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Person-centred health outcomes in the routine care for people with progressive pulmonary fibrosis: the COCOS-IPF project's European survey on healthcare professionals' views and practices

Vivien Somogyi[1], Anouk Delameillieure[2], Silja Schenk[3], Liesbet Van Bulck[2], Sofie Breuls[2], Nazli Üçkuyu[4], Zehra Nur Töreyin[4], Nikola Stenzel[3], Nesrin Moğulkoç[4], Wim Wuyts[5], Steve Jones[6], Liam Galvin[6], Jeanette Boyd[7], Thomy Tonia[8,9], Fabienne Dobbels[2*†] and Michael Kreuter[1†]

Abstract

Background Idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis (PPF) are interstitial lung diseases (ILD) that carry a high burden and mortality. IPF/PPF experts and patients call for standardized care, outcome harmonization and holistic management in these complex and devastating diseases, with a focus on person-centeredness. In this cross-sectional international survey study, we aimed to gather information on the person-centred health outcomes European healthcare professionals (HCPs) already use or deem important for use in routine care for IPF/PPF. This work is part of the COCOS-IPF project on developing a Core Outcome Set (COS) for and with patients with IPF/PPF.

Methods With the input of IPF/PPF experts, psychologists and patients, we developed an online survey for European multidisciplinary HCPs with IPF/PPF expertise. The survey was programmed in Qualtrics^{XM}, piloted and distributed via the networks of the COCOS-IPF consortium. We used content analysis to create an overall list of outcome domains mentioned in the survey, classified these according to the COMET (Core Outcome Measures in Effectiveness Trials) taxonomy and calculated the frequency of all outcomes mentioned.

Results A total of 149 experts, mainly pulmonologists (n = 120, 81%) working in ILD expert centres, from 31 European countries participated. Of the 40 different outcome domains mentioned, the majority referred to \`physiological/clinical\` (n = 773, 81%) and \`life impact\` (n = 138, 14%) outcome domains. Of these, \`lung function' (*n* = 280, 29%), 'exercise capacity' (*n* = 123, 13%) and \`quality of life\` (*n* = 103, 11%) were reported as most frequently used person-centred health outcomes. Survey respondents deemed the same three outcome domains the most important for use

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[†] Fabienne Dobbels and Michael Kreuter jointly directed the work.

*Correspondence:
Fabienne Dobbels
Fabienne.dobbels@kuleuven.be

Full list of author information is available at the end of the article

in the routine clinical IPF/PPF care, supplemented by chest symptoms. Pulmonologists reported mainly about routine use of `lung function` ($n = 252$, 26%), while allied HCPs put more focus on outcomes related to physical condition and whole body status.

Conclusions HCPs have identified 40 different outcomes domains in a European multidisciplinary survey on person-centred health outcomes in IPF/PPF. Lung function, exercise capacity, quality of life and chest symptoms were rated as the most relevant health outcomes to be assessed routinely in clinical care. These insights can help to support the development of a COS for IPF/PPF clinical care.

Keywords Idiopathic pulmonary fibrosis, Progressive Pulmonary Fibrosis, Core Outcome Set, Person-centred outcomes

Background

Idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis (PPF) are rare fibrotic interstitial lung diseases that carry a high socioeconomic burden and a limited life expectancy of 3 to 5 years after diagnosis if left untreated [1]. Patients mostly suffer from cough, breathlessness, poor quality of life due to physical limitation, psychological impairment and social isolation [2–4]. The diagnostic and therapeutic management of these patients is highly complex and is therefore often centred in specialized interdisciplinary clinics.

Despite major advances in early diagnosis and in medical, pharmacological treatment of IPF/PPF, person-centred integrated care is still in its infancy. Several studies revealed gaps in care, for example regarding the delivery of care. A recent review reported that Interstitial Lung Diseases (ILD) centres of expertise implemented various care models to support patients and caregivers in their unmet needs, which will lead to better outcomes [5, 6]. The European IPF Patient Charter also summarized and recommended five action categories in which urgent change in terms of holistic patient care is recommended [7].

Standardized outcome reporting can improve person-centeredness of the provided care and promote shared decision-making. It can also help to monitor and benchmark care over time. Outcomes can be defined as *“the results of care in terms of patients’ health over time”* [8] or *“a collection of reliable and valid endpoints that represent what matters most to individual patients in their day-to-day lives. These outcomes may represent how patients feel, or function, or how they view their quality of life”* [9]. However, outcomes and the way they are operationalized and integrated in both clinical care and research vary widely between settings and countries, generating difficulties to compare current practices and results [10]. Moreover, treatment is usually carried out by physicians due to the nature of the disease and the high level of expertise required of pneumologists specializing in IPF/PPF. It is currently not fully known which outcomes healthcare professionals - including allied healthcare professionals - consider important or already evaluate in their routine clinical practice for patients with IPF/PPF.

The aims of this cross-sectional study were therefore to gather information on person-centred health outcomes currently used by healthcare professionals with interdisciplinary background in routine pulmonary fibrosis care across Europe and to identify which outcomes healthcare professionals consider most important to measure and to act upon in routine clinical care. This study is part of the COCOS-IPF project that aims to develop a Core Outcome Set and its corresponding measures for use in both IPF/PPF clinical care and research by involving different stakeholder views.

Methods

We developed a structured online English open survey questionnaire with a cross-sectional multinational design for European interdisciplinary healthcare professionals working in routine pulmonary fibrosis care. A convenience sample was used.

Sample and selection of participants

Inclusion criteria for participation in the survey were: having clinical expertise on IPF/PPF, being a healthcare worker (medicine, nursing, psychology, social workers, physiotherapists, etc.) in one of the 51 European countries, being able to understand written English and willing to complete a short online anonymous survey. Only answers from participants who met the eligibility criteria were used in the analysis. Only European participants were eligible for inclusion in the study, as the Core Outcome Set is to be developed based on the European representation of the reported health outcomes.

Recruitment strategy and data collection

We recruited healthcare professionals via European respiratory health organisations, including national pulmonary societies and the European Respiratory Society (ERS), who shared a link on their website and social media account. Furthermore, an e-mail and newsletter were sent directly to the healthcare professional members of Assembly 9 (“Interstitial Lung Diseases”) and 12

("Allied Respiratory Professionals") of ERS. Moreover, the survey was distributed through the COCOS-IPF consortium partners` networks, consisting of clinicians, social scientists and patient representatives and on the project's website [11]. No incentives to participate were offered. Given our study aims, no target sample size was set a priori.

Three weeks after the launch of the survey, we reviewed how many participants responded, their geographical location and discipline. We discussed with the consortium members how to actively reach out to the underrepresented groups (e.g. to non-medical disciplines or to some underrepresented European regions). Here, we primarily relied on the professional contacts of the COCOS-IPF consortium partners` networks.

Development and content of the survey

Three healthcare professionals from Germany, the United Kingdom and Turkiye with a medical or nursing background piloted the survey, using online cognitive debriefings, performed by two consortium members, and the "think-aloud" technique. Remarks on the clarity of instructions or wording of the questions were tabulated and adaptations were made where necessary to make sure the survey was comprehensive, clear and functional.

The survey (see supplementary material) was programmed within the Qualtrics^{XM} software and divided into two sections. The first section gathered demographic and work-related data from the participants. The second section aimed to collect data on the outcomes used in participants' respective clinical settings, i.e. in clinical care, for research purposes and/or for clinical decision-making and on outcomes put forward by participants that should be measured, but are not yet considered in routine clinical care.

Data analysis

We used descriptive statistics to analyse the items with pre-defined response options. The responses to the 'open-ended', 'adaptive' and 'selection' questions were analysed by means of both qualitative and quantitative (manifest) content analysis, following the methodology of Krippendorf [12]. We created an overall list of outcomes and calculated the frequency of all outcomes mentioned by the professional participants. Similar responses from one participant were counted only once. We classified outcomes with similar meanings into one of the 38 outcome categories of the COMET (Core Outcome Measures in Effectiveness Trials) taxonomy that refer to five core outcome areas (i.e. death, physiological/clinical, life impact, resource use and adverse events, respectively) [13]. Yet, given that the COMET outcome categories are formulated rather broadly, we decided not to use the COMET outcome labels, but to group outcomes with a similar meaning in meaningful outcome domains. For example, rather than using the outcome category "Respiratory, thoracic and mediastinal outcomes", we created outcome domains within this category, such as lung function, breathlessness, cough, respiratory infection, respiratory muscle strength, etc. as this allows for a more granular understanding of the outcomes considered or deemed valuable for clinical care by healthcare professionals. Disease progression outcomes were defined as outcomes directly related to the disease progression (e.g., all-cause mortality and acute exacerbation). Differences between countries and disciplines were also reported descriptively, as the small number of participants in the respective categories prevented us from performing formal statistical testing of group differences.

Although we made every effort to clearly define what we meant by 'outcomes' in our study materials, we still received some data referring to specific measures of outcomes (often without mentioning the outcome that is targeted), or data that rather referred to processes of care instead of outcomes of care. Therefore, only "true" outcomes reported by the participants were included in the analyses. For example, if a participant indicated an outcome measure instead of an outcome, we replaced the outcome measure with the outcome to which the outcome measure referred. This decision was made by the consortium during iterative interactive discussions of the results. For example, the 6 min walk test was mentioned several times, yet this was replaced by the outcome "exercise capacity". Participants without any data entry, so-called blanks, were excluded. All other fully or partly completed responses were included in the data analysis.

The study was approved by the institutional review board of KU Leuven. We reported the results of the survey using the 'Checklist for Reporting Results of Internet E-Surveys' (CHERRIES) (see supplementary material) [14].

Results

Sample characteristics

We received responses from 202 participants from 31 different European countries (Table 1). Entries of 149 participants were eligible for inclusion in the data analysis (Table 1). The United Kingdom (*n* = 18, 12%), Germany (*n* = 14,9%) and Hungary (*n* = 14,9%) were best represented (Table 1). Most participants were pulmonologists (*n* = 120, 81%) and most of them were working in specialized clinics for ILD (*n* = 115, 77%) (Table 1). Participants were mainly involved in outpatient care (*n* = 125, 20%), inpatient care (*n* = 121, 19%) and the diagnostic phase of patient care (*n* = 114, 18%) (Table 1).

Table 1 Characteristics of the survey participants (*n* = 149)

Country of respondent	
Albania	*n* = 1 (1%)
Austria	*n* = 2 (1%)
Azerbaijan	*n* = 1 (1%)
Belgium	*n* = 2 (1%)
Bulgaria	*n* = 3 (2%)
Croatia	*n* = 3 (2%)
Czech Republic	*n* = 2 (1%)
Denmark	*n* = 1 (1%)
Finland	*n* = 2 (1%)
France	*n* = 3 (2%)
Georgia	*n* = 1 (1%)
Germany	*n* = 14 (9%)
Greece	*n* = 8 (5%)
Hungary	*n* = 14 (9%)
Iceland	*n* = 1 (1%)
Ireland	*n* = 4 (3%)
Italy	*n* = 10 (7%)
Latvia	*n* = 1 (1%)
Malta	*n* = 2 (1%)
Netherlands	*n* = 4 (3%)
Norway	*n* = 1 (1%)
Poland	*n* = 7 (5%)
Portugal	*n* = 5 (3%)
Republic of Moldova	*n* = 1 (1%)
Romania	*n* = 4 (3%)
Serbia	*n* = 2 (1%)
Spain	*n* = 12 (8%)
Sweden	*n* = 4 (3%)
Switzerland	*n* = 6 (4%)
Turkey	*n* = 10 (7%)
United Kingdom	*n* = 18 (12%)
Stakeholder group/profession	
Lung function technician	*n* = 2 (1%)
Nurse	*n* = 6 (4%)
Physiotherapist	*n* = 13 (9%)
Psychologist	*n* = 2 (1%)
Pulmonologist	*n* = 120 (81%)
Radiologist	*n* = 4 (3%)
Researcher	*n* = 2 (1%)
Care trajectory	
Inpatient care	*n* = 121 (20%)
Outpatient care	*n* = 125 (20%)
Intensive patient care	*n* = 41 (7%)
Diagnostic phase	*n* = 114 (18%)
Palliative/end-of-life care	*n* = 71 (12%)
Clinical trial	*n* = 71 (12%)
Clinical research	*n* = 65 (11%)
Lung transplantation	*n* = 1 (0,2%)
Lung function test	*n* = 1 (0,2%)
Non-invasive ventilation unit	*n* = 1 (0,2%)
Sleep medicine	*n* = 1 (0,2%)
Basic research	*n* = 1 (0,2%)
Translational research	*n* = 2 (0,3%)

Table 1 (continued)

Country of respondent	
Preclinical research	*n* = 1 (0,2%)
Rehabilitation unit	*n* = 1 (0,2%)
Specialized clinic for ILD	
Yes	*n* = 115 (77%)
No	*n* = 34 (23%)

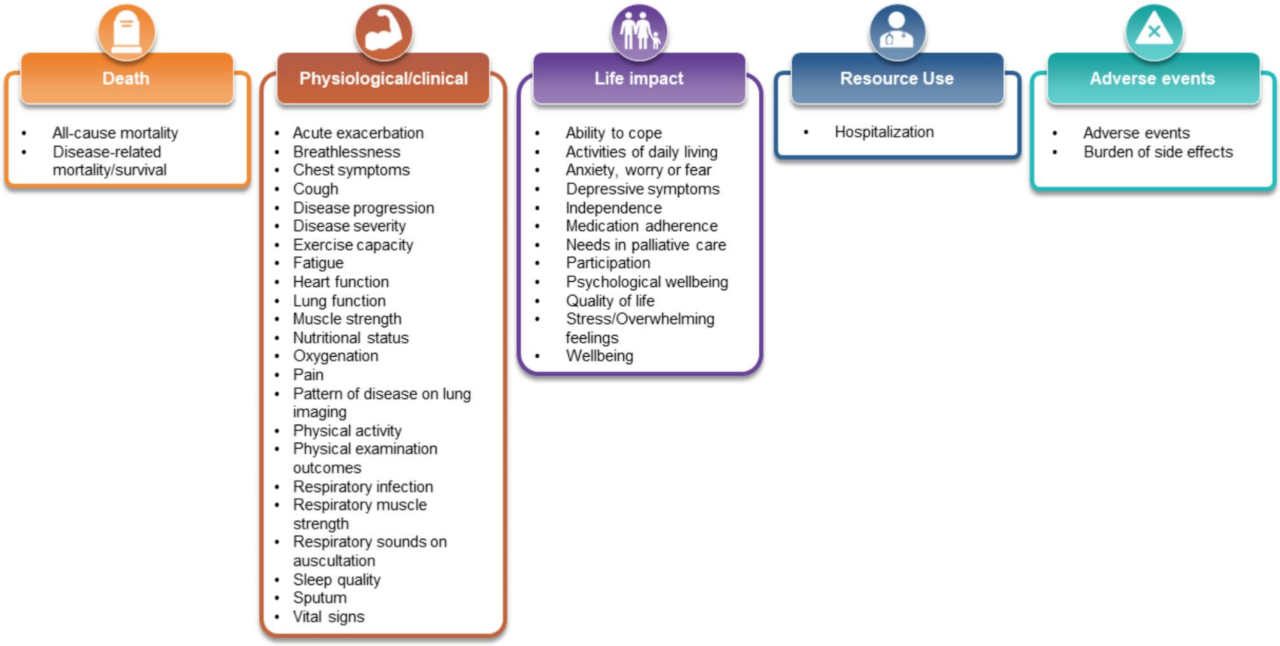

Fig. 1 Overview of the 40 outcome domains identified by the survey classified in the five COMET core areas. *Legend: The orange core area represents the outcome domains related to `Death`, the red `Physiological/clinical`, the purple `Life impact`, the blue `Resource use` outcome domains and the green core area outcome domains related to ´Adverse events`*

Table 2 Examples of outcome domains and examples of responses of participants falling within these outcome domains

Outcome domain	Examples of clinical outcomes given by survey participants
Acute exacerbation	Exacerbation, acute exacerbation, exacerbation frequency
All-cause mortality	Death, survival, life expectancy
Breathlessness	Breathlessness, dyspnea, dyspnea severity
Burden of side effects	Side effects, side effects of treatment, side effects on renal and liver function
Chest symptoms	Chest pain, respiratory symptoms, symptom control
Exercise capacity	Exercise capacity, functional capacity, exercise tolerance
Lung function	Forced vital capacity (FVC), diffusion capacity (DLCO), deterioration of lung function
Oxygenation	Saturation, partial pressure of arterial oxygen, respiratory failure
Pattern of disease on lung imaging	HRCT progression, CT progression, annual radiological progression
Physical activity	Daily physical activity, mobility, physical functioning
Sleep quality	Apnea hypopnea index, sleep problems, oxygen desaturation index
Quality of life	Health status, quality of life, health-related quality of life

Outcome domains reported

The total number of items reported by participants was 1171. Using content analysis, these items could be grouped into 40 different outcome domains covering the five COMET areas (Fig. 1). Examples of the reported individual outcomes with the assigned outcome domains are listed in Table 2.

Most outcome domains used in routine IPF/PPF care referred to the COMET area of `physiological/clinical` outcomes (*n* = 773, 81%) (see Figs. 1 and 2 also). Of these, `lung function` (*n* = 280, 29%) and `exercise capacity` (*n* = 123, 13%) were the most frequently reported health outcome domains (Fig. 2). Domains referring to the COMET area `life impact` (*n* = 138, 14%), except for

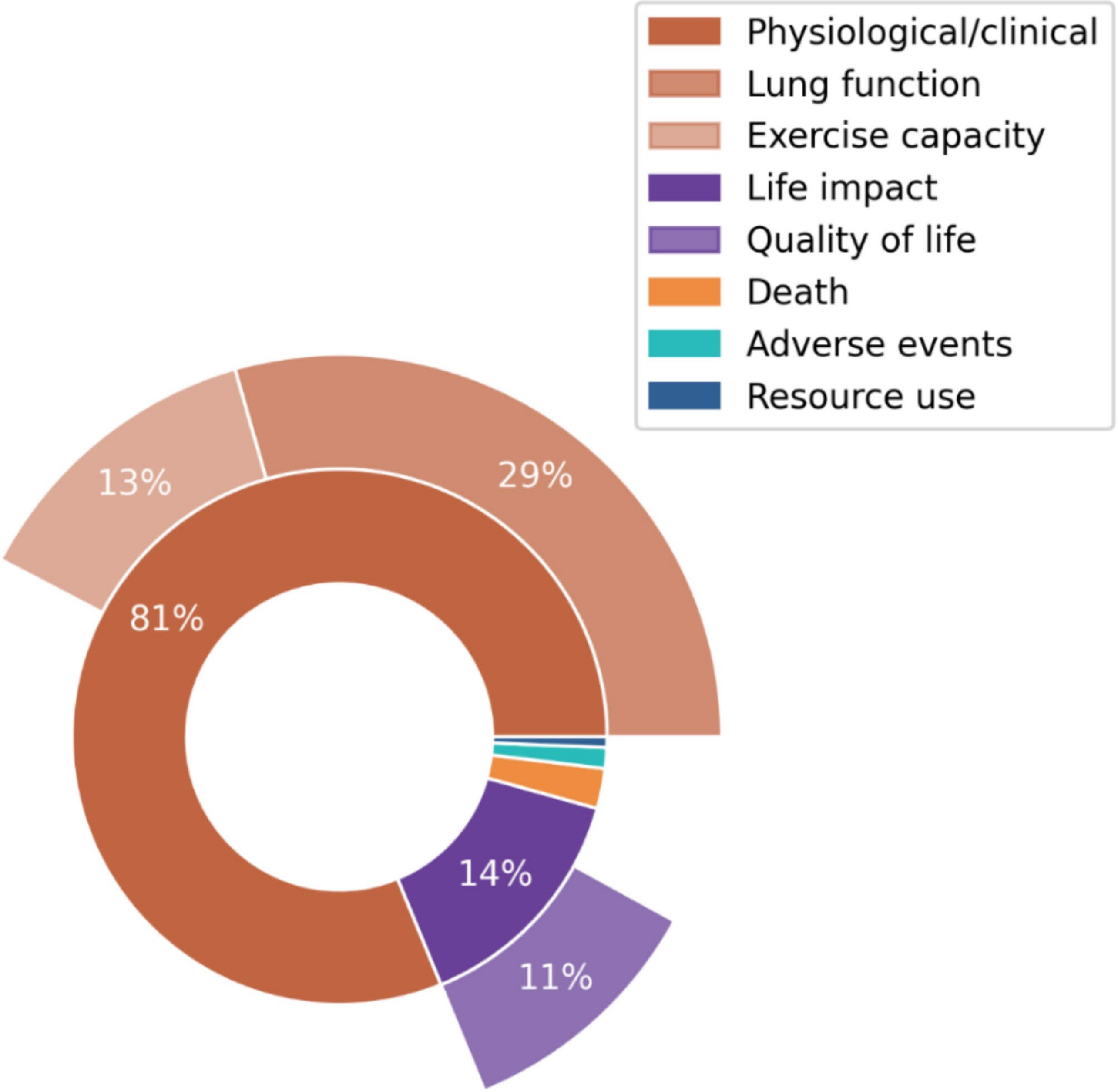

Fig. 2 Most frequent COMET core areas and outcome domains used in routine IPF/PPF care by survey participants. *Legend: inner circle: relative distribution of the five core COMET areas. Outer circle: the most frequently mentioned outcome domains grouped within the respective COMET core areas*

‘quality of life’ ($n = 103$, 11%), were not frequently used in the routine care of IPF/PPF patients (Fig. 2).

Regarding the respective setting of use of health outcomes, `lung function` ($n = 69$, 28%), `quality of life` ($n = 39$, 16%) and `exercise capacity` ($n = 30$, 12%) were most frequently used for research purposes. `Lung function` ($n = 132$, 28%), `exercise capacity` ($n = 62$, 13%) and `pattern of disease on lung imaging` ($n = 52$, 11%) were mostly used in clinical care. From the clinically used health outcomes, mainly `lung function` ($n = 79$, 31%), `chest symptoms`, `exercise capacity` and `pattern of disease on lung imaging` ($n = 28$, 11% each) were used for clinical decision-making. The most relevant disease progression parameters were `lung functional deterioration` ($n = 28$, 23%), `all-cause mortality` ($n = 27$, 22%), `progression pattern of disease on lung imaging` ($n = 23$, 19%) and `progression of chest symptoms` ($n = 21$, 17%).

When asking participants about the most important health outcomes to measure and act upon in routine clinical care of IPF/PPF patients, `lung function` ($n = 66$, 27%), `quality of life` ($n = 46$, 19%), `chest symptoms` (*n* = 33, 14%) and 'exercise capacity' (*n* = 25, 10%) were deemed most relevant.

Geographic differences

A variety of outcome reporting was seen without notable differences between countries (Fig. 3). Albania and Georgia with one participant each, respectively were the only countries reporting that they do not address any outcomes in clinical IPF/PPF practice.

Differences between healthcare professional disciplines

No notable differences in outcomes used were observed between healthcare professionals working in specialised ILD centres of care versus non-specialized care settings.

Yet, some differences were noted, depending on the discipline of the respondents. The most frequently evaluated health outcome domains by pulmonologists were 'lung function' (*n* = 252, 26%), 'pattern of disease on lung imaging' (*n* = 96, 38%) and 'exercise capacity' (*n* = 87, 34%) (Fig. 4). Physiotherapists mentioned `exercise capacity

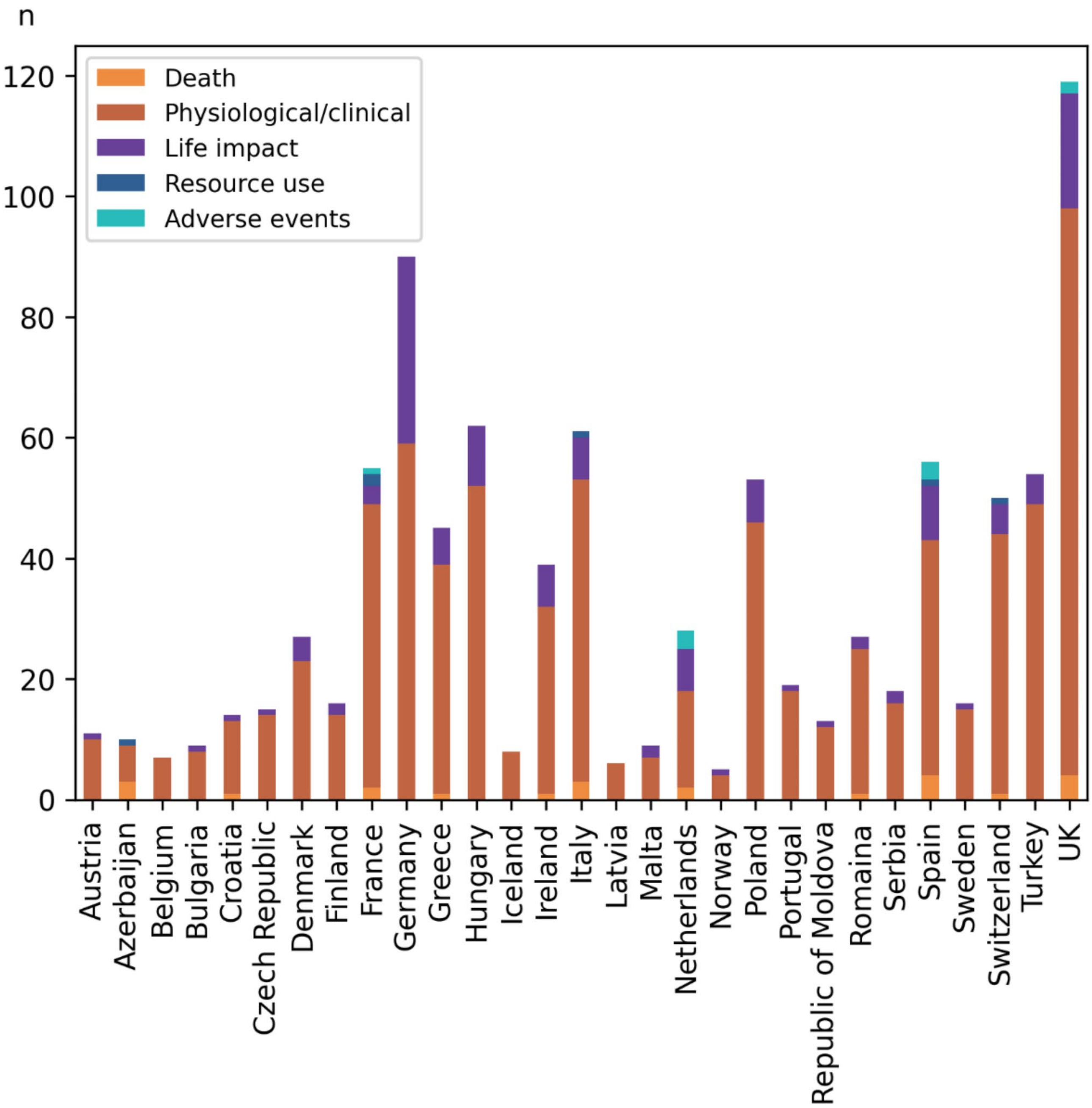

Fig. 3 Most frequently used COMET core areas in IPF/PPF routine care among countries. *Legend: The x-axis represents the European countries having responded to the survey, the y-axis the absolute number of respondents*

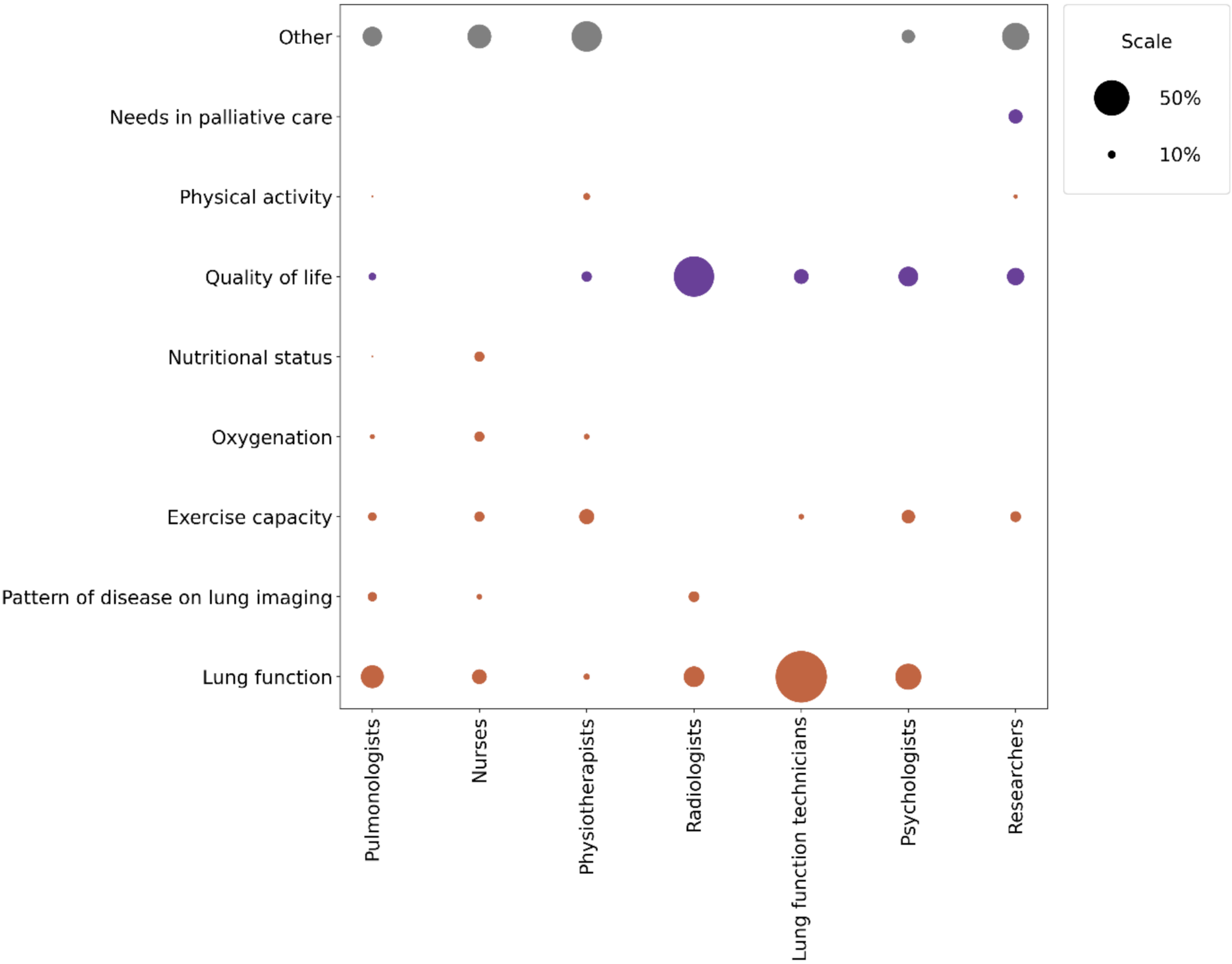

Fig. 4 Most frequently used outcome domains in routine IPF/PPF care by stakeholder groups. *Legend: The x-axis shows different healthcare professional groups that participated in the survey. The y-axis shows the most frequently reported outcome domains. The circles show the relative distribution of the most frequently reported outcome domains within each healthcare professional group.*

(*n* = 24, 3%) and `physical activity` (*n* = 10, 1%) and nurses `oxygenation` and `nutritional status` (*n* = 2, 0,2% each) as most frequently used routine health outcomes in IPF/PPF care (Fig. 4). In addition to the outcome domain 'patterns of disease on lung imaging (n = 1, 14%), radiologists mentioned `quality of life` (n = 4, 57%) and `lung function` (n = 2, 29%) as most frequently used outcome domains (Fig. 4). Lung function technicians reported mostly about the routine assessment of `lung function` (n = 11, 73%) (Fig. 4). Psychologists reported `lung function` (n = 4, 36%), `quality of life` (n = 3, 27%) and `exercise capacity` (n = 2, 18%) as most commonly used outcome domains reflecting the most common results of all survey participants (Fig. 4). Researchers also mentioned, alongside other frequently mentioned outcomes, the `needs for palliative care` (n = 4, 19%) as one of most frequently used health outcomes in the routine care of pulmonary fibrosis patients (Fig. 4).

Discussion

There is a need for consistent and meaningful outcome assessment and harmonization of endpoints for a standardized clinical care and a better European-wide comparability of research findings [15]. Therefore, the aim of this European multidisciplinary survey amongst ILD expert healthcare professionals was to generate relevant insights on the person-centred outcomes currently used in IPF and PPF care or deemed most relevant to be included in a Core Outcome Set for clinical practice. A wide range of outcomes was identified, which we could classify in 40 outcome domains.

`Lung function`, `exercise capacity` and `quality of life` were prioritized as most important health outcome domains reported by European multidisciplinary ILD experts. No clear differences were noted between European countries, with healthcare professionals mainly reporting about the use of `physiological/clinical` and `life impact` outcomes in the routine care of IPF/PPF patients. Our survey also revealed that many outcomes referred to aspects of disease progression, such as `all-cause mortality`, `pattern of disease on lung imaging`, `lung function` and `chest symptoms`. Although the relatively small number of participants per country prevented us from testing differences statistically, we might prudently conclude also that the outcomes that matter most to healthcare professionals are relatively similar irrespective of country. It is thereby worth noting that healthcare professionals from 31 different European countries participated, ensuring that the viewpoints from different healthcare systems are captured, which is important when developing a Core Outcome Set.

The observation that several outcome domains are linked to disease progression is not surprising. Indeed, the diseases for which we want to develop a Core Outcome Set (IPF/PPF) are characterized by a progressive nature and are associated with significant disease burden and mortality. Yet, the rank order of most important outcome domains differs depending on the healthcare profession. Physicians put more emphasis on clinical and respiratory outcome domains, whereas physiotherapists considered `exercise capacity` and `physical activity` as one of the most relevant outcome domains for use in routine progressive pulmonary fibrosis care. Nurses reported outcome domains assessing the whole body status such as `oxygenation` and `nutritional status` as most frequently used person-centred health outcomes in IPF/PPF care. This underlines the need for interdisciplinary care, i.e. that care should address both medical and non-medical needs, necessitating the input and collaboration of professionals with different expertise.

In contrast, we could not observe differences between specialized and non-specialized IPF/PPF clinics. Although the numbers are again too small to perform statistical analyses, this might indicate that the same outcomes are deemed important irrespective of setting or organization of care. It is known, however, that patients treated in tertiary centres of ILD expertise have better outcomes, such as better diagnostic accuracy and treatment adequacy, which in turn can result in a slower disease progression, a better survival and reduced healthcare costs [5, 16, 17]. Yet recent evidence shows that this is not related to structural characteristics of care [18]. This implies that the way outcomes are being addressed might be more critical than whether or not care is being provided in a specialised clinic. Furthermore, patients are most likely to have similar care needs, which require attention regardless of the specialisation of care. Hence, our Core Outcome Set should be used to improve patient care even in healthcare settings where patients do not have access to specialised centre-based care.

Interestingly, survey participants mainly reported clinical or physiological outcomes and only mentioned a few non-medical outcomes, such as health-related quality of life or outcomes related to palliative care needs. This underlines that the care for people with IPF/PPF currently focuses most on medical needs and less on psychosocial aspects, although participants at the same time recognize that care should span the entire disease cycle from diagnosis to the end of life. Patient advocacy organizations nevertheless advocate to also consider person-centred outcomes when assessing clinical status and progress in the routine care of people with IPF/PPF. In research, we also see that studies mainly used health-related quality of life as secondary endpoints, and the chosen measures often failed to demonstrate significant effects due to the lack of sensitivity on less advanced diseases. Moreover, the measures used might not be specific enough to capture those aspects of quality of life that matter most to patients and clinicians or because socio-cultural differences have not been taken into account [19, 20]. Non-medical outcomes will hopefully receive further attention both in clinical care and research, given that the European Medicines Agency (EMA) and the U.S. Food and Drug Administration (FDA), for instance, recommend using non-medical outcomes or so-called patient-reported outcomes as efficacy endpoints in clinical trials and provided guidelines in place to develop outcome measures in a culturally sensitive way [21, 22]. These efforts are also supported by previous scientific initiatives [9, 15, 23]. Moreover, registry databases should also incorporate non-medical outcomes, as this is important to have a comprehensive understanding of the outcomes of a real-world population of IPF/PPF patients [24]. The insights of our survey, together with input from patients and available research evidence, will form the basis to identify a Core Outcome Set, consisting of both medical and non-medical outcomes to better capture the key aspects of a patient's health.

Methodological considerations

We were able to reach a large number of participants from different European countries and with different professional backgrounds, despite IPF/PPF are rare lung diseases and hence the number of healthcare professionals with expertise in this specific area is presumably rather limited. Our focused and broad recruitment strategies might have been beneficial in this regard.

Yet, we don't know if professionals from other non-European countries would give similar responses. Although we hypothesize that non-European healthcare professionals would deem similar outcome domains important to be used in clinical care, the survey should be expanded to other parts of the world to confirm this. Moreover, despite the relatively large sample size, it is possible that we missed the opinion from non-English speaking healthcare professionals, for instance nurses, as the survey was only available in English. Indeed, most participants were pulmonologists, which might be more familiar with reading and speaking English, and other disciplines were less represented. This might on the other hand merely reflect the physician-driven care model that is currently prevailing within IPF/PPF care across Europe, which was also shown in a benchmarking report of the European patient advocacy organisation EU-PFF [25]. Nevertheless, to avoid language bias, we will also provide materials in languages other than English for the future steps within our Core Outcome Set development process to ensure a larger participation from stakeholders (healthcare professionals and patients) feeling less confident to respond in English.

Moreover, the outcomes reported often lacked further specification or outcomes were confused with outcome measures. To keep the survey as short as possible, we did not include questions asking participants to clarify what they meant by a given outcome or how this outcome is currently being addressed in routine care. Focus groups or one-on-one interviews with a purposive sample of European healthcare professionals from different disciplines could have been an alternative, yet this was not possible due to time constrains and language issues (e.g. to run the interviews, prepare the transcripts and analyse the data). Our survey is nevertheless unique because of its pan-European large participation and was able to identify already 40 possible outcome domains to consider within routine care, which forms a good basis, alongside other stakeholder involvement, to develop a Core Outcome Set for clinical care and research in IPF/PPF. Third, although we followed a standardized way of outcome categorization recommended by the COMET initiative (which is the lead organisation providing guidance on COS development), there is no consistent method of grouping individual outcomes into outcome domains. In order to minimize the risk of interpretation bias of single researchers, consortium members from different professional backgrounds worked independently on the categorization and created a shared solution in an iterative consensus process.

Conclusion

We conducted a clinically oriented multinational interdisciplinary survey with European healthcare professionals on the most important health outcomes used in IPF and PPF. This is one of the crucial steps in forming the basis of an international Delphi study aiming to reach consensus on the Core Outcome Set to be considered in routine care of pulmonary fibrosis patients for improving patients' quality of care and life. A broad spectrum of outcome domains was detected without major differences between European countries, healthcare disciplines and centres´ specializations for ILD. \`Lung function\`, \`exercise capacity\` and \`quality of life\` were the most frequently used health outcome domains and \`lung function\`, \`exercise capacity\`, \`quality of life\` and \`chest symptoms\` the most frequently reported outcome domains deemed most important for use in clinical routine care of patients with a progressive form of pulmonary fibrosis.

Abbreviations

CHERRIES	Checklist for Reporting Results of Internet E-Surveys
COMET	Core Outcome Measures in Effectiveness Trials
COS	Core Outcome Set
EMA	European Medicines Agency
ERS	European Respiratory Society
FDA	Food and Drug Administration
GDPR	General Data Protection Regulation
HCPs	Healthcare professionals
IPF	Idiopathic pulmonary fibrosis
IRB	Institutional review board
ILD	Interstitial lung diseases
PPF	Progressive pulmonary fibrosis

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12931-025-03146-4.

Supplementary Material 1: **Appendix 1**: Checklist for Reporting Results of Internet E-Surveys (CHERRIES). **Appendix 2**: Survey Healthcare Professionals.

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Author contributions

- Development of the protocol: VS, AD, SS, LvB, SB, NÜ, ZNT, NS, NM, WW, SJ, LG, JB, TT, FD, MK - Development and piloting of the survey: VS, AD, SS, ZNT, FD; - Determining the recruitment strategy and identifying eligible participants: VS, AD, SS, NÜ, ZNT, NM, ST, TT, MK; - Data analysis: VS, AD, FD; - Drafting the manuscript and figures: VS, AD, LvB, SB, FD, MK; - Critical revisions of the manuscript: VS, AD, SS, LvB, SB, NÜ, ZNT, NS, NM, WW, SJ, LG, JB, TT, FD, MK.

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Data availability

Data can be obtained from the first and corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The institutional review board (IRB) of KU Leuven (Belgium) waived the need for ethical approval as no personal information was collected. The study and the used Qualtrics^{XM} software adhere to the General Data Protection Regulation (GDPR) guidelines. Participation to the survey was voluntary and participants could decline to take part or leave the survey at any time. The information provided was kept completely confidential. The survey was analysed anonymously, and no e-mail addresses or IP addresses were collected as part of the survey. E-mail addresses were only used to distribute the survey and were not made available to the consortium. The data were only reported in an aggregated form.

Consent for publication

The authors explain that there are no issues relating to the journal's policies and confirm that the content of the manuscript has not been published, or submitted for publication elsewhere. No images are personal or clinical details of participants are presented.

Competing interests

Wim Wuyts: grants paid to institution from Roche, Sanofi, Alentis and Boehringer Ingelheim. - Liam Galvin and Steve Jones: unrestricted grants to EU-PFF from Boehringer Ingelheim, Roche, Trevi Therapeutics, Chiesi Pharmaceuticals, Bristol Meyer Squibb, Vicore Pharma, CSL Behring, and Ferrer.- Michael Kreuter: consulting fees from GSK, Boehringer, AstraZeneca, Pliant, and BMS. Yet, these authors declare that these disclosures did not influence the results and/or discussion reported in this paper.

Use of artificial intelligence

We hereby declare that AI has been used to ensure grammatical accuracy.

Author details

[1]Mainz Center for Pulmonary Medicine, Dept of Pneumology, Critical Care & Sleep Medicine, Mainz University Medical Center and of Pulmonary, Marienhaus Clinic Mainz, Mainz, Germany
[2]Dept of Public Health and Primary Care, Academic Centre for Nursing and Midwifery, KU Leuven, Kapucijnenvoer 7, Box 7001, Leuven B-3000, Belgium
[3]Dept of Psychology and Psychotherapy, Psychologische Hochschule Berlin (PHB), Berlin, Germany
[4]Dept of Pulmonary Medicine, Ege University Medical School, Ege University Hospital, Izmir, Turkey
[5]Dept of Chronic Diseases and Metabolism, Laboratory of Respiratory Diseases and Thoracic Surgery, Dept of Respiratory Diseases, Unit for Interstitial Lung Diseases, KU Leuven, University Hospitals Leuven, Leuven, Belgium
[6]European Pulmonary Fibrosis Federation (EU-PFF), Brussels, Belgium
[7]European Lung Foundation (ELF), Sheffield, UK
[8]European Respiratory Society, Lausanne, Switzerland
[9]Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland

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