ILD incidence and prevalence. A recent multi-country systematic review of 80 studies reported the prevalence of idiopathic pulmonary fibrosis [(IPF) the most common form of ILD] to range from 7 to 1,650/100,000 population². Another study estimated the median incidence of ILD as 7.22 [interquartile range (IQR) 5.57–8.96]/100,000 for men and 4.34 (IQR 3.36–6.29)/100,000 for women in the UK and European Union in 2017³. Separate analyses of UK primary care databases suggested that the incidence of IPF increased between 2000 and 2008⁴ and between 2000 and 2012⁵. The incidence and prevalence of ILD in Ireland is not accurately known at present.

Patient registries have the potential to contribute to the understanding of incidence, impacts, treatment and outcomes of chronic conditions and to optimise planning of healthcare resources for diagnosis and treatment. The recent report from the Future of Registries Taskforce emphasised the importance of maintaining the sustainability of registries to optimise patient care and ensure efficient use of healthcare resources in Ireland⁶. Patient registries for ILD are currently implemented in Australasia⁷, European Union countries⁸ and the UK⁹ among others. However, registry data is not always complete at a national level as some specialist centres in each country are not contributing data to their national registries. The UK registry regularly publishes reports⁹ and makes data available for analysis. For example, the UK registry data showed an increasing prescription of antifibrotic therapies for IPF at presentation from approximately 32% in 2013 to 72% in 2023¹⁰ and a reduction in surgical biopsies from 14% in 2013 to 5.5% in 2022¹¹.

There is no ILD national registry in Ireland. Accurate data on the numbers of patients on treatment, receiving pulmonary rehabilitation and attending specialist ILD clinics are not available making planning for delivery of care at a national level difficult.

The Irish Thoracic Society (ITS) piloted a national registry of IPF in 2016, but this was incomplete as some specialist centres did not participate, and sustained funding was not available to expand or continue with data collection. Data from this pilot registry reported 324 day-cases and 657 inpatient hospitalisations for IPF with usage of 6,452 inpatient hospital bed-days in 2016¹². In their report in 2018, the ITS ILD Registry estimated that 1-2 new patients received a diagnosis of IPF every day in Ireland¹³.

The Irish Lung Fibrosis Association (ILFA) is the national patient organisation supporting patients diagnosed with lung fibrosis, their families, and respiratory medicine healthcare professionals (HCPs) specialising in lung fibrosis. ILFA supports the establishment of an ongoing national registry for ILD. ILFA commissioned this survey to gain an understanding of patient and HCP attitudes to data collection and further analysis of that data if a national registry was available. This new understanding could support the establishment of an ILD registry in Ireland.

Methods

The survey questions were developed by ILFA in collaboration with the ILFA Patient and Public Involvement (PPI) Research Advisory Group (which includes people living with ILD). The survey was not reviewed by an institutional ethics committee. However, the PPI Research Advisory Group was tasked with reviewing the project to ensure the research aligned with ILFA's mission and values and to safeguard participants' confidentiality, rights and best interests.

The survey was promoted to patients and to healthcare professionals (HCPs) specialising in ILD diagnosis on ILFA's website and social media channels. Responses were collected online on a form hosted on the Qualtrics platform (<https://www.qualtrics.com/en-gb/>) via a link on the ILFA website¹⁴ which was opened for data input in November 2023. Prior to data entry, respondents were advised that the purpose of the survey was to collect information to help ILFA plan for the future benefit of its members, that personally identifiable information would not be collected and that all respondents' data would be pooled for analysis and reporting. After patient respondents had entered their demographic data, they were presented with a description of a proposed national registry to collect anonymised medical information on ILD and advised that their anonymised data would be accessible to registry staff and could be made available to health researchers on request. Patients were asked to rate their comfort with inclusion of data on their demographics, medical history and treatment, impacts of ILD on their health and information on their carers (if any) in a registry. They were also asked to rate their comfort with giving consent to further use of their data for research on ILD, healthcare and resource planning and the cost of

medicines research. A 4-point scale was used to rate patient comfort with inclusion or use of their data: very comfortable = 4, quite comfortable = 3, some reservations = 2, very uncomfortable = 1. HCPs were asked to score the utility of registry data on patient demographics, family history, treatments, symptoms, comorbidities, impacts of ILD on patient health and information on carers. A 4-point scale was used to rate the utility of registry data: very useful = 4, somewhat useful = 3, not very useful = 2, not at all useful = 1. Responses were expressed as the average scores (range 0-4) for each question. Patients and HCPs were also asked to describe reservations and concerns and could enter free-text comments. There was no statistical estimation of sample size.

Results

Responses were received from 138 patients (125 lung fibrosis and 13 post-lung transplant) and 35 healthcare professionals. Responses were collected between 6 and 23 November 2023 and the median time to complete the survey was 6.4 minutes.

Demographics

Patient demographics are illustrated in Table 1. The demographic features were typical of the characteristics observed in other studies of ILD patient populations. Only 4 (11%) of the HCPs were currently inputting data into existing registries.

Table 1. Patient demographics

Total patient population [n =138 (100%)]		n (%)
Diagnosis*	lung fibrosis	112 (81)
	other ILD	13 (9)
	post-lung transplant	13 (9)
Sex	male	80 (58)
	female	58 (42)
Age category (y)	31-40	2 (1)
	41-50	6 (4)
	51-60	18 (13)
	61-70	57 (41)
	71-80	47 (34)
	≥81	8 (6)
Lung fibrosis patient population [n=125 (100%)]		n (%)
Time since diagnosis (y)	in the last year	31 (25)
	1-2 years ago	21 (17)
	2-3 years ago	19 (15)
	3-5 years ago	32 (26)
	>5 years ago	22 (18)
On oxygen	yes	52 (42)
	no	73 (58)
On antifibrotic therapy	yes	78 (62)
	no	47 (38)
Employment status	working full-time	7 (6)
	working part-time	4 (3)
	looking after home/family	5 (4)
	retired	83 (66)
	unable to work due to illness or disability	25 (20)
	other	1 (1)

*as reported by patient

Patient responses

Patient responses to selected questions are shown in Table 2. In addition to the results reported here, a large proportion of patients reported being “very comfortable” or “quite comfortable” with data collection on ethnicity, familial connection with other patients, living circumstances, relationship with and availability of carers at home, symptom details and impacts on daily living (including ability to work and financial), history of assessment for transplant and access to clinical care. A high proportion of patients (range 70-78%) reported that they would be “very comfortable” with providing consent for their data to be used for research purposes.

When summarised by broad categories of data type the average scores of patient comfort were (1) consent to use of data for various purposes: 3.68 (2) history of condition and current status: 3.56 (3) demographic information: 3.54 (4) medical information: 3.51 (5) impacts on patient: 3.46 and (6) carer information: 3.43. (Maximum possible score was 4.0.)

Table 2: patient responses

Question: how comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?						
	very comfortable [n (%)]	quite comfortable [n (%)]	some reservations [n (%)]	very uncomfortable [n (%)]	total respondents* [n (%)]	average score**
Time of onset of symptoms to diagnosis	89 (67)	37 (28)	4 (3)	2 (1)	132 (100)	3.61
Type of care/treatment	89 (67)	34 (26)	8 (6)	1 (1)	132 (100)	3.60
Other conditions that may impact prognosis	77 (61)	38 (30)	10 (7)	1 (1)	126 (100)	3.52
Full record of all symptoms	79 (63)	34 (27)	9 (7)	3 (2)	125 (100)	3.51
Impact on family friends	82 (63)	31 (23)	14 (11)	2 (1)	129 (100)	3.50

Question: If a national ILD Registry is developed, how comfortable would you be in giving your consent for your data to be used for the following purposes:						
	very comfortable [n (%)]	quite comfortable [n (%)]	some reservations [n (%)]	very uncomfortable [n (%)]	total respondents* [n (%)]	average score**
Research into the condition	106 (78)	24 (18)	4 (3)	1 (1)	135 (100)	3.74
Healthcare planning	99 (74)	30 (22)	4 (33)	0 (0)	133 (100)	3.71
Cost of medicine research	96 (72)	28 (21)	8 (6)	1 (1)	133 (100)	3.65
Resource planning	94 (70)	33 (24)	7 (5)	1 (1)	135 (100)	3.63

*total possible sample n = 138

**maximum possible score = 4.0

HCP responses

HCP responses to selected questions are shown in Table 3. A high proportion of HCPs reported that registry information on treatment, symptoms, impact on patient well-being and time since diagnosis would be “very useful”.

When summarised by broad categories of data type the average scores of HCP opinion of utility were (1) medical information: 3.85 (2) history of condition and current status: 3.79 (3) impacts on patient: 3.67 (4) demographic information: 3.31 and (5) carer information: 3.31. (Maximum possible score was 4.0.)

Table 3: HCP responses

Question: How useful to you as a HCP would each of the following types of information be if held on the ILD Registry?						
	very useful [n (%)]	somewhat useful [n (%)]	not very useful [n (%)]	not at all useful [n (%)]	total respondents* [n (%)]	average score**
Type of care/treatment	32 (94)	2 (6)	0 (0)	0 (0)	34 (100)	3.94
Comorbidities - other conditions that may impact patient prognosis	31 (91)	3 (9)	0 (0)	0 (0)	34 (100)	3.94
Impact on patient's overall well-being	31 (88)	4 (11)	0 (0)	0 (0)	35 (100)	3.89
Level of cough	30 (88)	3 (9)	1 (3)	0 (0)	34 (100)	3.85
Time of onset of symptoms to diagnosis	29 (83)	6 (17)	0 (0)	0 (0)	35 (100)	3.83
Transplant options	28 (82)	6 (18)	0 (0)	0 (0)	34 (100)	3.82
Level of breathlessness	29 (83)	5 (14)	1 (3)	0 (0)	35 (100)	3.80

Level of fatigue	28 (82)	5 (15)	1 (3)	0 (0)	34 (100)	3.79
Current access to hospitals, clinics, dieticians and HCPs	25 (71)	6 (17)	1 (3)	0 (0)	35 (100)	3.77
Full record of all symptoms	27 (79)	5 (15)	2 (6)	0 (0)	34 (100)	3.74

*total possible sample n = 35

**maximum possible score = 4.0

Reservations/concerns

The majority of patient respondents (70%) did not report any concerns about the registry data. Some patients and HCPs expressed concerns on security and privacy of data held on the registry (see Table 4). Some HCPs expressed additional concerns on GDPR compliance and on the work needed to maintain the registry on an ongoing basis.

Table 4. Concerns and observations reported by patients and HCPs [number of respondents (%)]

Patients %, (n=87)		HCPs %, (n=25)	
No concerns	61 (70)	No concerns	10 (40)
Hope results raise awareness/improve research	11 (13)	Confidentiality/GDPR compliance	6 (24)
Who has access/confidentiality /anonymity	8 (9)	Registry would need to be kept up to date	5 (20)
Findings to be used for research only, not commercial	3 (3)	Time needed to input data/maintain registry	5 (20)
Security/hacking	3 (3)	Who would be responsible for inputting data/administration	3 (12)
Other 3 (3)	3 (3)	Suggest other data points to be included	3 (12)

Discussion

In summary, the patient respondents reported high levels of comfort with the collection and use of their demographic and medical data for a potential national ILD registry. The level of comfort was highest with the collection and use of data under the category “history of condition and current status”. Patient respondents were particularly comfortable with providing consent for the use of their data for research into the condition. The HCP respondents reported that data on

“medical condition”, “history of condition and current status” and “impacts on patients” were the most useful categories. Both groups reported concerns on confidentiality and security of the data. In addition, HCPs reported concerns on GDPR compliance and the logistics of maintenance of the registry.

This research survey identified important concerns that HCP have regarding the workload involved with a potential ILD registry. 20% of respondents raised concerns about how data would be entered and kept up-to-date, and the time involved in maintaining a registry. These factors need to be considered when establishing an ILD registry to ensure engagement, continued enrolment of patients, and data accuracy are maintained, particularly in a resource-depleted health system such as the Irish Health System. Long-term maintenance of registries was a key recommendation in the recent Future of Registries Taskforce report⁶.

There are some limitations to interpretation of this survey. The total number of potential patient respondents who viewed the survey link on ILFA’s social media channels could not be measured and is not known. Therefore, the response rate (actual/potential respondents) cannot be calculated. As this was an online survey only, it was completed by patient respondents who are familiar and comfortable with usage of digital tools with a consequent risk of selection bias. The attitudes of patients who are not familiar or comfortable with electronic tools were not captured and may be different.

Establishing a national registry for ILD will support budgeting and healthcare resource planning. Accurate knowledge of the number of ILD patients and the health impacts of their condition can support early delivery of effective treatments (e.g. pharmaceutical, pulmonary rehabilitation) thereby reducing hospitalisations and the financial cost of care. Likewise, being able to access data from patients not accessing specialist services offers the opportunity to highlight the variability of care delivered in non-specialist settings. Understanding disease incidence, patient characteristics, details of diagnosis and treatment, and clinical outcomes of patients with ILD can result from a patient registry. This understanding would support better care for patients and ultimately a national clinical care programme for ILD, significantly improving mortality and quality of life for patients.

Declarations of Conflicts of Interest:

The survey was funded by the Irish Lung Fibrosis Association. There are no conflicts of interest for any of the authors.

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