

Scoping review of exposure questionnaires and surveys in interstitial lung disease

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ABSTRACT

Background Many interstitial lung diseases (ILDs) have clear causal relationships with environmental and occupational exposures. Exposure identification can assist with diagnosis, understanding disease pathogenesis, prognostication and prevention of disease progression and occurrence in others at risk. Despite the importance of exposure identification in ILD, there is no standardised assessment approach. Many questionnaires are in clinical and research use, yet their utility, applicability, relevance and performance characteristics are unknown.

Objectives This scoping review aimed to summarise the available evidence relating to ILD exposure assessment questionnaires, identify research gaps and inform the content for a future single evidence-based ILD questionnaire.

Methods A scoping review based on Arksey and O'Malley's methodological framework was conducted. Eligibility criteria: Any questionnaire that elicited exposures specific to ILD was included. A modified COSMIN Risk of Bias Framework was used to assess quality. Sources of evidence: Relevant articles were identified from MEDLINE and EMBASE up to 23 July 2023.

Results 22 exposure questionnaires were identified, including 15 generally pertaining to ILD, along with several disease-specific questionnaires for hypersensitivity pneumonitis (n=4), chronic beryllium disease, sarcoidosis and silicosis (1 questionnaire each). For most questionnaires, quality was low, whereby the methods used to determine exposure inclusion and questionnaire validation were not reported or not performed. Collectively the questionnaires covered 158 unique exposures and at-risk occupations, most commonly birds, mould/water damage, wood dust, asbestos, farming, automotive mechanic and miners. Only five questionnaires also provided free-text fields, and 13 queried qualifiers such as temporality or respiratory protection.

Conclusions Designing a robust ILD-specific questionnaire should include an evidence-based and relevance-based approach to exposure derivation, with clinicians and patients involved in its development and tested to ensure relevance and feasibility.

INTRODUCTION

Interstitial lung diseases (ILDs) are a large and heterogeneous group of disorders that

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Many interstitial lung diseases (ILDs) are associated with occupational and environmental exposures. Exposure assessment questionnaires exist, but their quality and relevance are unknown.

WHAT THIS STUDY ADDS

⇒ 22 exposure questionnaires, either specific to certain ILDs or for all ILDs, encompassing 158 exposures were identified. Most questionnaires were of low quality, whereby development methods of derivation and validation were not outlined or not performed.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This manuscript highlights the need for an evidence-informed ILD-specific exposure questionnaire. Designing a robust ILD-specific questionnaire should include an evidence-based approach to questionnaire derivation and validation.

cause inflammation and/or fibrosis of the lung parenchyma. Many forms of ILD lead to progressive and irreversible lung scarring (pulmonary fibrosis), and are associated with high morbidity and early mortality.¹ The burden and prevalence are increasing over time, with an estimated 180–220 ILD cases per 100 000 people each year.² While some forms of pulmonary fibrosis are idiopathic (ie, of unclear aetiology), many ILDs have clear causal relationships with inhaled environmental and occupational exposures. These primarily include the smoking-related ILDs, asbestosis, silicosis and hypersensitivity pneumonitis.^{3–6} However recent data suggest that other forms of ILD, including those thought to be idiopathic, are associated with inhaled exposures, including air pollution, secondhand smoke and occupational exposures to vapours, gases, dusts and fumes.^{7–9} Idiopathic pulmonary fibrosis (IPF) diagnosis has been linked to air pollution and specific

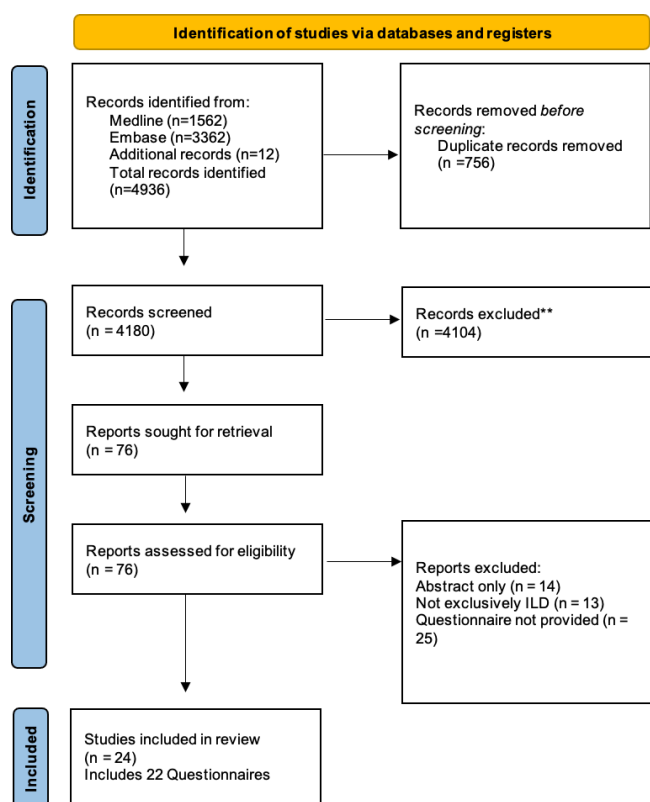


Figure 1 Flow diagram of study selection. IL, interstitial lung diseases.

inhaled occupational exposures,^{7 8 10 11} while patients with connective tissue disease (CTD) appear to be at higher risk of developing ILD after occupational exposures to silica.^{9 12} A comprehensive framework for ILD pathogenesis and most importantly, prevention, requires a deeper understanding of the exposures that impact the risk of developing the disease. Despite the importance of inhaled exposures on the risk of ILD, there is no standardised approach to characterising these exposures and no single questionnaire is thought to perform sufficiently to be in widespread use. While efforts have been made for the development of questionnaires and job exposure matrices for specific clinical contexts and diagnostic categories,^{8 13 14} there is an urgent need for a high-yield, clinically relevant questionnaire that identifies disease-causing exposures in patients with, or at-risk for, ILD. Such a questionnaire is useful to identify potentially causative exposures, to assist with compensation and other benefits and to identify current exposures where remediation may improve disease outcomes. Without such a tool, patients may be misdiagnosed and mismanaged, and there will be lost opportunities for exposure removal and enhanced understanding of disease pathobiology and the effectiveness of interventions.

Several questionnaires are available for clinical and research settings to identify exposures associated with, and potentially causative of ILD. These exist in clinics, in registry surveys, as online resources and in textbooks.^{8 13–17} The utility, applicability, relevance and

performance characteristics of these questionnaires and surveys are unknown. It is also unclear which of the questionnaires are being used, and in what specific settings. To develop an effective and meaningful exposure questionnaire, the current tools in use and their elicited data must be collected, synthesised and cross-checked with clear evidence of association. This will provide a comprehensive overview of the types of exposures being elicited, heterogeneity across questionnaires, modern relevance of specific exposures and knowledge gaps.

Objectives

The objective of this study was to conduct a scoping review of the literature to identify all questionnaires in use to identify exposures associated with a diagnosis of ILD. We aimed to summarise available evidence relating to exposure assessment questionnaires, identify research gaps and subsequently to inform the content for a single evidence-based ILD exposure questionnaire.

METHODS

Search strategy

We conducted a scoping review based on Arksey and O'Malley's methodological framework,¹⁸ and outlined our methods a priori.¹⁹ We searched MEDLINE and EMBASE from inception (MEDLINE-1964, EMBASE-1947) up to 23 July 2023 for any study reporting an exposure questionnaire in the assessment of ILD (search strategy—online supplemental appendix table 1). Studies were excluded if the questionnaire was not available or not made available on request. We also searched grey literature (ie, non-traditional publication sources) by using the terms 'interstitial lung disease'; 'ILD', 'HP', 'CTD-ILD', plus 'exposure' and 'questionnaire', 'survey', 'tool', in Google Search up to 23 July 2023, and contacted ILD registries to obtain exposure questionnaires.

Inclusion/exclusion criteria

Questionnaires in all languages were eligible for inclusion. Questionnaires were required to be specific for ILD, including diagnoses of IPF, idiopathic interstitial pneumonias (IIP), CTD-related ILD, unclassifiable ILD and other forms of pulmonary fibrosis. They were not required to be specific for known exposure-related ILDs.

Data extraction and analysis

Potential questionnaires were reviewed by two independent assessors (HB and SE) for consideration of eligibility. Discrepancies were discussed with a third author (KAJ). Included questionnaires underwent data extraction using a data extraction template designed for this review, which included year of publication, country, target population, publication source/where accessed and methods of synthesis and validation. All data were extracted by two independent assessors. Specific exposures, environmental scenarios and job titles/roles

Table 1 Table of included questionnaires

Name	Format	Leading questions/mode of response/number of exposures/qualifiers
CHEST ¹⁶	English; paper	Have you ever been exposed to the following at work/ home/elsewhere? Yes/no response for some exposures, free text for occupations, free-text exposure section, 64 exposures
Kreuter (GRS) ²¹	German/English; paper	Do you or did you have professional or private contact with the following hazardous substances or do/did you carry out the following activities? Yes/no responses only, 37 exposures. Jobs and hobbies have a time course
UCSF ¹⁵	English; paper	If you were repeatedly exposed to any of the following in the 3 years before your breathing problem started, answer 'Yes'. Yes/no response only, 50 exposures
Jackson ²²	English; paper and electronic	Ask if the subject was exposed 'most days of the week' to any of the following in the 3 years before the breathing problem started; has ever worked as one of the following, answer 'Yes'. Yes/no, with free-text field available, 40 exposures. Duration and frequency per week
Lee ⁹	English; EMR	Leading question not specified. Yes/no, with free-text field available, 13 exposures
Singh ²³	English; paper	No leading question. Yes/no responses only, 12 exposures. 'Duration' and 'remarks'
NJ ²⁴	English; paper	Does your home have any of the following?; Have you ever worked in any of the following occupations or locations? Yes/no responses only, 60 exposures
Carlier ²⁵	French/English; paper	Have you been exposed to any of the substances listed below? Yes/no responses, other exposures free-text field, 39 exposures. List specific dates of exposure; asks about PPE: yes/no, specify
Fisher ¹⁷	English; paper	Answer 'Yes' if you were repeatedly exposed or worked in any of the following in the 3 years before your breathing problem started. Yes/no responses only, 26 exposures
Sack ³⁴	English; paper	Have you ever been exposed at work to: Yes/no responses only, four exposures. Quantify exposure, when last exposure occurred, whether the exposure was 'mild, moderate, or severe'
Abramson ⁸	English; paper	Answer 'Yes' if you were repeatedly exposed to any of the following in your home or work environment in the 3 years before your breathing problems. Yes/no responses only, 14 exposures
Paolucci ¹¹	English; paper	Have you been exposed to; have you worked with... Yes/no responses only, 29 exposures
Reynolds ³⁵	English; paper	Work roles coded in job exposure matrix, 26 occupations. Job duration
Hoy ³¹	English; paper	Work roles, time spent in stone benchtop industry; specific tasks. Dose, duration, work tasks, respiratory protection
Vanderbilt ^{26 27}	English; paper	'Were you exposed to:' Yes/no responses only, 44 exposures. Amount of exposure 'high/ med/ low'
Kim ³³	English; paper	Have you engaged in any of the following occupations? Yes/no responses only. Exposure intensity: high: severe exposure, poor wearing of protective gear, middle: some exposure, intermittent wearing of protective gear, low: exposure not severe, wear protective gear regularly
Petnak ¹⁴	English; paper	Have you had any of the following in your home or work environment? Yes/no responses only, 30 exposures
Barnes ¹³	English; paper	Thinking about the places where you have commonly spent time, either now or in the past. Yes/no responses. Free-text field available, 18 exposures. How long from when you were first to last exposed?; Number of times exposed?; Daily, for large parts of the day; Daily, for short periods; A few times a week; A few times a month; A few times a year; How long since last exposed?; Do any of your symptoms improve when you are away from the exposure?

Continued

**Table 1** Continued

Name	Format	Leading questions/mode of response/number of exposures/qualifiers
Morrell ²⁸	English; paper	No leading question Yes/no responses only, nine exposures. ‘Duration and quantity’
Vasakova ²⁹	English; paper	Do you/did you have any of the below-stated items/conditions? Yes/no responses only, 118 exposures
Nathan ³²	French; paper	Were you in the following settings before the onset of disease? Yes/ no responses only, 54 exposures. ‘Sometimes or occasionally or never’
Cherry ³⁰	English; paper	No leading question Yes/no responses only, 34 exposures

CBD, chronic beryllium disease; EMR, electronic medical record; GRS, German Respiratory Society; HP, hypersensitivity pneumonitis; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; NJ, National Jewish; PF-ILD, progressive fibrosing interstitial lung disease; PPE, personal protective equipment; UCSF, University of California, San Francisco.

included in the questionnaire were extracted. Ancillary qualifying questions (eg, duration of exposure) were also extracted. Data extraction was performed by one reviewer (HB) and checked by a second reviewer (SE) for fidelity. Where there was a potential conflict of interest (whereby the reviewer was also an author of the study)—data extraction was checked by a third author (KH). Questionnaire demographics are described narratively. The frequency of inclusion of specific exposures or ancillary qualifying questions on questionnaires was tabulated.

Quality assessment

There is no single quality assessment tool which appropriately applied to our review. We chose to adapt the COSMIN Risk of Bias Checklist for patient-reported outcome measures to assess the risk of bias, as it is designed to assess the reliability and potential measurement error of outcome measure assessments, including patient-reported outcomes, performance-based outcomes or biomarkers.²⁰ We assessed the following domains: methods of questionnaire development; content validity; construct validity; cross-cultural validity; other (online supplemental appendix table 2).

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS

Search results

The search yielded 4936 records up to 23 July 2023, and following the screening, 22 unique questionnaires were identified (figure 1). The main reason for exclusion from abstract and full-text screening was that the questionnaire used was not provided in the text, or it was not clear that a questionnaire was used in the parent study. The details of the included questionnaires are outlined in table 1. Of the 22 included questionnaires, 10 were designed to capture exposures across all ILDs,^{9 15–17 21–27} 4

specifically for hypersensitivity pneumonitis (HP),^{13 14 28 29} 1 for chronic beryllium disease,³⁰ 1 for silicosis,³¹ 1 for sarcoidosis,³² 1 for IIP³³ and 1 for interstitial lung abnormalities (ILAs).³⁴ 10 questionnaires were created for clinical use,^{9 13 15 16 21 22 24 25 29 31} 3 for ILD registries,^{8 17 23} 5 for research use^{11 26 32–35} and 4 for reasons unspecified.

Contents of included questionnaires

For most included questionnaires, the methods used to determine how exposures were included were not reported (table 2). Jackson *et al* identified exposures from other published ILD questionnaires, then used a modified Delphi process of local ILD experts to determine relevant exposures for their local setting.²² Medical personnel undertook validation for understanding, response/recall difficulty and contextual relevance. Barnes *et al* performed a systematic literature review identifying all exposures reported in the literature specific to HP, and performed a modified Delphi process of international ILD experts to determine relevant exposures.¹³ Petnak and Moua developed their questionnaire after performing a systematic literature review to identify relevant exposures for all ILDs.¹⁴ Hoy *et al* developed a silicosis-specific exposure questionnaire using a multidisciplinary team of expert opinion, that included pulmonologists, occupational physicians, radiologists, respiratory scientists and occupational hygienists.³¹

An HP questionnaire reported by Barnes *et al* was tested by patients through cognitive interviews to ensure each item was clearly understood, relevant, non-redundant and reflected the concept intended to measure.¹³ Performance of the exposure questionnaire was reported in two studies. Barnes *et al* tested an HP exposure questionnaire in a multicentre study of 130 patients with HP and non-HP ILD and found that the use of the questionnaire identified an exposure in 33% of cases where a clinician did not.³⁶ Perluk *et al* assessed the performance of the Chest Questionnaire in a single-centre study of 62 patients and found clinician review identified exposures where the Chest Questionnaire did not in 47% of cases.³⁷

Table 2 Methods of questionnaire derivation and validation

Name/target population/intended use	Derivation/creation/validation
CHEST ¹⁶ undated USA ILD - clinical	Not reported
Kreuter (GRS) ²¹ 2018 Germany ILD - clinical and registry	Not reported
UCSF ¹⁵ undated USA ILD - clinical	Not reported
Jackson ²² 2020 Africa ILD - clinical	Exposures from other ILD questionnaires, Delphi by local ILD experts
Lee ⁹ 2021 USA ILD - clinical	Not reported
Singh ²³ 2017 India ILD - registry	Not reported
National Jewish ²⁴ undated USA ILD - clinical	Not reported
Carlier ²⁵ 2022 France ILD - clinical	Literature review
Fisher (care-PF) ¹⁷ 2019 Canada PF - registry	Not reported
Sack ³⁴ 2017 USA ILAs - study	Not reported
Abramson (AIPFR) ⁸ undated Australia IPF - IPF registry	Not reported
Paolucci ¹¹ 2018 Sweden IPF - study	From an asthma questionnaire derived by experts
Reynolds 2022 ³⁵ IPFJES UK IPF - study	Derived from mesothelioma JEM
Hoy ³¹ 2021 Australia Silicosis - clinical	Expert opinion by MDT
Vanderbilt Questionnaire ^{26 27} 2020 USA Familial ILD - study	Not reported
Kim ³³ 2017 South Korea IIP - study	Not reported
Petnak ¹⁴ 2020 USA HP - unclear	Systematic review of commonly reported exposures
Barnes ¹³ 2020 USA/Australia HP - clinical and study	Systematic review of exposures, selected exposures through Delphi of ILD experts, patient validation for content validity
Morrell ²⁸ 2013 HP - unclear	Not reported
Vasakova ²⁹ 2017 HP - clinical	Not reported
Nathan ³² 2022 France Paediatric sarcoidosis - study	Not reported
Cherry ³⁰ 2015 Canada CBD - study	Not reported

AIPFR, Australian idiopathic pulmonary fibrosis registry; CBD, chronic beryllium disease; GRS, German Respiratory Society; HP, hypersensitivity pneumonitis; IIP, interstitial pneumonias; ILAs, interstitial lung abnormalities; ILD, interstitial lung diseases; IPF, idiopathic pulmonary fibrosis; IPFJES, idiopathic pulmonary fibrosis job exposure study; JEM, job exposure matrix; MDT, multi-disciplinary team; PF, pulmonary fibrosis; UCSF, University of California, San Francisco.

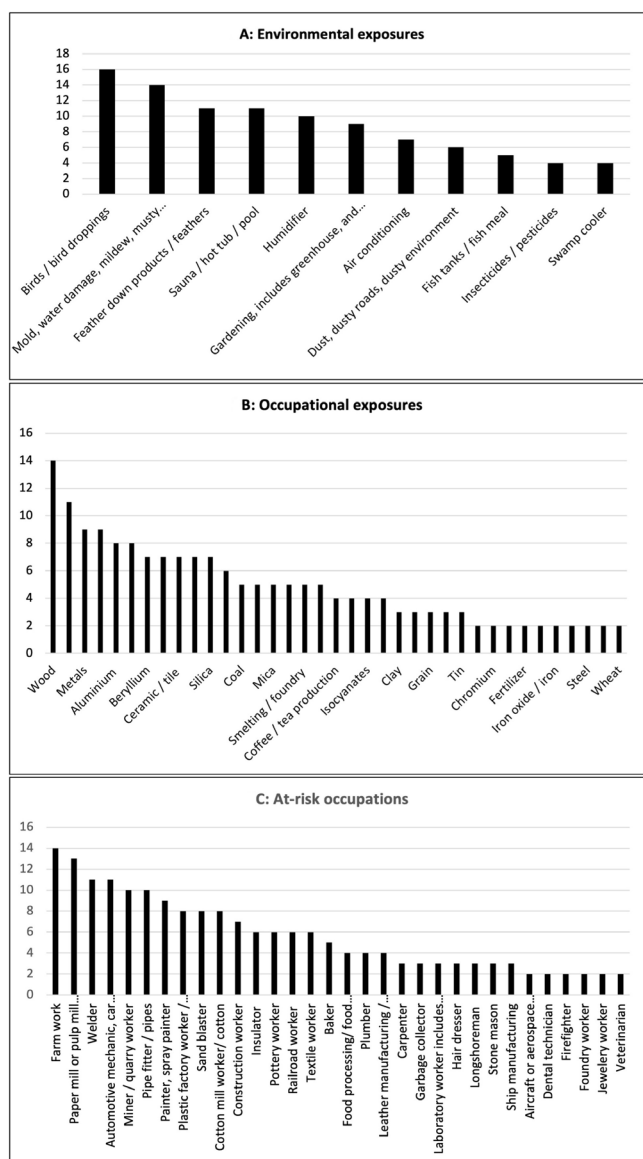


Figure 2 Frequency of exposures reported in questionnaires.

Across all 22 questionnaires, a total of 158 specific exposures were covered (figure 2). The specific exposures most included in the questionnaires were birds ($n=16$ questionnaires), mould/water damage ($n=14$), wood ($n=14$), farming ($n=14$), asbestos ($n=11$), metal fumes or metal working fluids ($n=11$). Across all 22 questionnaires, a total of 48 occupation settings were covered. The occupational settings most included in the questionnaires were farm work ($n=14$ questionnaires), paper mill workers ($n=13$), automotive mechanics ($n=11$) and miners ($n=10$) (online supplemental appendix table 3). Some elicited exposures were non-specific in description (eg, ‘dog’, ‘coffee/tea’), while others were more specific to occupation or setting (eg, stonemason). Only five questionnaires also provided a free-text field to provide additional information about potentially relevant exposures, via iteration. It is important to recognise that some exposures listed (eg, cat, dog) have not been linked to

ILDs in the literature. This is likely a result of re-purposing asthma exposures in an ILD questionnaire.

13 questionnaires attempted to qualify the dose or duration of the exposure(s). Often this was non-specific (eg, ‘high/medium/low’), without specifying the definitions of these parameters. One provided specific time references (eg, ‘daily, for large part of the day’, ‘a few times a year’) and four asked about dates of exposure, mainly related to work roles. Only two questionnaires enquired about the use of respiratory protection. Nine questionnaires enquired about potential exposures in a binary way (yes/no) without further detail elicited about potential exposure dose, duration or latency.

Quality assessment

Most studies were considered at high risk of bias, primarily because the methods of questionnaire development were not reported, and content, construct and cross-cultural validity were not assessed (table 3).

DISCUSSION

We aimed to map the evidence regarding available questionnaires designed to elicit exposures relevant to ILD. To our knowledge, this is the first scoping review to describe such findings. We identified 22 ILD exposure questionnaires used in clinical practice and/or research. Additional studies reported the use of a questionnaire, but were unable to be included as the questionnaire was not provided or referenced. Notably, some of the excluded studies assessed or reported the role of exposures on ILD diagnosis without referencing the use of a questionnaire. While taking a clinical history is important, utilisation of a questionnaire in ILD exposure assessment provides a systematic approach to ensure relevant exposures have been assessed, and consistently between patients. Without a systematic approach in the clinical or research setting, the role of inhaled exposures may be underestimated or misattributed. It also becomes difficult to aggregate and compare exposures across studies where the methods of assessment are not standardised. There is potential bias whereby association between exposure and disease is being determined without methods specified, or unable to be reproduced.

Any questionnaire or assessment tool should be derived using an evidence-based approach, and subsequently validated. Most questionnaires did not report their methods of synthesis, and it is assumed they were created by expert opinion or based on historical data. Without an evidence-based approach, there is a risk of perpetuation of incorrect or irrelevant exposures, particularly when environments, occupations and other potential situations of exposure have changed substantially since survey inception. Free-text fields to add additional relevant items are also important, to iteratively identify new or novel exposures and exposure scenarios such as specific hobbies or jobs.

Table 3 Quality assessment using the adapted COSMIN Risk of Bias Tool

Name/source	Reported methods of development	Content validity	Construct validity	Cross-cultural validity
CHEST ¹⁶	Not reported	Not reported	Not reported	Not reported
Kreuter (German Respiratory Society) ²¹	Not reported	Not reported	Not reported	Not reported
UCSF ¹⁵	Not reported	Not reported	Not reported	Not reported
Jackson ²²	Low risk	Not reported	Not reported	Not reported
Lee ⁹	Not reported	Not reported	Not reported	Not reported
Singh ²³	Not reported	Not reported	Not reported	Not reported
National Jewish ²⁴	Not reported	Not reported	Not reported	Not reported
Fisher (care-PF) ¹⁷	Not reported	Not reported	Not reported	Not reported
Sack ³⁴	Not reported	Not reported	Not reported	Not reported
Abramson (AIPFR) ⁸	Not reported	Not reported	Not reported	Not reported
Paolucci ¹¹	Not reported	Not reported	Not reported	Not reported
Hoy ³¹	Not reported	Not reported	Not reported	Not reported
Vanderbilt ^{26 27}	Not reported	Not reported	Not reported	Not reported
Kim ³³	Not reported	Not reported	Not reported	Not reported
Petnak ¹⁴	Low risk	Not reported	Not reported	Not reported
Barnes ¹³	Low risk	Low risk	Not reported	Not reported
Morrell ²⁸	Not reported	Not reported	Not reported	Not reported
Vasakova ²⁹	Not reported	Not reported	Not reported	Not reported
Nathan ³²	Not reported	Not reported	Not reported	Not reported
Cherry ³⁰	Not reported	Not reported	Not reported	Not reported

AIPFR, Australian idiopathic pulmonary fibrosis registry; UCSF, University of California, San Francisco.

Patient validation is essential to any questionnaire or tool. The COSMIN approach includes content validity (ie, does the item measure what it is intended to measure), construct validity (ie, is the item an adequate reflection of the construct to be measured) and cross-cultural validity (ie, has the questionnaire been studied in a diverse population). Only one questionnaire reported validation among patients. In addition, some phrases relating to the exposure itself or the duration of exposure were non-specific and open to interpretation. Lack of validation could lead to variable responses that are not reflective of the truth. An inherent limitation of ILD exposure questionnaires is that for many ILD-related exposures, there are no sufficiently sensitive and specific biological methods to confirm exposure (eg, serology or site test). Exposures may also differ across geographical locations, depending on different industries, environmental differences and climate. Any ILD exposure questionnaire would need to be further validated in the local setting, be translated for non-English speaking populations and adapted to local needs for optimal performance. The broad uptake of electronic medical records presents an opportunity for the widespread implementation of a standardised exposure questionnaire. This approach to rigorous exposure assessment should be applied across multiple settings to characterise the utility

and performance of such tools. Alternative methods to validate exposure items in a screening questionnaire could include in-depth interviews by occupational and environmental specialists to confirm exposure history. The format and style of the questionnaire may differ for specific settings, for example, in clinical practice (brief and easy to use) compared with research questionnaires (comprehensive but requiring a longer time to complete). Both should be evidence-informed, but questionnaires in each setting should be tailored to the overall purpose.

It can be difficult to determine what constitutes a relevant exposure, that is, how much is required to contribute to disease. Only half of the questionnaires asked about a dose and duration of exposure, yet this is an essential component of exposure assessment and ideally would be included in all questionnaires. Some exposures only asked about exposures dating back to 3 years, which would be insufficient in long latency exposures (eg, asbestos). The exposure dose and duration should be specific phrases that are understandable to patients and not open to variable interpretation. While the dose and duration of exposure required are affected by other intrinsic and extrinsic factors, understanding on average ‘how much is too much’ is essential to understand disease pathogenesis, and also to inform subsequent recommendations on



exposure avoidance. This assessment may differ between current and past exposures. Furthermore, many ILDs have a long period of latency (eg, asbestosis) and this would be important to capture, enabling further assessment of the biological plausibility of a causal relationship between exposure and outcome.

This review found multiple exposures which were commonly included across many studies. These exposures should be considered for inclusion in future ILD exposure questionnaires. However, we do not wish to imply that common or frequently reported exposures are necessarily synonymous with relevant exposures, and these should be mapped to the literature to confirm relevance. There is also a differential risk between exposure and disease; bird exposure is common, but bird exposure associated with ILD is relatively rare, whereas the risk of ILD among stonemasons and miners is considerably higher, highlighting the importance of disease or process-specific questioning. In addition, different exposures may be contributory to different ILDs. Exposure to beryllium is almost exclusively related to chronic beryllium disease, whereas vapours and fumes may be related to several ILDs including HP, IPF, CTD-ILD and others. Geographical variation is also important to note, and locally adapted questionnaires may perform best to elicit exposures relevant to the target patient population in specific regional settings.

There are limitations to our study. Despite attempts to conduct a broad search, we may have missed potentially relevant questionnaires, particularly those available in the grey literature. If not sufficiently reported, we may have missed methods of derivation. We arbitrarily decided on a method of quality assessment, which others may not consider applicable. We welcome further discussion in this area. We were potentially conflicted, whereby some authors of this review were also authors on included questionnaires. Where this occurred, we used alternative authors to extract data and check the fidelity of results.

Assessment of exposures in ILD is essential to understand the pathogenesis, to improve diagnostic confidence and to provide advice for medical management and the person's career (and hobbies) and future prevention for other exposed workers or household members. Furthermore, a systematic approach to exposure assessment may result in a more accurate understanding of the epidemiology and changing trends of certain occupational diseases. Our scoping review demonstrates that while there are several ILD exposure questionnaires available in the literature, there are gaps in the quality of the questionnaire development and validation. Designing a robust ILD-specific questionnaire should consider several aspects: the list of questionnaire/exposure items should be evidence-based, that is, not only based on the most reported but also mapped to the literature in terms of relevance and evidence. Both clinicians and patients should be involved in its development. Like other scales or questionnaires, it should be tested to ensure it is interpreted in the way in which it is intended, that is, content

and construct validity and reliability. Exposure questionnaires may also need to be re-tested and adapted to the local environment, and ensure equal representation across countries. Ultimately, similarly, standardised questionnaires should be used across registry, research and clinical activities to enable the pooling of results.

Our review provides a summary of evidence of currently available questionnaires, and highlights the gaps in quality, making it difficult for the respiratory and occupational community to accurately assess the relevance of specific exposures in the development of ILDs. This review provides a crucial first step to inform an evidence-based and relevance-based ILD-specific exposure questionnaire for future use.

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