Early View

Original article

Improving spirometry testing by understanding patient preferences

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Improving spirometry testing by understanding patient preferences
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Why do I need spirometry and what do my results mean? Survey of patient
experiences highlights need for clear information before, during and after
spirometry testing and underlines the important role of operators

Abstract:

The American Thoracic Society and European Respiratory Society commissioned a task force to update the technical standards for spirometry testing with the aim of increasing the accuracy, precision, and quality of spirometry measurements and improving the patient experience.

To inform the task force with patient experiences, European Lung Foundation, in collaboration with the task force, conducted an online survey in 10 languages between August and September 2018.

There were 1760 respondents from 52 countries. The majority were adults (97.1%) and the most common reasons for spirometry referral were diagnosis (35.5%) and management of an ongoing condition (60.9%). 53.2% reported regularly using inhalers.

Respondents were very experienced with spirometry: 89.9% completed more than one test; 48% completed 10 or more tests. However, most reported not knowing what FEV_1 means (59.4%) and only 39.6% knew their most recent FEV_1 ; the exception was respondents with cystic fibrosis (CF) who reported much greater knowledge.

Respondents rated as moderately or seriously problematic: being told to keep blowing when they felt nothing is coming out (31.4%), coughing (30.4%), tiredness (26.3%) and concern about shortness of breath (20.1%).

Overall, respondents found spirometry to be acceptable, however an important minority (17%) find it difficult. Patients want clear information before, during and

after the test, including information on stopping medications. Operators have an important role in increasing the ease of patients, and changes to the testing environment can increase patient comfort. Patients want access to their results and want to understand how they relate to their individual health.

Introduction

Spirometry is the most common test of lung function [1]. Unlike other laboratory tests, the patient's full cooperation, including maximal breathing efforts, is essential. Despite the ubiquity of this test, little is known about patients' experiences of completing a spirometry test. As part of an update of the technical standards for spirometry by the American Thoracic Society (ATS) and the European Respiratory Society (ERS) [2], a survey of people who had experience of spirometry was undertaken. This survey sought to provide the task force developing the technical standards for spirometry with more objective data on patients' experiences and perceptions of spirometry in order to better address the needs of the patients. Patient feedback was incorporated into the technical standard [2] and the key messages of the patient experience survey that were included in the 2019 standard are available in appendix A1 of the online supplement. The current paper seeks to give more detail about patients' experiences of spirometry and their views about areas for improvement.

In this paper, the term "respondent" is used for a person who answered the survey; "patient" is used for the person being tested, recognising that not all of them are patients; "operator" is the person conducting the test.

Methods

Members of the spirometry technical standard task force, patient representatives and the European Lung Foundation (ELF) designed an online questionnaire to

understand patients' experiences and preferences for spirometry testing. This survey was carried out to assist and inform the task force in developing an update of the ATS and ERS technical standard for spirometry.

The online questionnaire was hosted on SurveyMonkey for 2 months (between August and September 2018). A snowball sampling method was used to disseminate the survey with the aim of reaching as many patients from as many countries as possible.

The existing ELF, ATS and ERS patient and organisational networks were primarily used to promote the survey using social media and targeted newsletters. In addition, professionals involved in the task force used their networks and contacts with local patient organisations and national professional societies to disseminate the survey to their members. The survey was subsequently shared with a range of organisations, including ATS Patient Advisory Roundtable, Cochrane Airways, Canadian Lung Association, European Cystic Fibrosis Registry, Dutch Association of Lung Function Analysts (Nederlandse Vereniging van Longfunctieanalisten) and Tuberculosis Alert. The challenge to this approach is that although specific groups of patients can be targeted in this way, there is no way of calculating the actual reach or response rate.

The survey was open to adults and children who have had spirometry testing including people living with lung conditions and those that have had the test as part of screening, e.g. during work-related health checks. The survey was available in 10 languages: Dutch, English, French, German, Greek, Italian, Polish, Portuguese,

Russian and Spanish. A copy of the survey is provided as appendix A2 in the online supplement.

The survey had seven sections:

- 1. Respondent demographics
- 2. Reason for referral to spirometry and current medication
- 3. Forced expiratory volume in 1 second (FEV₁) (understanding and knowledge of their result)
- 4. Experience of spirometry tests (frequency, location and information and advice received)
- 5. Spirometry preferences (mouthpieces, nose clips and test duration)
- 6. Barriers and benefits of spirometry
- 7. Suggestions for improvement

Respondents were also asked to give more information about these topics in free text boxes. The survey finished by asking respondents to share any additional comments or experiences of spirometry. At the end of the survey respondents were invited to sign up to receive the results of the survey via a separate form.

Results

The survey received 1760 responses. Questionnaire data was analysed using SPSS (Version 25). 43% completed the questionnaire in English (see table 3 in the online supplement for language responses data). English language free text responses were

analysed using thematic analysis and themes were validated for other language responses by team members. Questionnaire percentages will be presented along with further detail from the thematic analysis for each survey section.

Respondent demographics

While the majority of the responses were from Europe, patients from 52 countries around the world completed the questionnaire (see table 4, online supplement). The most frequent countries of residence were Germany (16.5%), UK (16.1%), Belgium (11.9%), USA (10.9%), Spain (10.9%), Italy (10.1%) and the Netherlands (8.5%). Although the study was open to both children and adults, the majority of respondents were adults (97.1%, see table 5, online supplement). 53.2% reported regularly using preventer, rescue or reliever inhalers.

The reason for initial referral for spirometry was diagnosis (35.5%) or an ongoing condition. Table 1 shows the reasons for attendance in detail; respondents could select more than one option.

Table 1: Reasons for initial spirometry referral

	N	%
Total	1759	100
Investigating a problem with your breathing / to get a diagnosis	625	35.5
Chronic obstructive pulmonary disease (COPD)	301	17.1
Asthma	296	16.8
Cystic fibrosis (CF)	165	9.4
Pulmonary fibrosis (for interstitial lung disease)	117	6.7

Bronchiectasis	86	4.9
Idiopathic pulmonary fibrosis (IPF)	76	4.3
Occupational health testing	65	3.7
Pre-operative testing as part of your work-up for surgery	24	1.4
Lung cancer	18	1.0
Neuromuscular disease	13	0.7

The majority of respondents had their spirometry test in a hospital (66.7%) or primary care (13.4%) setting, with only 1.5% reporting home spirometry.

Experience of spirometry testing and understanding of FEV₁

Respondents were very experienced with spirometry testing; 89.9% had completed more than one spirometry test and 48% reported having had 10 or more spirometry tests. However, most reported not knowing what FEV₁ means (59.4%) and only 39.6% said they knew their most recent FEV₁. Patients with cystic fibrosis (CF) were more likely (73.5%) than other conditions (e.g. asthma 44.9%, COPD 43.9%) to understand FEV₁ and have knowledge of their current FEV₁ (75.2% compared to 34.8% for asthma and 44.9% for COPD). Patients with CF complete spirometry more regularly as part of their ongoing management, compared with other lung conditions, and children with CF need to be tested more frequently to take account of their growth. Age may also play a part, as respondents with CF were more likely to be younger, and older adults tend to have lower levels of 'health literacy', or the ability to obtain, process and understand basic health information [3]. However it did not apply to other conditions: for all respondents, 63.4% of those aged over 50

reported knowing what FEV_1 meant, compared with 53.22% of those aged 50 and under.

Patients want to be able to understand their results and what they mean for them. Many reported not understanding how their spirometry results relate to their specific condition. They would like to be able to have access to these results (either on paper or available digitally) and be able to compare them to their previous results. Patients would also like to understand how their results rate for someone with their lung condition (56.3%), and how they rate for a healthy person of their age and height (53%).

While the majority reported that the difficulty of performing spirometry was acceptable to them, a minority (17%) did find it difficult, and this was especially so for respondents with IPF (26.8%). Some were very concerned about the test and some expressed feeling anxiety about the results. Some felt vulnerable and found the process embarrassing, especially when they found the test hard to do or when they produced sputum or excess saliva.

14.1% of participants reported not getting information about spirometry at the time of testing and 38.3% reported that they did not receive any information about withholding inhalers prior to the test.

Spirometry preferences

The majority of patients would prefer to receive information about spirometry verbally (59.4%), but many also wanted a printed handout (40.6%). A smaller but significant proportion prefer to receive information electronically (28.1%), especially

those aged between 18 and 50. Patients would like to know what to expect from the test and what the potential benefits of completing the test are. 65.2% would like to understand what it means if their result has changed from the last time they did spirometry.

Many had used only one type of mouthpiece (43.4%) or had no preference about mouthpiece (18.4%). The majority had used a nose clip (85.3%) with 16.6% reporting nose clip as a moderate or serious problem for them. Many of the patients who reported anxiety cited the nose clip as problematic.

Benefits and barriers of spirometry

When asked about perceived benefits of spirometry, the most common rated benefits were improved knowledge of lung function (62.5%) and getting a diagnosis (42.4%).

Participants were asked to rate how problematic potential issues with spirometry were for them on a four-point Likert scale (not, minor, moderately and severely problematic) with a 'not relevant' option. The issues that were rated most frequently as moderately or severely problematic are presented in Table 2. Many of these issues are reflected in the qualitative narrative below.

Table 2: Percentage of respondents rating potential issues about spirometry testing as moderately or severely problematic

Potential issue rated as moderately or severely problematic	%
To keep blowing even though you do not feel anything is coming out	31.4
Coughing	30.4

Feeling tired after the test	26.3
Concerns about shortness of breath due to the test	20.1
Concerns about ability to complete the test	17.5
Feeling dizzy	17.5
Nose clip uncomfortable	16.6
Dryness in mouth	13.2
Not given enough information about why the test is done	12.1
Mouth piece uncomfortable	12.0
Not given enough information about how to perform the test	11.7
Requirement to withhold inhalers prior to the test	11.4
Lack of support from healthcare professionals running the test	9.8
Feel embarrassed during the test (e.g. shouted at to blow)	9.7

Overall view about spirometry and ideas for improvement

Respondents were asked to provide feedback about their views on spirometry and any suggestions for improvement. 1422 respondents completed this section with responses varying from a few words to very long responses. The answers in English were coded for themes and validated in other languages, and themes are described below.

A necessary discomfort

Though many respondents gave suggestions about how spirometry testing could be improved, it is important to reflect that many people find spirometry testing acceptable and not problematic: "It's a quick painless test. What's to improve?".

While some respondents found the test uncomfortable, they felt it was a necessary, and temporary, discomfort: "I know some people don't like it... but I see it as a necessity". For a small proportion of respondents, spirometry is very worrisome or "causes extreme anxiety". The operator should be mindful of this and have strategies for those who find the test stressful or anxiety-inducing (such as practicing before the test). "I would like for health professional to listen to my concerns and at least show concern."

The importance of the operator

Many respondents emphasised the importance of the operator. Those who have had many tests feel it makes a real difference how friendly and encouraging the operator is: "a sympathetic, helpful and considerate nurse can do wonders during this test." Some felt the operator needed to fulfil the role of a cheerleader and that it made a difference to their results: "even if I have done it so often, I really need the health assistants' instructions and encouragement". Patients also felt operators need to "have empathy before, during and after the test" and that it is important to check if the patient is ready for the next blow and how they feel about having the test.

Patients also felt that it was important that operators did not express frustration when patients struggle to perform spirometry: "it would help if the technician/therapist did not express disappointment when I have trouble completing the test". Though many felt encouragement or coaching is important, some felt that "perhaps a gentler approach" than shouting instructions to blow was needed.

Clear guidance about inhaler use and performing the test

Many patients felt they were not given clear guidance about using their inhaler before the test. It was suggested that they would like a reminder a week before the test of when to stop taking their inhaler in preparation for spirometry and which respiratory medications they should continue to use.

Respondents said it is really important to feel prepared for what is going to happen during the test and then be talked through the process. This knowledge may be taken for granted, particularly if the patient does regular spirometry tests, but it should not be. The process should be explained before each test: "my results are best when each test is explained at the start, and each step is called out to me during the test."

Changes to the testing environment and process

Respondents suggest that some small changes can make the process much more pleasant, for example providing "sputum pots, water and tissues without the need to ask". Patients would like a recovery period between tests and not to feel rushed and have somewhere to sit and recover for a few minutes afterwards: "not a good idea to walk distances or drive when feeling light-headed or dizzy afterwards". Some patients would like somewhere "more private" when completing the test as they have concerns about infection due to their lung condition or feel embarrassment due to difficulty in completing the test. Some respondents suggested that better adjustability of machines would be positive as sitting awkwardly is not conducive to achieving good results.

Patients want to understand why they need a spirometry test, what their results are and what they mean for them. They would like to have access to their results (either on paper or available digitally) "without asking" and be able to compare them to their previous results. Some respondents requested a comparison to norms for a healthy person with the same age/height/weight or for someone with their condition. Patients would like these results and explanations without having to ask for them and prefer that operators not "presume I understand what the score means". Patients would also like to know if there is anything they could do to improve their results. They feel this would be important information at the end of a spirometry test and suggest that operators "talk about results with me rather than waiting for my consultant to do so". Patients can be better supported to access and interpret their results: "I always have to ask for my results and ... feel like I'm being a nuisance asking for them. I have no understanding of the context of my results i.e. how I compare to others of my age with my condition? Are my results viewed as good or bad?"

Discussion

This large, multi-country survey of patients' experience of spirometry suggests that, for the most part, people perceive spirometry as a necessary test that they tolerate well. Respondents suggested some areas of improvement and these were consistent across country of residence. These were: importance of clear information before,

during and after the test; operator empathy; and changes to the testing process and environment.

Clear information

This study highlights some areas of best practice around providing information; while most people prefer a face-to-face explanation it is important to have written information available. Patients want to know what their result means and, for those having repeat tests, access to their previous result would also be beneficial. A significant proportion of respondents reported confusion about withholding their inhaler prior to the test. To reduce the risk of patients unnecessarily stopping essential treatment, clear information about which respiratory medications should be withheld and for how long should be provided with the time of appointment, and a reminder should be considered.

Whilst patients want to know their spirometry results, in many facilities conducting spirometry the policies and procedures do not permit the operator to divulge this information. Since operators are well positioned to discuss measurements of lung volumes with the patients, and since many operators are also trained in patient education, spirometry facilities should consider reviewing and revising their policies regarding the information that operators may discuss with patients without crossing the line into interpretation of the results or diagnosis.

In addition, the ELF factsheet, "Testing your lungs: spirometry" [4], was co-produced with patients and addresses many of the common questions raised by survey respondents, including how to prepare for the test, what the results mean, and what

happens if the results are normal or abnormal. The factsheet is available in 15 languages and professionals can download it for use in their clinics.

Operator empathy and changes to test procedure

Some patients suggested that over-coaching was off-putting and stressful and a gentler approach by operators may be warranted while still being their "cheerleader". Respondents valued privacy, time between tests to recover and a place to sit afterwards, and provision of supplies such as tissues and a sputum pot.

Thought should be given to those who do find the test stressful or anxiety-provoking to ensure that they do not avoid their spirometry tests. Suggestions such as having a practice or time to get used to the nose clip may help those who are feeling overwhelmed.

Study strengths

This study was designed with patients and received a large number of responses across many countries in ten languages. It provides a clear picture of patients' experience of spirometry testing and how this can be improved. By seeking to engage patients and gather views widely from across many countries, through surveys such as these, we are able to provide a valuable explorative approach and highlight areas for future research.

Tips for healthcare providers when conducting spirometry tests

- Provide clear advice to patients in advance of the test, including the reasons for carrying the test out and whether they need to discontinue using medication and inhalers
- Ensure that tests are carried out in a quiet, private space and prepare the room in advance, for example by providing sputum pots, tissues and water
- Give clear verbal instructions to patients before and during the procedure, even if the patient is experienced in taking spirometry tests
- Between manoeuvres in a testing session, always ask the patient if they are ready to proceed before continuing the series
- Allow time for a practice test and avoid rushing patients who are anxious or having difficulty taking the test
- Give encouragement to patients during the test but avoid shouting instructions
- Allow patients sufficient time to recover after the test
- Inform the patient of their lung volume values, if permitted by local protocols. If appropriate, provide a comparison with their previous results or predicted values.
- Healthcare professionals who interpret spirometry are encouraged to explain results to their patients and provide comparisons to normal values

Limitations

There are several methodological challenges to gathering patient perspectives. Our approach to gathering patient responses was pragmatic, aiming to maximise the number of responses within the timeframe and resources available.

Challenges include the self-selection bias of the approach used. Individuals who complete a survey tend to have had a very good or very bad experience and are keen to communicate this, which may result in fewer responses from the moderate middle ground and bias the findings [5]. In addition, computer literacy and internet access also limit those who are able to participate. By using patient organisations to help disseminate the survey, we may also have had a higher proportion of responses from well-informed patients who are highly engaged in their healthcare.

This study provides a wide-range of views about spirometry testing and suggestions for practice for both respiratory services and individual operators. While spirometry is well tolerated by most, small changes to the procedure may help those who find it stressful and further information about results and the procedure would be welcomed by most.

References

- 1. Ranu H, Wilde M, Madden B. Pulmonary function tests. *Ulster Med J* 2011; 80(2): 84–90.
- 2. Graham BL, Steenbruggen I, Miller MR, Barjaktarevic IZ, Cooper BG, Hall GL, Hallstrand TS, Kaminsky DA, McCarthy K, McCormack MC, Oropez CE, Rosenfeld M, Stanojevic S, Swanney MP, Thompson BR. Standardization of Spirometry 2019 Update. An Official American Thoracic Society and European Respiratory Society Technical Statement. *Am J Respir Critic Care Med* 2019; 200: 8: 70–88.
- 3. Chesser AK, Keene Woods N, Smothers K, Rogers N. Health literacy and older adults: A systematic review. *Gerontology & Geriatric Medicine*; 2016; 2:1–13.
- 4. European Lung Foundation. Testing your lungs: spirometry. https://www.europeanlung.org/assets/files/en/publications/spirometry-en.pdf. Date last updated: July 2018. Date last accessed: 16 September 2020.
- 5. Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. *The Patient Patient Centred Outcomes Research* 2014; 7: 235-241.

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Appendix A1: Key messages from 2019 Technical Standard

A preliminary analysis of an online survey completed by 1760 spirometry patients from 52 countries conducted in August and September 2018 by the European Lung Foundation yielded the following key messages. A complete analysis of the results is forthcoming in a future publication. The task force gratefully acknowledges the support of the European Lung Foundation, the work done on this survey by Barbara Johnson, Courtney Coleman and Pippa Powell, and the input from so many patients regarding their spirometry experiences.

Most patients found the level of difficulty of the test to be either mostly acceptable or completely acceptable

Though many patients gave suggestions about how spirometry testing could be improved, it is important to note that 90% of patients found spirometry testing acceptable and not problematic. While some patients found the test to be uncomfortable, they felt it was a necessary, temporary discomfort.

Some small changes can make the process more pleasant

Patients would like to have water, tissues and sputum pots provided without having to ask. Patients would like a recovery period between maneuvers and not to feel rushed. Patients would like somewhere to sit to recover for a few minutes afterwards. Patients would like privacy when completing spirometry – some patients were embarrassed by their difficulty in completing the test, others had concerns about infection due to their lung condition.

Give clear information about what to expect during the test

Patients felt that it is very important to be prepared for what is going to happen during the test and then to be coached through the process.

Patients want access to spirometry results and their meaning

Patients want to be able to understand their results and what they mean for them. Many reported not understanding what their results mean. They would like to be able to have access to these results (either paper results or available digitally) and be able to compare them to their previous results. Some respondents requested a comparison to normal values for healthy persons with the same age, height, and weight or for someone with their condition. Patients would like these results and explanations without having to ask for them. Patients would also like to know whether there is anything they could do to improve their results. They feel this

would be important information at the end of a spirometry test.

The operator is of great importance

Many patients emphasized the importance of the operator. Those who have had several tests felt that it made a real difference how friendly and encouraging the operator was. Some felt that the operator needed to fulfil the role of a cheerleader and that it made a difference to their results. Patients also felt that operators need to "have empathy before, during and after the maneuver" and that it is important to check if the patient is ready and how they feel about performing the next maneuver.

Patients also felt that it was important that operators did not express disappointment when patients have trouble completing the test. Though many felt that encouragement or coaching is important, some patients would have preferred a gentler approach rather than shouting instructions to blow.

Spirometry testing is very worrying for some

Some patients were very concerned about the test and some expressed feeling anxiety about the results. Some felt vulnerable and found the process embarrassing especially when they found the test hard to do or expectorated sputum.

Give clear instructions about medication use prior to spirometry testing

One quarter of patients felt that they were not given clear guidance about using their prescribed medications before the test. Some patients would like a reminder a week before the test regarding which medications they should withhold and for how long.

Design the testing station with the patient in mind

Some patients suggested that having equipment that could be adjusted to suit their size and posture would be helpful as sitting awkwardly is not conducive to achieving good results.



Introduction

The aim of this survey is to find out more about your experience of spirometry testing - a breathing test which measures the amount of air in your lungs and how quickly you can breathe out. Please only complete this survey if you have had your spirometry measured by a doctor, nurse or other healthcare professional.

The anonymous survey responses will help to understand patients' experiences of spirometry and help us to agree on the most appropriate spirometry testing methods. A group of healthcare professionals working with the ATS (American Thoracic Society) and the ERS (European Respiratory Society) will look at scientific and clinical evidence, as well as patient opinions and experiences from this survey.

If you are under 12 years of age, we request that your parent or carer answers the questions in consultation with you. If you are aged between 12 and 17 years, please complete the survey by yourself, if possible. However, the help of a parent or carer is welcome.

This survey has been designed by experts in lung health and patient experts. The survey is coordinated by the European Lung Foundation: http://www.europeanlung.org/

The survey will take about 5-10 minutes to complete and will be open until 21 September 2018.

Thank you for helping us with this work.



About you
* 1. What is your age group?
4-11 years
12-17 years
18-30 years
31-50 years
51-70 years
71-90 years
91+ years
* 2. What is your country of residence?
* 3. What is the reason that you were first referred to spirometry? (Select all that apply)
Investigating a problem with your breathing / to get a diagnosis
Asthma
Bronchiectasis
Chronic obstructive pulmonary disease (COPD)
Cystic fibrosis
Idiopathic pulmonary fibrosis (IPF)
Lung cancer
Neuromuscular disease
Pulmonary fibrosis (for interstitial lung disease)
Pre-operative testing as part of your work-up for surgery
Occupational health testing
Other (please add details)

No	
Yes	
Do you know	what the term 'FEV1 score' means? If yes, please provide details below.
) No	
Yes	
Do vou know	your current FEV1 score?
	the amount of air a person can blow out in one second after taking a deep breath. I
elp to indicate	whether a person's airways are narrowed, which can be a sign of a lung disease.
No	
No, but in futur	re tests, I would like to know that score
Yes, my curren	nt FEV1 score is



Tell us about your experiences of taking part in spirometry

to the control of the
* 7. How many tests have you completed?
1 test
2-5 tests
6-10 tests
More than 10 tests
* 8. If you have ongoing monitoring or check-ups with your healthcare team, how often is spirometry used to monitor your lung condition?
Not applicable - I do not have ongoing monitoring
Monthly
Every 6 months
Annually
Every few years
Other (please add details)



Tell us about your experiences of taking part in spirometry (continued)

When answering the following questions, we would like you to think about the most recent time you did a spirometry test
* 9. Where did you receive your spirometry test?
Primary care (e.g. family doctor, nurse's clinic)
Local hospital
University hospital
At home
At a public screening event
At work as part of health screening/checks
Other (please add details)
* 10. Did you receive any information on why the spirometry had to be done, how it's done and how to prepare? No Yes I can't remember Other (please specify)
* 11. How would you like to receive information about the spirometry test? (Select all that apply) Verbally by the doctor ordering the test or the healthcare practitioner measuring the test On a printed handout Electronically (on your tablet, PC or smart-phone) Via video-instruction / video-procedure Other (please specify)

12 Did you receiv	e any advice about withholding inhalers prior to the test?
	e any advice about withholding inhalers phor to the test?
No	
Yes	
I can't remember	
Not applicable	
13. Which of the fo	ollowing mouthpiece(s) have you used for spirometry? Select all that apply.
	.
Other (please specify)	

	14. If you have used several types of mouthpieces, please tell us which mouthpiece you preferred.
	On preference
	I have only used one type of mouth piece
	Please tell us why you preferred that mouthpiece
4	15. It is recommended that a nose clip is worn when a person is doing spirometry. This helps to make sure that all the air is breathed out through the mouthpiece, instead of escaping through the nose.
	Did you use a nose clip when you completed your most recent spirometry test? No
	Yes I can't remember
th	Yes
th m	Yes I can't remember I. If yes, please share with us your experience with the nose clip. For example, was it easy to put on? Did to health professional help make sure it was in the right position? Was it comfortable? Did the nose clip take the test easier or less easy? I. Approximately, how long did the test last for (including meeting, instructions and performing the test)? Less than 5 minutes
th m	Yes I can't remember I. If yes, please share with us your experience with the nose clip. For example, was it easy to put on? Did to health professional help make sure it was in the right position? Was it comfortable? Did the nose clip take the test easier or less easy? I. Approximately, how long did the test last for (including meeting, instructions and performing the test)?

No Yes No opinion How acceptable to you was the level of difficulty of the test?	* 18. Was the lengtl	n of the test acceptable	e to you?		
No opinion How acceptable to you was the level of difficulty of the test? Not at all acceptable Somewhat acceptable Mostly acceptable Completely acceptable No opinion		•			
. How acceptable to you was the level of difficulty of the test? Not at all acceptable Somewhat acceptable Mostly acceptable Completely acceptable No opinion	Yes				
Not at all acceptable Somewhat acceptable Mostly acceptable Completely acceptable No opinion	No opinion				
Not at all acceptable Somewhat acceptable Mostly acceptable Completely acceptable No opinion					
	19. How acceptable t	o you was the level of	difficulty of the test?)	
d any comments about the difficulty of the test below	Not at all acceptable	Somewhat acceptable	Mostly acceptable	Completely acceptable	No opinion
d any comments about the difficulty of the test below				\bigcirc	
	dd any comments about	the difficulty of the test belo	ow		



Barriers and benefits to spirometry testing

When answering the following questions, we would like you to think about your overall experiences of spirometry - regardless of whether you have done the test one time or multiple times.

	Serious problem	Moderate problem	Minor problem	No problem at all	Not applicable
I was not given enough information about why the test was done	0			0	0
I was not given enough information about how to perform the test	\bigcirc	\bigcirc	\circ	\bigcirc	\bigcirc
Concern about whether I could do the test		\circ		\circ	
Concern about whether the test would be painful	\bigcirc	\bigcirc	\circ	\bigcirc	\bigcirc
Concern about whether the test would cause shortness of breath					
Not covered by my insurance					
Lack of support from healthcare professionals running the test	0	0	0	0	0
Lack of support from my family	\bigcirc	\circ		\bigcirc	
Feeling embarrassed performing the test (e.g. being shouted at to "blow")?	0	0	0	0	0
Dryness in mouth					
Coughing					
Requirement to withhold inhalers prior to the test	\bigcirc			\bigcirc	\bigcirc
Mouth piece uncomfortable			0		0
Nose clip uncomfortable					
Feeling dizzy					
To keep blowing even though you do not feel anything is coming out	\bigcirc			\bigcirc	\bigcirc
Feeling tired after the test	0		0	0	0
other (please add details)					

* 21	. What information would you like to obtain before doing the spirometry test? (Select all that apply)
	Information about what to expect when doing the test
	Potential negative experiences when doing the test
	Potential harm from performing the test ("contraindications")
	Benefits to you of undertaking spirometry
	Other (please add details)
* 22	. What information would you like to obtain from the results of the spirometry test? (Select all that apply How your scores rate for a healthy person of your age/height
	How your scores rate for someone with your lung condition
	Understand what it means if your score has changed from the last time you did spirometry
	Other (please add details)
* 23	. What do you feel were the benefits of taking part in spirometry? (Select all that apply)
	Getting a diagnosis for your lung condition
	Improved knowledge about lung function and/or your lung health
	Increased ability to manage your lung condition day to day
	Increased independence
	A trigger to discuss your lung health and any risks, such as smoking, with your health professional
	Increased knowledge about the impact of your workplace and any risks to your lung health
	Knowing you can do the test
	Don't know
	Other (please add details)

. As someone	who has participated	d in spirometry, h	ow could it have b	een improved for	you?
· K	Blocks above				
i. If you would em below.	like to share any add	iitionai comments	or experiences re	egaraing spiromet	ry, piease enter



Thanks and getting involved

Thank you for taking the time to complete the survey.

If you would like to receive the results of the survey and updates on the project please follow this link to enter your email address:

https://www.surveymonkey.co.uk/r/spirometry_get_involved

Please note that the European Lung Foundation will only contact you in relation to this survey and to send you updates about this project. We will not share your email address with any third parties. Your email address will be stored on our secure servers and we will retain your email only for as long as is necessary to provide you with the service stated above.

Please contact Courtney Coleman at the European Lung Foundation if you have any queries: courtney.coleman@europeanlung.org.

Online Supplement

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Appendix A1: Patient Experience Key messages from 2019 Technical Standard

Appendix A2: Spirometry Survey

Table 3: Frequency and Percentage of Language Responses

Table 4: Frequency and Percentage of Responses by Country of Residence

Table 5: Frequency and Percentage of Age-Ranges

Table 3: Frequency and Percentage of Language Responses

	N	%
English	756	43.0
Dutch	309	17.6
German	282	16.0
Spanish	203	11.5
Italian	167	9.5
Polish	15	0.9
French	14	0.8
Portuguese	8	0.5
Greek	3	0.2
Russian	3	0.2
Total	1760	100.0

Table 4: Frequency and Percentage of Responses by Country of Residence

	No. of respondents	% of respondents
Germany	291	16.5
UK	283	16.1
Belgium	209	11.9
Spain	191	10.9
USA	191	10.9
Italy	177	10.1
Netherlands	149	8.5
Canada	53	3.0
Australia	44	2.5
Ireland	25	1.4
Poland	16	1.0
France	12	0.7
Switzerland	12	0.7
Austria	11	0.6
Mexico	10	0.6
New Zealand	10	0.6
Sweden	8	0.5
Portugal	7	0.4
Serbia	5	0.3
Greece	4	0.2
Brazil	3	0.2
Chile	3	0.2
Colombia	3	0.2
Ecuador	3	0.2

Pakistan	3	0.2
Argentina	2	0.1
India	2	0.1
Kenya	2	0.1
Malta	2	0.1
Peru	2	0.1
Philippines	2	0.1
Ukraine	2	0.1
Bolivia	1	0.1
Bosnia Herzegovina	1	0.1
Bulgaria	1	0.1
Croatia	1	0.1
Denmark	1	0.1
Estonia	1	0.1
Finland	1	0.1
Georgia	1	0.1
Kuwait	1	0.1
Malaysia	1	0.1
Nigeria	1	0.1
Paraguay	1	0.1
Puerto Rico	1	0.1
Romania	1	0.1
Russia	1	0.1
South Africa	1	0.1
Venezuela	1	0.1
Zambia	1	0.1

Zimbabwe	1	0.1
Total	1756	99.8
Missing Data	4	0.2

Table 5: Frequency and Percentage of Age-Ranges

	N	%
4 – 11 years	36	2.0
12 – 17 years	16	0.9
18 – 30 years	122	6.9
31 – 50 years	576	32.7
51 – 70 years	870	49.5
71 – 90 years	129	7.3
91 years+	10	0.6