Report date: 17/01/2024

Irish Lung Fibrosis Association

Stakeholder Survey - Potential ILD Registry November 2023

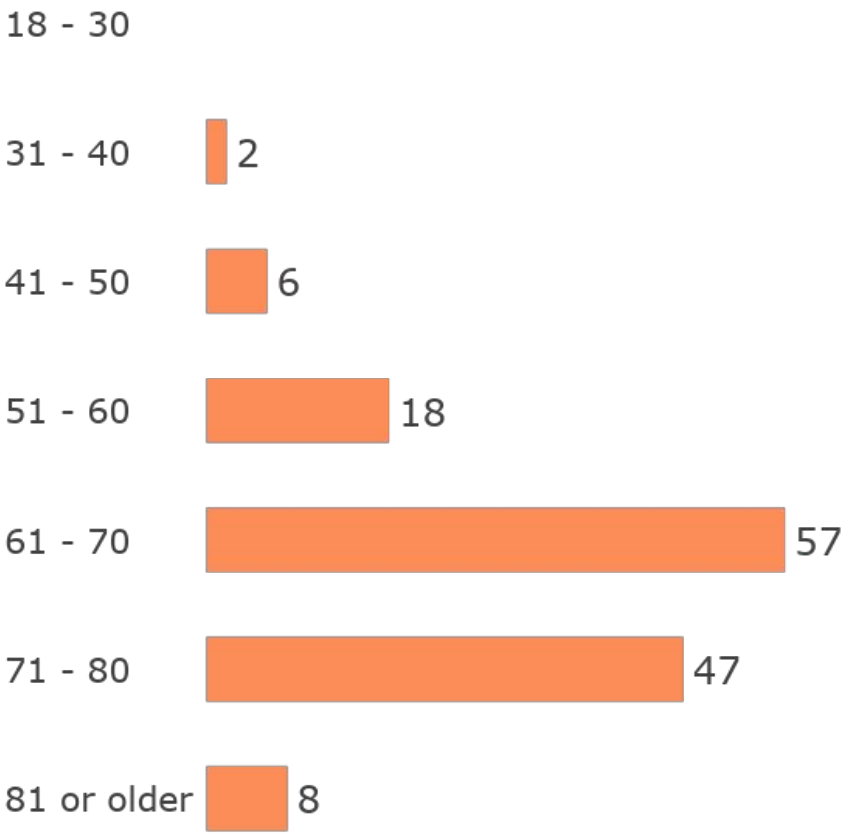
Irish Lung Fibrosis Association
www.ilfa.ie

Introduction

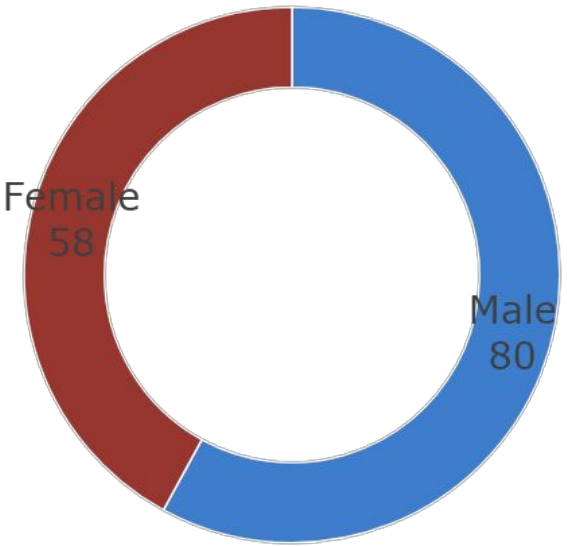
- Survey of ILFA stakeholders conducted November 6th - November 26th 2023
- Responses collected online
- Total respondents = 198, including:
  - 125 lung fibrosis patients and 13 post-transplant patients
  - 35 healthcare professionals
  - 13 caregivers / family members of lung fibrosis patients
  - 6 caregivers / family members of patients who have since passed away
  - 6 “others” not in the above categories
- Median response duration = 6.4 minutes

Patients - Respondent Profile (n=138)

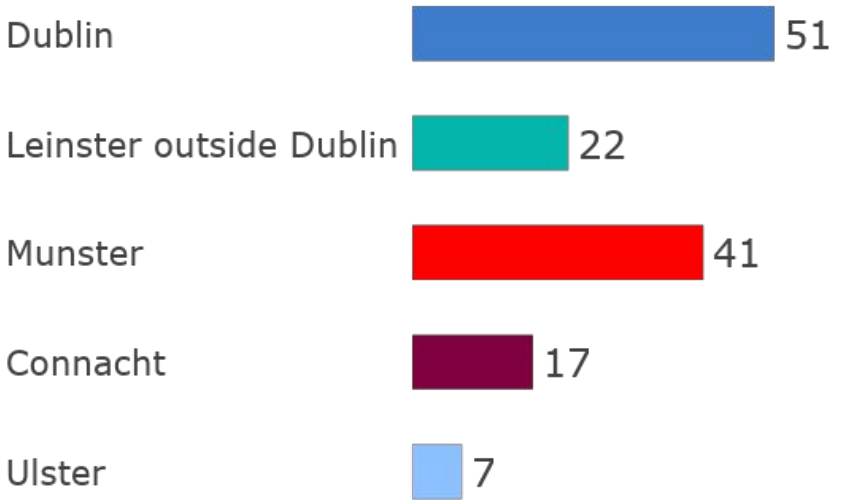
Age Group



Gender Identity

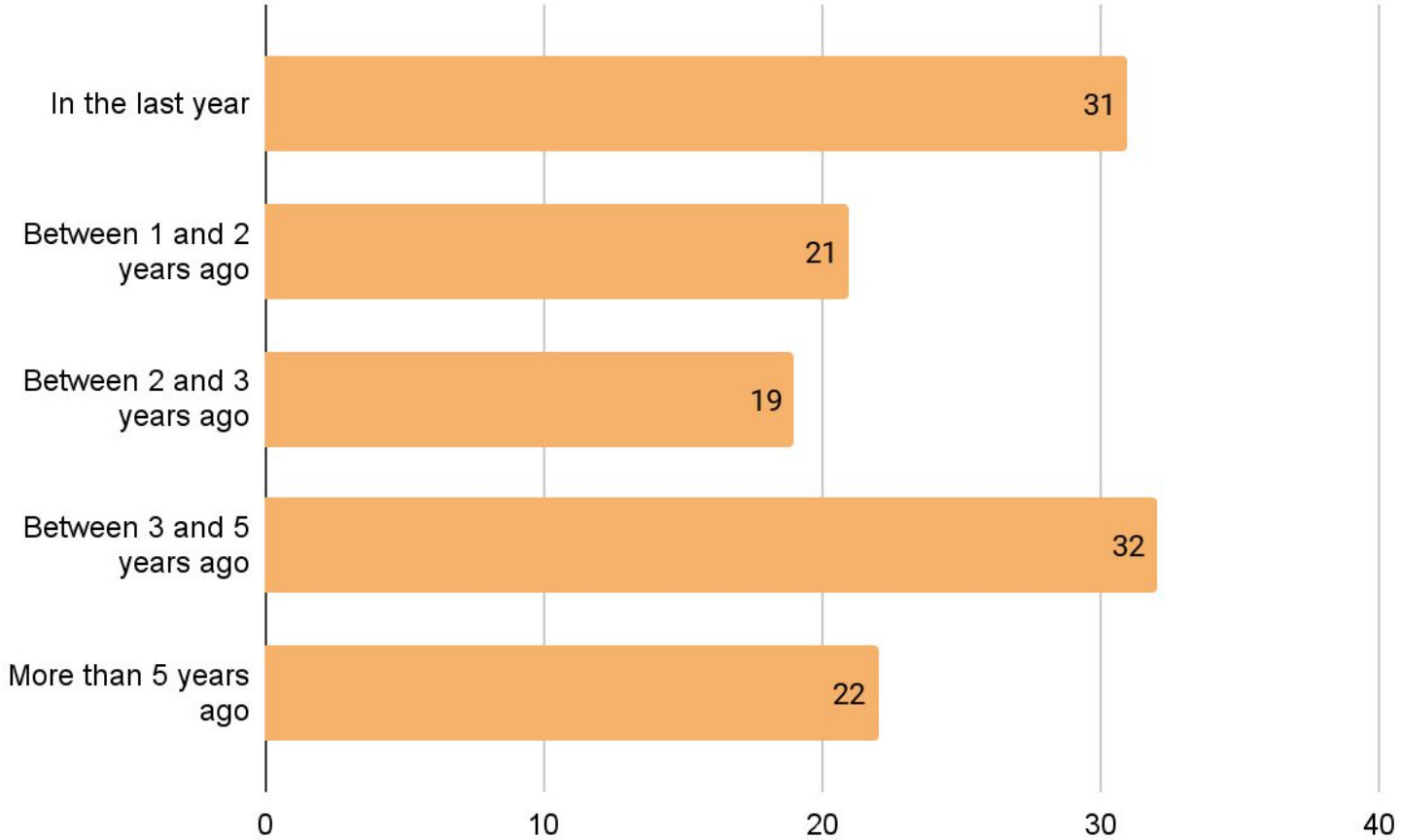


Area



Patients - Time since diagnosis

When were you first diagnosed with lung fibrosis? (n=125)



112/125 indicated thaey had Idiopathic Pulmonary Fibrosis

Introduction of ILD Registry

Having provided their demographic details, respondents were presented with the following introduction to the concept of a proposed national Interstitial Lung Disease Registry:

"A national Interstitial Lung Disease (ILD) Registry is currently proposed and ILFA is seeking your input to identify the priorities that should be included in this registry. The purpose of this survey is to help guide those developing the registry to make sure that it meets the needs of all stakeholders.

There is currently no central registry of Lung Fibrosis patients in Ireland. Patient registries are designed to collect anonymous, relevant, and appropriate information about people diagnosed with specific health conditions. Registry information is valuable to help understand how many people are diagnosed with a condition, and to plan for future healthcare resources and services.

The proposed ILD Registry would contain anonymised information that may be accessible to the staff who administer the registry. Information from the registry may be made available to health researchers who request data (information). Your data would be anonymised which means that it would not be possible for someone to identify you from the data contained in the registry."

Patients' Comfort with Inclusion of Demographic Data

Certain demographic information (i.e. details which describe the social characteristics of patients) will be necessary and fundamental to the proposed ILD Registry. This will include age, sex and geographic location.

Other demographic information may also be included in the ILD Registry. **How comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
Ethnicity	75	29	6	0	110	3.63
Employment status	71	39	7	0	117	3.55
Educational status	81	37	11	0	129	3.54
Familial connection with other patients	65	31	10	1	107	3.50
Living circumstances	70	39	10	2	121	3.46

Patients' Comfort with Inclusion of Medical Information

Certain medical information will be necessary and fundamental to the proposed ILD Registry. This will include your diagnosis. Other medical information may also be included in the ILD Registry. **How comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
Type of care / treatment currently being received	87	34	8	0	129	3.61
Treatments - drugs, whether or not using oxygen etc.	80	33	10	2	125	3.53
Other conditions that may impact your prognosis	77	38	10	1	126	3.52
Full record of all symptoms	79	34	9	3	125	3.51
Level of cough	80	32	11	3	126	3.50
Transplant assessment - whether or not carried out	83	29	10	5	127	3.50
Level of breathlessness	78	38	9	3	128	3.49
Level of fatigue	78	31	11	4	124	3.48
Transplant listing if applicable	81	29	9	7	126	3.46
Transplant suitability if assessment carried out	81	29	12	6	128	3.45

Patients' Comfort with Inclusion of History of Condition and Current Status

Certain information about the history of your condition will be necessary and fundamental to the proposed ILD Registry. This will include the name of your GP and the date of your initial diagnosis. Other information about the history of your condition may also be included in the ILD Registry. **How comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
Time of onset of symptoms to diagnosis	89	37	4	2	132	3.61
Type of care / treatment currently being received	89	34	8	1	132	3.60
Current access to hospitals, clinics, dieticians, healthcare professionals	83	39	6	2	130	3.56
Time between initial consultation with GP to diagnosis	83	37	6	4	130	3.53
Historical access to hospitals, clinics, dieticians, healthcare professionals	81	39	7	3	130	3.52

Patients' Comfort with Inclusion of "Impacts on You"

Certain medical information will be necessary and fundamental to the proposed ILD Registry. This will include your diagnosis. Other medical information may also be included in the ILD Registry. **How comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
The impact on your family / friends	82	31	14	2	129	3.50
The impact on your ability to work	81	40	11	2	134	3.49
The impact on your overall well-being	81	35	12	3	131	3.48
The impact on your hobbies, social life, day-to-day living	82	29	16	3	130	3.46
The financial impact on you	73	36	17	4	130	3.37

Patients' Comfort with Inclusion of Carer Information

Certain information about those caring for patients may also be included in the ILD Registry. **How comfortable or otherwise would you be as a patient with the following information being held about you on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
Relationship with carer - e.g. family, friend, professional carer	85	40	5	4	134	3.54
Availability of carer - e.g. whether full-time, part-time, as needed	80	40	8	4	132	3.48
Physical ability of carer	76	36	18	4	134	3.37
Financial impact on carer	70	35	23	3	131	3.31

Patients' Comfort with Giving Consent for Use of Data

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:

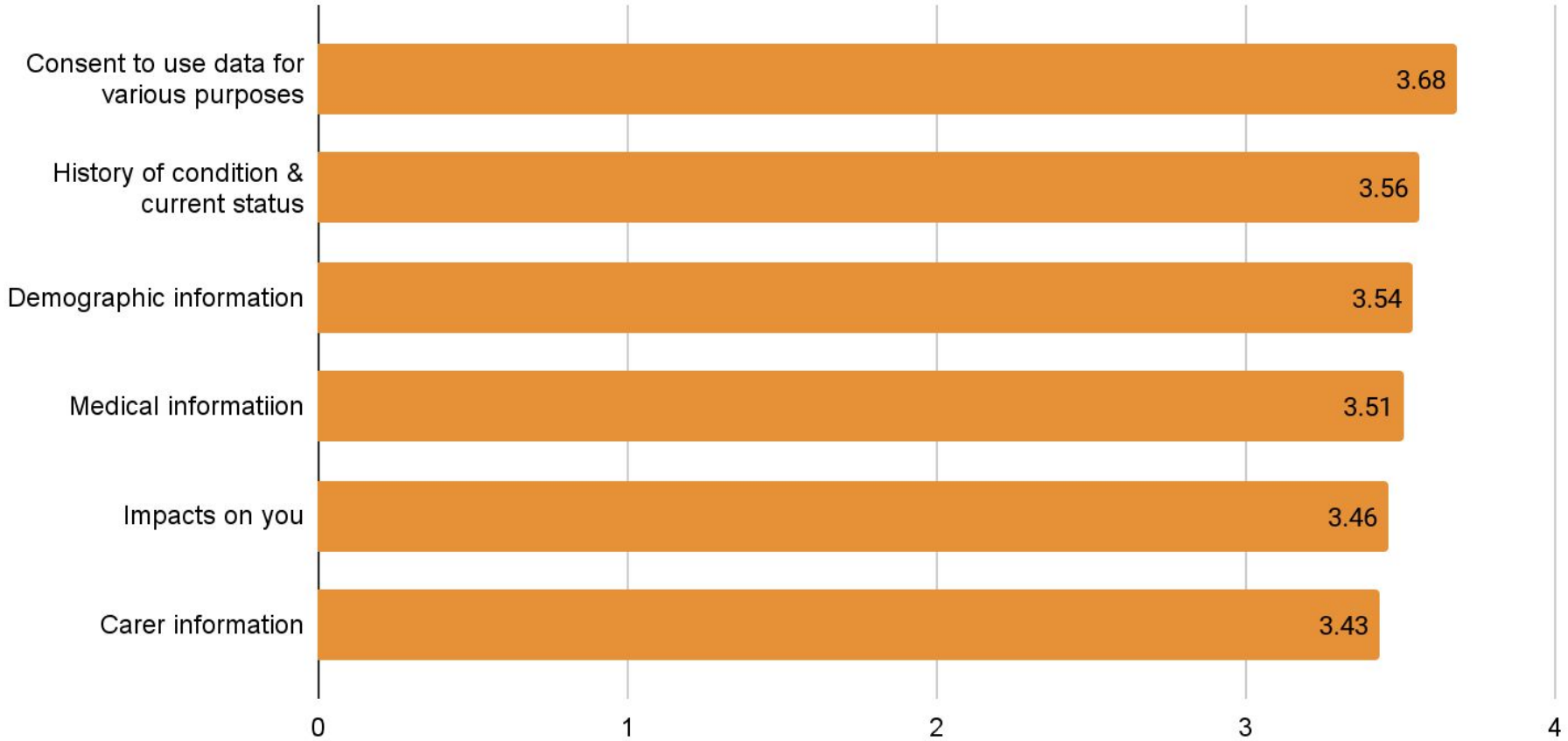
Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Comfort by number of respondents	Very comfortable	Quite comfortable	Some reservations	Very uncomfortable	Patients answering	Average
Research into the condition	106	24	4	1	135	3.74
Healthcare planning	99	30	4	0	133	3.71
Cost of medicine research	96	28	8	1	133	3.65
Resource planning	94	33	7	1	135	3.63

Average Patients' Comfort with Categories of Data Used

Average score on comfort aggregated for each category of data collected and use of data.

An average of 4 would represent all respondents being very comfortable with the collection / use of a category of data.



Utility for HCPs of Demographic Data

Certain demographic information will be necessary and fundamental to the proposed ILD Registry. This will include age, sex and geographic location. Other demographic information may also be included in the ILD Registry. **How useful to you as a healthcare professional would each of the following types of information be if held on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Utility by number of respondents	Very useful	Somewhat useful	Not very useful	Not at all useful	HCPs answering	Average
Familial connection with other patients	27	4	1	0	32	3.81
Living circumstances (e.g. living alone, with spouse etc.)	22	8	3	0	33	3.58
Ethnicity	15	10	6	1	32	3.22
Employment status	13	15	4	1	33	3.21
Educational status	5	15	14	0	34	2.74

Utility for HCPs of Medical Information

Certain medical information will be necessary and fundamental to the proposed ILD Registry. This will include the patient's diagnosis. Other medical information may also be included in the ILD Registry. **How useful to you as a healthcare professional would each of the following types of information be if held on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Utility by number of respondents	Very useful	Somewhat useful	Not very useful	Not at all useful	HCPs answering	Average
Treatments - drugs, whether or not using oxygen etc.	33	1	0	0	34	3.97
Type of care / treatment currently being received	32	2	0	0	34	3.94
Co-morbidities - other conditions that may impact patient prognosis	31	3	0	0	34	3.91
Level of cough	30	3	1	0	34	3.85
Transplant options	28	6	0	0	34	3.82
Level of breathlessness	29	5	1	0	35	3.80
Level of fatigue	28	5	1	0	34	3.79
Full record of all symptoms	27	5	2	0	34	3.74

Utility for HCPs of History of Condition and Current Status

Certain information about the history of the patient's condition will be necessary and fundamental to the proposed ILD Registry. This will include the name of the patient's GP and the date of the initial diagnosis. Other information about the history of the patient's condition may also be included in the ILD Registry. **How useful to you as a healthcare professional would each of the following types of information be if held on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Utility by number of respondents	Very useful	Somewhat useful	Not very useful	Not at all useful	HCPs answering	Average
Type of care / treatment currently being received	34	1	0	0	35	3.97
Time of onset of symptoms to diagnosis	29	6	0	0	35	3.83
Current access to hospitals, clinics, dieticians, healthcare professionals	28	6	1	0	35	3.77
Time between initial consultation with GP to diagnosis	25	10	0	0	35	3.71
Historical access to hospitals, clinics, dieticians, healthcare professionals	25	8	2	0	35	3.66

Utility for HCPs of Impacts on Patients

Certain information about the impacts of ILD on patients may also be included in the ILD Registry. **How useful to you as a healthcare professional would each of the following types of information be if held on the ILD Registry?**

Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Utility by number of respondents	Very useful	Somewhat useful	Not very useful	Not at all useful	HCPs answering	Average
The impact on the patient's overall well-being	31	4	0	0	35	3.89
The impact on the patient's hobbies, social life, day-to-day living	26	8	1	0	35	3.71
The impact on the patient's ability to work	24	10	1	0	35	3.66
The impact on the patient's family / friends	20	15	0	0	35	3.57
The financial impact on patients	21	12	2	0	35	3.54

Utility for HCPs of Carer Information

Certain information about those caring for patients may also be included in the ILD Registry. **How useful to you as a healthcare professional would each of the following types of information be if held on the ILD Registry?**

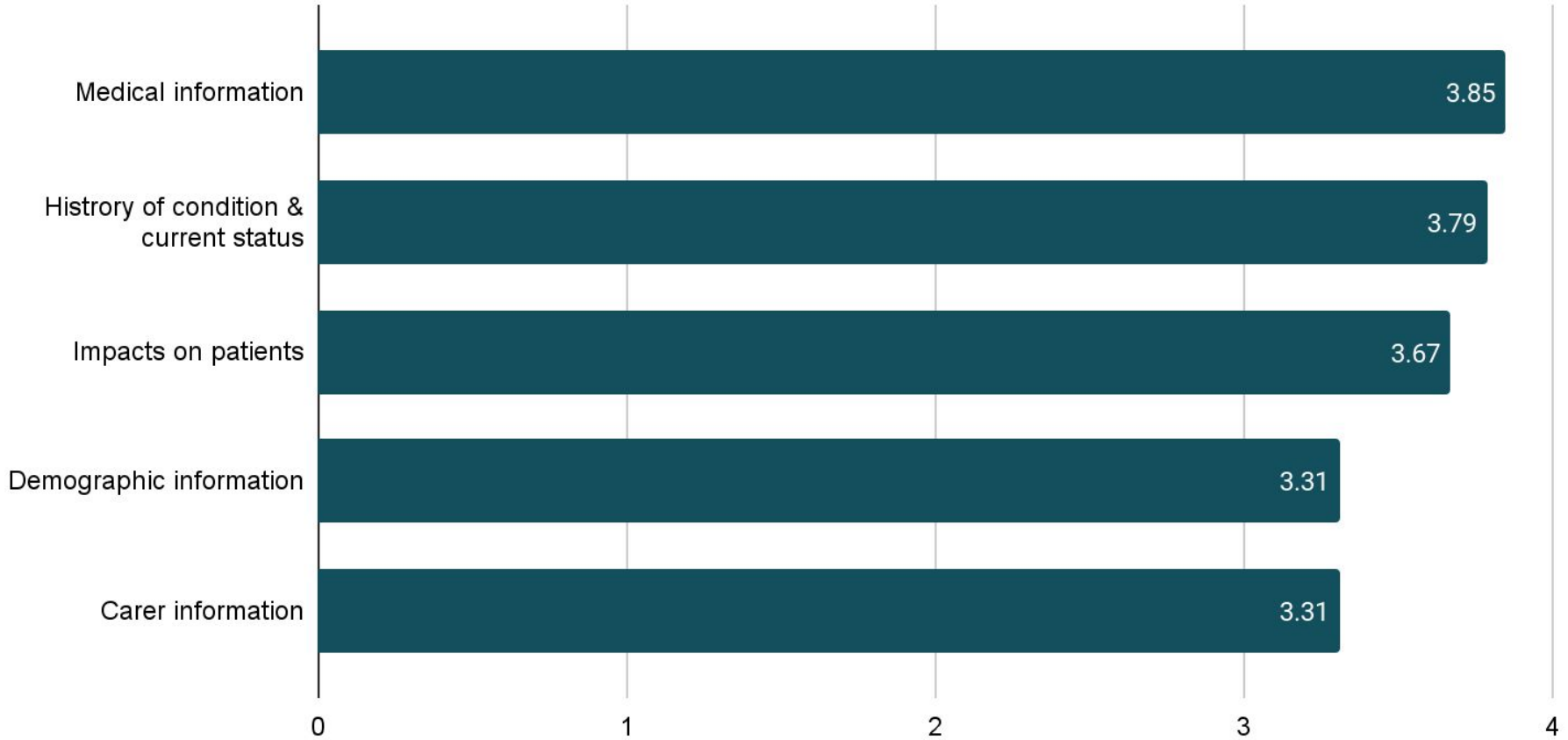
Assigning scores as follows: Very comfortable=4; Quite comfortable=3; Some reservations=2; Very uncomfortable=1

Data / Utility by number of respondents	Very useful	Somewhat useful	Not very useful	Not at all useful	HCPs answering	Average
Availability of carer - e.g. whether full-time, part-time, as needed	18	14	2	1	35	3.40
Physical ability of carer	16	16	1	2	35	3.31
Patient's relationship with carer - e.g. family, friend, professional carer	18	11	5	1	35	3.31
Financial impact on carer	15	13	6	1	35	3.20

Average HCP Utility of Various types of Data

Average score on utility aggregated for each category of data collected.

An average of 4 would represent all respondents finding the collection / use of a category of data very useful.

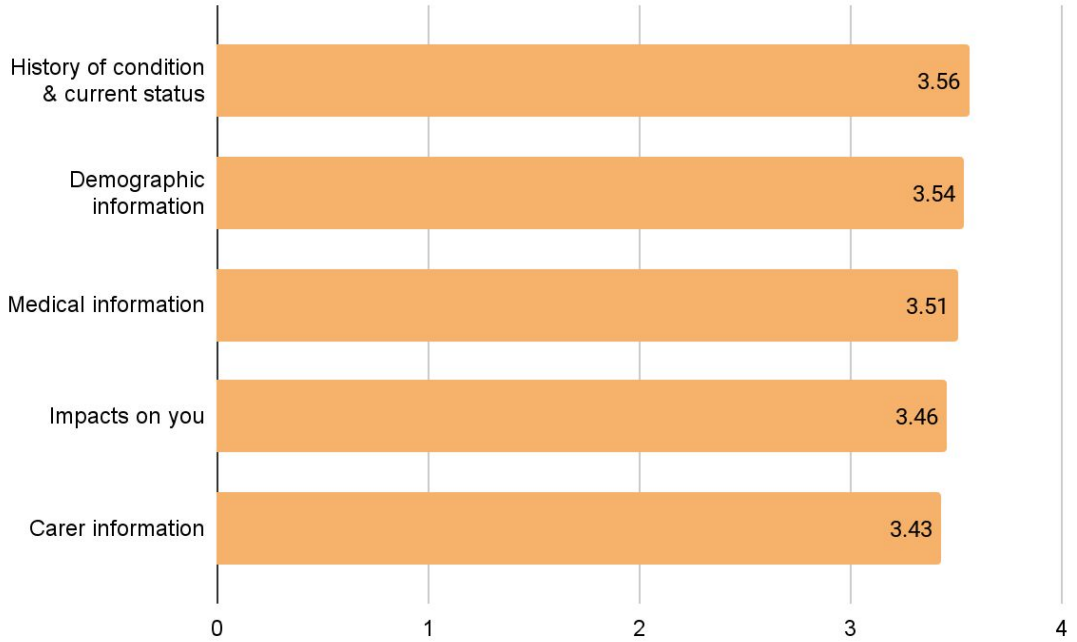


Comparing Comfort of Patients with Data Use and Utility of HCPs for Various types of Data

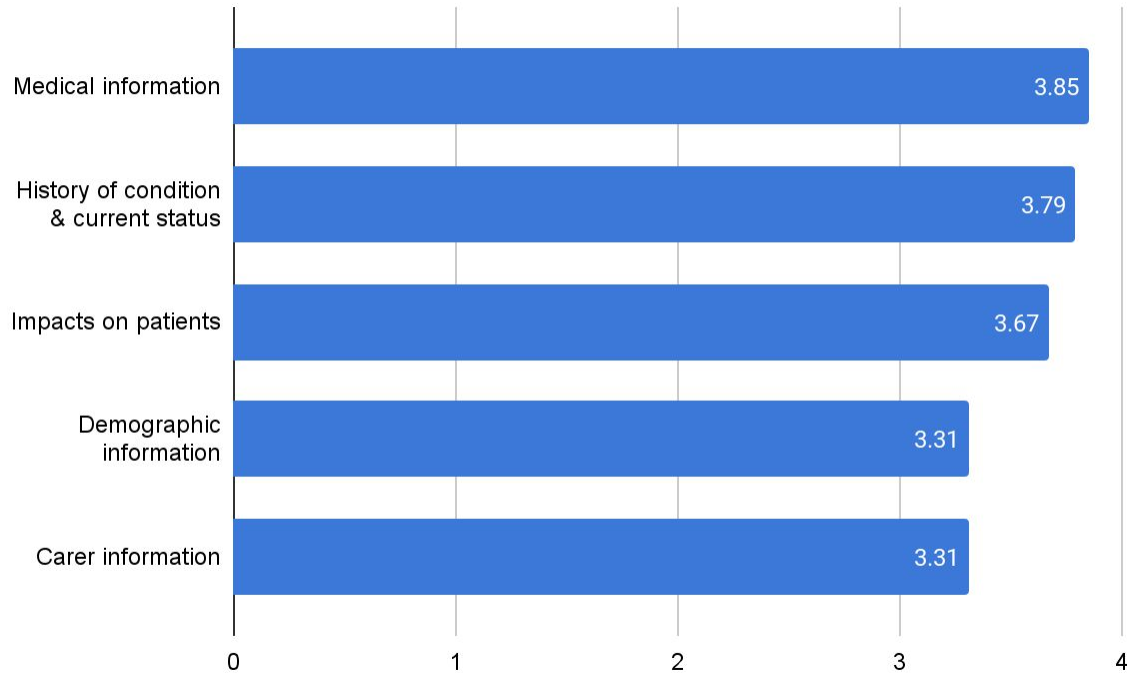
Average score on comfort (patients) and utility (HCPs) aggregated for each category of data collected.

An average of 4 would represent all patients being very comfortable with data use and all HCPs finding the collection / use of a category of data very useful.

Patients (comfort with use of data)



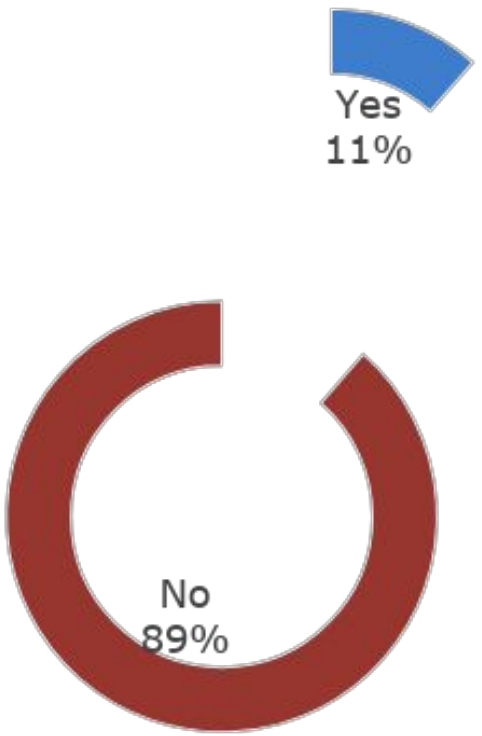
HCPs (utility of data)



Currently Inputting Data to a Registry

As a healthcare professional, do you currently input data into existing registries?

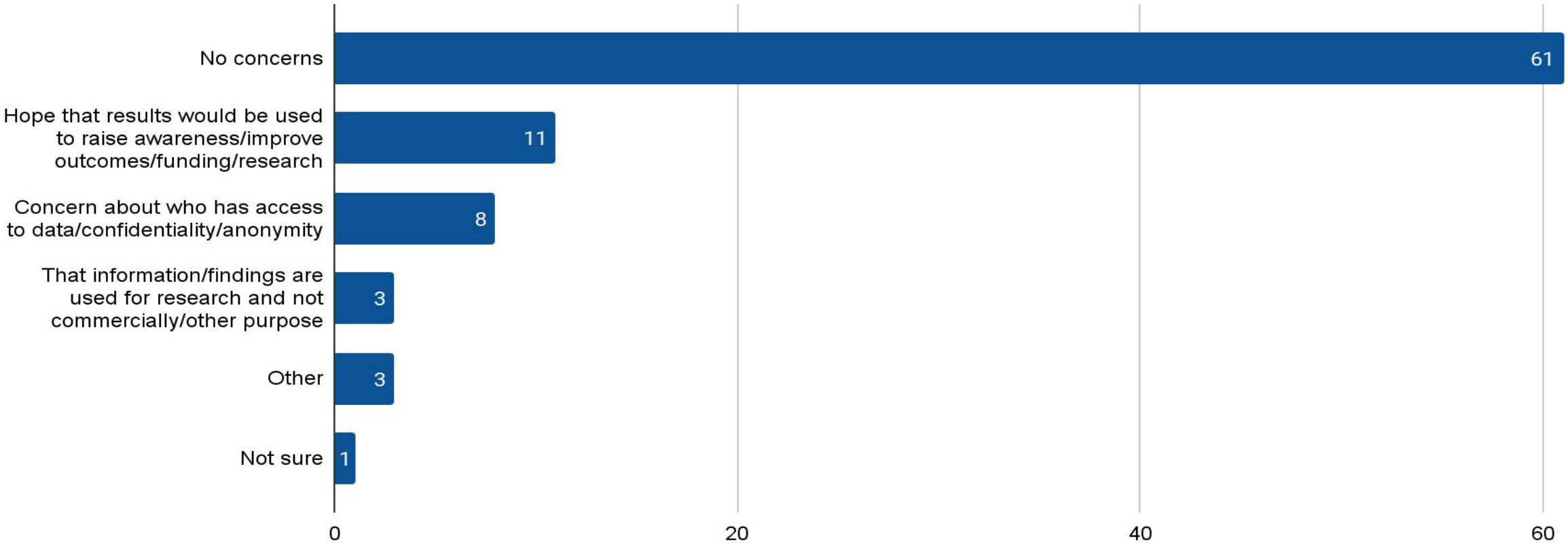
n=35



Concerns or Reservations - Patients

What, if any, concerns or reservations would you have about the development of a national ILD registry?

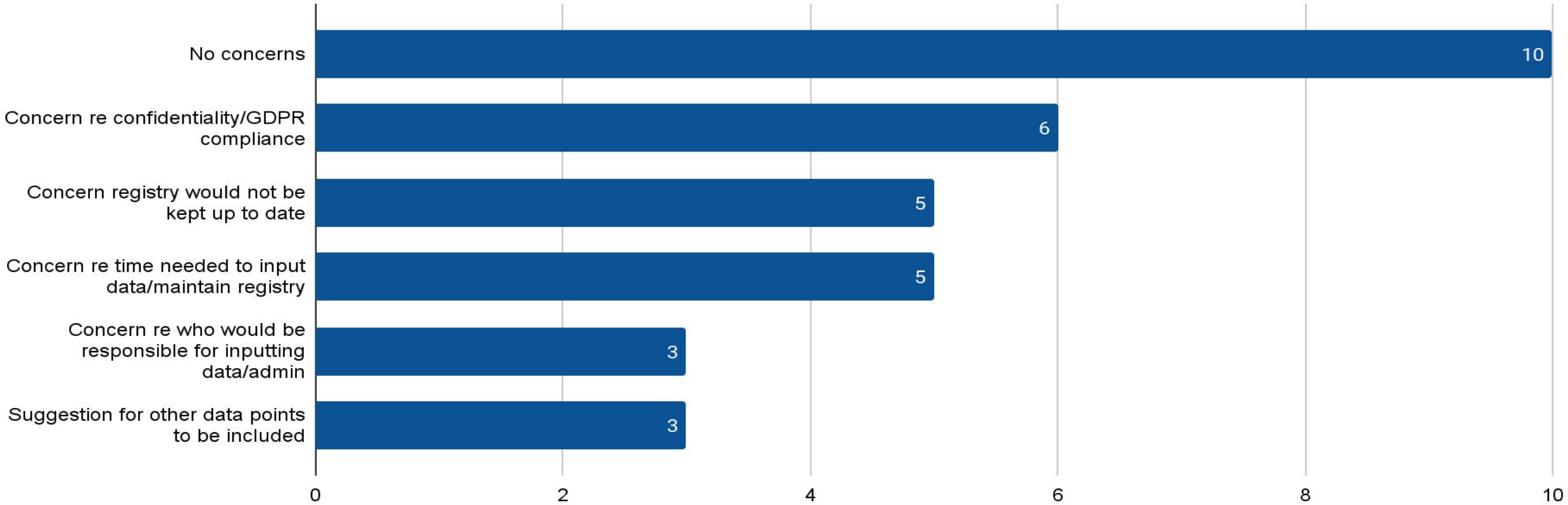
n=87



Concerns or Reservations - Healthcare Professionals

What, if any, concerns or reservations would you have about the development of a national ILD registry?

n=25



Concerns or Reservations - Carers

What, if any, concerns or reservations would you have about the development of a national ILD registry?

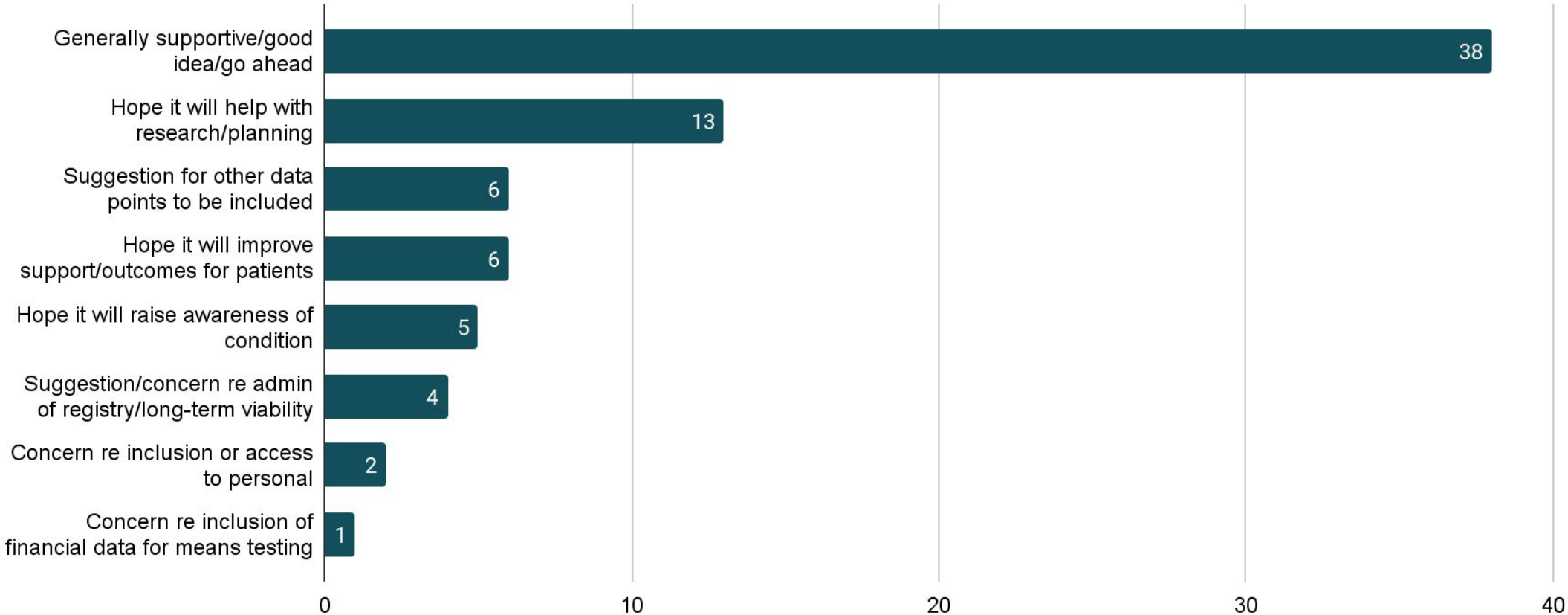
n=6

- Good governance
- I think a register would be a great idea i think people may learn from it and we all learned as the disease progressed and as a health care professional i was not still knowledgeable enough.
- I think is is a good idea
- Not sure that I can see any problem about it
- That it collate family connections
- Would need to be sustainable in the long term to be effective so would need to be part of a committed State funded programme

Any Further Comments

Please add any further comments you may have about the development of this proposed ILD Registry

n=55 comments across all respondents



Summary

- **Patient comfort** with use of data
    - Patients showed high levels of comfort with the collection and use of various types of data for a potential National ILD registry
    - Comfort was highest with the collection and use of data under the category "History of condition and current status"
    - Patients were particularly comfortable with providing their consent for the use of their data for research into the condition.
- **Patient concerns** – the most common concerns expressed by patients were around who would have access to the data on a potential ILD Registry, and the confidentiality and security of the data.
- **Utility for Healthcare Professionals** of various categories of data
    - Healthcare Professionals indicated that the categories of data which would be most useful to them would be "Medical Condition", "History of condition and current status" and "Impacts on Patients"
    - While still considered useful, there is evidence to suggest that data in the categories "Demographic information" and "Carer information" would be relatively less useful to Healthcare Professional than the other categories of data.
- **Healthcare Professional Concerns** – the most common concerns expressed by Healthcare Professionals were around confidentiality and GDPR compliance, as well as logistical concerns about maintaining a potential ILD Registry.