



BMJ Open Impact of omitting annual reviews for COPD on patient reported care quality—outcomes from the Asthma+Lung COPD patient passport

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ABSTRACT

Background Regular clinical reviews of people with COPD provide an opportunity to optimise management and are recommended in national and international guidelines. However, there are limited data about the relationship between having an annual review and other aspects of care quality, which might influence decision-making by healthcare professionals and commissioners.

Method Using data from 74 827 people with COPD completing the Asthma+Lung UK COPD Patient Passport, between 2014 and 2022, we conducted adjusted logistic regression (adjusting for year) and compared receipt of key items of care between those reporting that they had had an annual review (65.3%) and those who did not (34.7%). To further capture patient experience, we also analysed 4228 free-text responses to the 2021 Asthma+Lung UK annual COPD survey to the question ‘What is the one thing that could improve your COPD care?’

Results We found that the absence of an annual review was associated with significantly worse COPD care across all domains studied; in particular, inhaler training (yes: 80.8% vs no: 38.4%, adjusted OR (AOR): 8.18, 95% CI (7.89 to 8.47), having a written care plan (89.6% vs 56.9%, AOR 6.68 (95% CI 6.35 to 7.05) and medication knowledge (72.6% vs 33.6%, AOR 5.73 (95% CI 5.51 to 5.96). Thematic analysis of the 2021 COPD survey responses identified three areas to improve care: (1) access and support from healthcare services, (2) improved treatment effectiveness and (3) interaction between COPD and the social environment.

Discussion Failure to deliver annual COPD reviews is associated with worse patient-reported experience of care quality. In parallel, people with COPD express a desire for greater support and access to healthcare services.

INTRODUCTION

Annual Chronic Obstructive Pulmonary Disease (COPD) reviews provide an opportunity for patients to meet with a clinician with appropriate expertise to review their current health status, address any unmet care needs and provide onward referral if necessary. In the UK, for example, National Institute for Health and Care Excellence (NICE)

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study provides new information about the links between providing an annual COPD review and COPD care quality.
- ⇒ This study uses a large sample of patients with COPD who filled out the online Asthma+Lung UK COPD passport and highlights the importance of attending an annual review for care quality.
- ⇒ This study includes qualitative data, which provides the patient’s voice on aspects needed to improve COPD care quality.
- ⇒ The lack of patient demographics and measures of disease severity among those completing the COPD passport limits the analyses that can be performed.
- ⇒ There is a risk of bias through digital exclusion, as the online survey format will not have been accessible to some individuals.

COPD guidelines recommend that the review includes. Clinical assessments (lung function, Oxygen Saturation (SpO₂), Body Mass Index (BMI)), addressing tobacco dependence, medication reviews (including inhaler technique), support for self-management and a review of needs (pulmonary rehabilitation (PR), social services, onward referral). Ensuring that the NICE ‘Five Fundamentals’ of COPD care are addressed.^{1 2} Delivered correctly, this should reduce exacerbation risk and improve the health status of people with COPD.^{1–3} Given health system constraints, it is useful for clinicians and commissioners of healthcare to understand the impact of omitting this aspect of care.

We, therefore, aimed to assess the impact of annual COPD reviews on other domains of patient-reported quality of care. Using data from Asthma+Lung UK’s COPD Patient Passport survey. In addition, to provide further information about patient experience, we undertook thematic analysis of patient

Table 1 Asthma and Lung UK Chronic Obstructive Pulmonary Disease (COPD) patient passport responses

	Yes (%)	No (%)	Not sure (%)
Q1: My diagnosis of COPD was confirmed with a breathing test called spirometry.	77.8 (n=58 216)	10.6 (n=7933)	11.6 (n=8233)
Q2: I understand my COPD. My doctor or nurse has explained where to find information and advice on COPD, and where I can get emotional support (if I need it).	42.0 (n=31 420)	37.2 (n=27 823)	20.8 (n=14 973)
Q3: I get support to manage my care and have agreed a written plan with my doctor or nurse about how I will manage my COPD.	23.6 (n=17 658)	61.5 (n=45 972)	14.9 (n=10 570)
Q4: I contact my General Practitioner (GP), nurse or pharmacist to get a free flu vaccination each year. I am up to date with my coronavirus vaccines, and I have had the one-off pneumonia vaccine.	76.0 (n=56 220)	19.5 (n=14 582)	4.5 (n=3372)
Q5: If I smoke, I am offered support and treatment to stop every time I meet my doctor or nurse. (n=26 019 after the removal of non-smokers).	67.0 (n=17 458)	23.2 (n=6056)	9.8 (n=2505)
Q6: I know the importance of keeping active and eating well.	83.2 (n=62 264)	6.3 (n=4412)	10.5 (n=7493)
Q7: I have discussed the benefits of pulmonary rehabilitation and if I can be referred.	35.0 (n=25 495)	54.8 (n=41 025)	10.2 (n=7673)
Q8: I have received advice about ongoing exercise and nutrition.	37.0 (n=27 273)	56.0 (n=40 256)	7.0 (n=6481)
Q9: I know what all my medicines and inhalers are for and when to take them. I ask my doctor, nurse or pharmacist if I'm not sure.	79.5 (n=59 522)	10.4 (n=7761)	10.1 (n=6822)
Q10: I have been trained in how to use my inhalers. My doctor or nurse checks how I use my inhaler at least once a year, and when I get a new type of inhaler. I ask my pharmacist if I have questions.	61.8 (n=46 218)	29.0 (n=21 732)	9.2 (n=6166)
Q11: I have a flare-up (exacerbation) plan, so I know what to do and who to contact if my symptoms get worse suddenly.	47.0 (n=35 145)	35.9 (n=26 164)	17.1 (n=12 837)
Q12: I have discussed keeping a rescue pack of medicines for a flare-up at home with my doctor or nurse. If I have a rescue pack at home, I understand when to use it.	45.1 (n=33 719)	42.3 (n=30 876)	12.6 (n=9468)
Q13: I see my doctor or nurse at least once a year to review my health, my care and my treatment, and have time to discuss all the steps mentioned previously.	65.3 (n=48 344)	23.2 (n=17 265)	11.5 (n=8409)

responses to a survey question about how their COPD care could be improved.

METHODS

Asthma+Lung UK Passport

The Asthma+Lung UK COPD Patient Passport (<https://passport.blf.org.uk/>) is an online self-management support tool that allows people with COPD to answer 13 questions (table 1) about the care they have received and their understanding of their condition. The passport was created in 2014 by a group of people with COPD, clinicians in the Northwest England Respiratory Team and the Primary Care Respiratory Society.⁴ Respondents are asked to indicate either yes, no or not sure to each of the questions. Since 2014, the passport has undergone minor iterations in wording. To align with NICE quality standards and public feedback (online supplemental table E1).⁵ Patients are signposted to the online passport via targeted online advertising or by their medical team during a clinical consultation. Once patients have completed the

passport, they receive an online personalised report which they are encouraged to share with their respiratory team. Data for this analysis covered the 8 years from 2014 to December 2022.

Asthma+Lung UK COPD survey

The Asthma+Lung UK annual online COPD survey, conducted between December 2020 and April 2021, captures more detailed information across patient experience.⁶ To analyse individual free-text responses to the question 'What is the one thing that would improve the care of your COPD?' We conducted a thematic analysis according to Braun and Clarke's guidelines.⁷

Participants completing the annual COPD survey consent to their data being used for research purposes. The purpose of the COPD passport is to support patient self-management and no person identifiable data are collected. Individual consent for analysis was not deemed necessary by the Asthma+Lung UK information governance process. Anonymised data sets were shared with the research team by the data team at Asthma+Lung UK.

Thematic analysis

As the data set was large, we conducted a breadth and depth analysis method before undertaking the thematic analysis.⁸ Two individual researchers (PJW and LB) conducted the thematic analysis. For the first stage of the analysis, the two researchers individually read the responses and reviewed the word frequency results to get an overall sense of the data. The second step was for the researchers to start to code the data, separately using an inductive open coding approach. Once the researchers had created their own set of codes, they met to discuss these.

As a final step, the researchers developed the themes which best described the data and which the codes could be organised into. To develop these themes, the researchers met multiple times to discuss, agree and refine each of them. The thematic analysis process was conducted using NVivo software.

Patient and public involvement

Patients and the public were involved in the original development of the COPD passport, which was created by Asthma+Lung UK.⁴ Changes to the wording of the questions before 2019 have been described previously and are described in online supplemental table E1. The most significant changes being that to question 4, which now includes the COVID-19 vaccine and question 10, which has had two iterations since 2014. The first including inhaler training in addition to reviews and since 2019 the question has included inhaler training including new inhalers.

Statistical analysis

Descriptive statistics were used to present number and percentage of respondents to each passport domain. The impact of attending an annual review on other care parameters was assessed using binary logistic regression model. Yes responses were coded as 1 and no, not sure and blank responses were coded as 0. The model was adjusted for the year of completion. Data are presented as percentages, adjusted OR (AOR), 95% CI.

RESULTS

COPD Patient Passport: annual reviews and patient-reported care quality

The initial dataset contained 74 950 responses. After removing responses which only answered one question and duplicates 74 827 responses remained for analysis. The percentage of yes, no and not sure responses to each question is displayed in table 2. 65.3% of responders reported having an annual review, and this was associated with better quality of care across all domains (table 1). This association was the strongest for having had an inhaler review and training (80.8% vs 38.4%), (AOR 8.18 (95% CI 7.89 to 8.47), having a written care plan (89.6% vs 56.9%), (AOR 6.68 (95% CI 6.35 to 7.05) and medication knowledge

(72.6% vs 33.6%), (AOR 5.73 (95% CI 5.51 to 5.96) and (figure 1). A sensitivity analysis excluding the COVID-19 period (2020–2022) yielded similar results (online supplemental table E2).

Changes over time

The pattern of responses over the past 8 years shows a downward trend in positive responses since 2014 for most passport domains (online supplemental figure E1). The only exception is training and knowledge on inhaler technique, which has seen an increase in yes responses from 51.5% in 2014 to 61.0% 2022. This is likely due to the amendment to the question wording to include a wider range of healthcare professionals (online supplemental table E1). The largest decline in yes responses from 2014 to 2022 has been among the following passport domains. Receiving advice about ongoing exercise and nutrition, which had 48.3% yes response in 2014 to 36.6% in 2022, discussions with doctor or nurse about rescue pack of medications and knowledge on how to use these, 58.4% in 2014 to 45.7% in 2022, having a written care plan, 29.3% in 2014 to 23.6% in 2022 and having an acute exacerbations of chronic obstructive pulmonary disease (AECOPD) action plan, knowledge of who to contact, which was 58.3% in 2014 and 47.0% in 2022. Again, we observe a decline the amount of yes responses to attending an annual review, which was 78.5% in 2014 to 64.6% in 2022. The pattern of yes, no and not sure responses over time among those who attended an annual review and who did not are displayed graphically in the online supplement (online supplemental figures E2–E13).

Patient's voice: improving COPD care

There were 8232 responses to the 2021 survey. After removing duplicate and incomplete responses, 4228 responses remained for analysis. The sample population was 44.6% female, with a mean age 66.3 (8.9) years, and a majority white ethnicity (96%), while 47.8% reported household incomes <£20 000 (47.8%) (online supplemental table E3).

Three core themes emerged from survey responses (1) increased access and greater support from healthcare services, (2) improved treatment effectiveness and (3) interaction between an individual's respiratory health and social, cultural and environmental factors (table 3, figure 2).

Theme 1: increased access and greater support from healthcare services

This was the most prevalent and overarching theme identified during the analysis. Most respondents stated they thought that increased access, help and support from either specialist teams such as COPD nurses, local GPs and specialist services such as PR would improve their condition, as well as that this support should be being provided more regularly. It was also apparent

Table 2 Association between attending an annual review and other aspects of Chronic Obstructive Pulmonary Disease (COPD) care

	Annual review yes (n=48 344)	Annual review no (n=26 483)	AOR (95% CI)
Q1: My diagnosis of COPD was confirmed with a breathing test called spirometry.	Yes: 40 409 (69.4%) No: 17 807 (30.6%)	Yes: 7935 (47.8%) No: 8676 (52.2%)	2.37 (2.29 to 2.46)
Q2: I understand my COPD. My doctor or nurse has explained where to find information and advice on COPD, and where I can get emotional support (if I need it).	Yes: 25 935 (82.5%) No: 5485 (17.5%)	Yes: 22 409 (51.6%) No: 20 998 (48.4%)	4.61 (4.45 to 4.78)
Q3: I get support to manage my care and have agreed a written plan with my doctor or nurse about how I will manage my COPD.	Yes: 15 827 (89.6%) No: 1830 (10.4%)	No: 32 517 (56.9%) Yes: 24 653 (43.1%)	6.68 (6.35 to 7.05)
Q4: I contact my GP, nurse or pharmacist to get a free flu vaccination each year. I am up to date with my coronavirus vaccines, and I have had the one-off pneumonia vaccine.	Yes: 40 419 (71.9%) No: 15 799 (28.1%)	Yes: 7925 (42.6%) No: 10 684 (57.4%)	3.55 (3.43 to 3.68)
Q5: If I smoke, I am offered support and treatment to stop every time I meet my doctor or nurse. (n=26 019 after the removal of non-smokers)	Yes: 12 393 (71.0%) No: 5065 (29.0%)	Yes: 3408 (39.8%) No: 5153 (60.2%)	3.67 (3.48 to 3.88)
Q6: I know the importance of keeping active and eating well.	Yes: 42 882 (68.9%) No: 19 380 (31.1%)	Yes: 5462 (43.5%) No: 7103 (56.5%)	3.07 (2.95 to 3.20)
Q7: I have discussed the benefits of pulmonary rehabilitation and if I can be referred.	Yes: 20 554 (80.6%) No: 4938 (19.4%)	Yes: 27 790 (56.3%) No: 21 545 (43.7%)	3.33 (3.21 to 3.45)
Q8: I have received advice about ongoing exercise and nutrition.	Yes: 22 979 (84.0%) No: 4393 (16.0%)	Yes: 25 365 (53.5%) No: 22 090 (46.5%)	4.58 (4.41 to 4.75)
Q9: I know what all my medicines and inhalers are for and when to take them. I ask my doctor, nurse or pharmacist if I'm not sure.	Yes: 43 203 (72.6%) No: 16 313 (27.4%)	Yes: 5141 (33.6%) No: 10 170 (66.4%)	5.73 (5.51 to 5.96)
Q10: I have been trained in how to use my inhalers. My doctor or nurse checks how I use my inhaler at least once a year, and when I get a new type of inhaler. I ask my pharmacist if I have questions.	Yes: 37 352 (80.8%) No: 8861 (19.2%)	Yes: 10 997 (38.4%) No: 17 617 (61.6%)	8.18 (7.89 to 8.47)
Q11: I have a flare-up (exacerbation) plan, so I know what to do and who to contact if my symptoms get worse suddenly.	Yes: 28 328 (81.6%) No: 6815 (18.4%)	Yes: 19 680 (49.6%) No: 20 004 (50.4%)	4.36 (4.21 to 4.50)
Q12: I have discussed keeping a rescue pack of medicines for a flare-up at home with my doctor or nurse. If I have a rescue pack at home, I understand when to use it	Yes: 28 035 (83.2%) No: 5679 (16.8%)	Yes: 20 309 (49.4%) No: 20 804 (50.6%)	5.00 (4.83 to 5.18)

AOR, adjusted OR; AR, annual review.

from the data that respondents wanted increased access to clinical and diagnostic testing, as well as greater provision for mental healthcare. Finally, individuals also stated that they felt stigmatised and that greater understanding from healthcare workers would improve their care.

Theme 2: improved treatment effectiveness

The second theme identified was a desire for an improvement in treatment effectiveness. This encompassed pharmacotherapy such as inhalers as well as medications such as antibiotics. Alongside pharmacological treatments, some survey respondents stated that having novel bronchoscopic and or surgical interventions would improve their COPD. Respondents also stated that more investment and research into novel medications should be a priority for healthcare services and the government.

Theme 3: interaction between individual respiratory health and social, cultural and environmental factors

This final theme encompasses how individuals' lived environment, socioeconomic and cultural factors interact with their COPD, and how respondents wish for these factors to improve or change in order for their care quality to improve. Respondents stated how increases in social security and support would drastically improve their quality of life (QOL), such as financial support and blue badges to allow easier parking. Air pollution was noted as a problem by many respondents, who either highlighted how high pollution negatively affects their condition and how they wanted more action to be taken to address this. This could include stopping people from smoking cigarettes in public outdoor spaces and banning wood-burning stoves. As well as the outdoor environment,

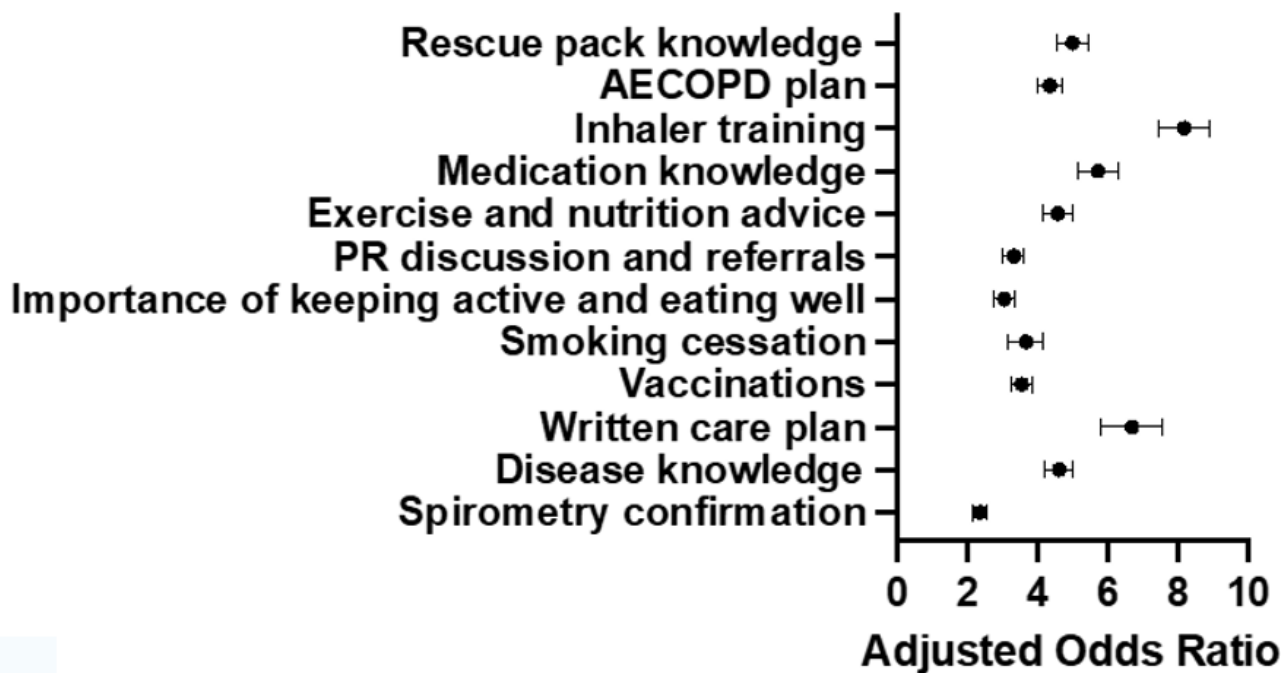


Figure 1 Annual review attendance and other aspects of Chronic Obstructive Pulmonary Disease (COPD) care.

survey respondents also highlight how poor indoor conditions, such as living in cold and damp housing effects their condition.

Finally, respondents stated that they wish there was more general understanding from the public, family and friends as to what it is like to live with a chronic respiratory disease, in addition to better education and knowledge for both the public and healthcare workers regarding COPD.

DISCUSSION

Omission of COPD annual reviews reduces the odds of receiving a range of evidence-based aspects of care which are known to improve quality of life (QOL) and reduce acute exacerbations and risk of hospitalisation. Consistent with this, people with the condition express a desire for greater access and support from healthcare services.

Using medications properly with correct techniques is essential for patients with COPD. Improper inhaler technique can lead to underdosing and under treatment,⁹ thus increasing inhaler consumption and exacerbation risk.¹⁰ Reducing the frequency and severity AECOPD is a cornerstone of COPD care and failing to address poor inhaler technique, medication knowledge and self-management skills will have negative consequences for patients and healthcare services.

The inadequate provision of care for people with COPD clearly precedes the COVID-19 pandemic⁴ and displays no positive trends. Fiscal austerity measures since 2010 have had a negative impact on health, particularly on those living with chronic diseases.^{11 12} This manifests in several ways. Cuts to public health and healthcare budgets have a direct effect on service

provision and waiting times. Indirect effects, via increasing levels of unemployment, poverty and cost of living, make life more difficult for people with long-term health conditions.^{11 13} A clear link has been demonstrated between deprivation and living in a cold and or damp house and the likelihood of having frequent acute exacerbations of COPD.⁶ It is widely accepted that COPD is a disease of poverty, effecting people disproportionately who have a lower socioeconomic status.¹⁴ Authors have recently argued that COPD as a condition should be viewed as a manifestation of ‘structural violence’, something that has been done to individuals (eg, growing up and living in poverty) not that something they have done to themselves (eg, smoking).¹⁵ This model also highlights the effects of low status of COPD, delayed diagnosis and poor care.

Although attending an annual review is an acknowledged component of COPD care, a further issue is the quality of these reviews when they occur. We found that not only are many patients not having annual reviews, but also that many individuals who have had them report significant gaps in their care and in their understanding of their condition. Particularly inhaler training, medication knowledge, written care plans and spirometry testing. Our data do not allow us to say why this is the case, but there are a number of possible explanations. Related to healthcare resource allocation and training. It is likely that with diminishing healthcare resources and increasing service pressures, clinicians may not have adequate time for reviews to be done properly. A second question also arises regarding appropriate training, support and equipment, to

Table 3 ‘What is the one thing that would improve the care of your Chronic Obstructive Pulmonary Disease (COPD) ?’ – thematic analysis

Theme 1. Increased access and greater support from healthcare services	Participant quote (gender, age band)
Subtheme: increased access, help and support from either specialist team such as COPD nurse, local General Practitioners (GPs) and specialist services such as pulmonary rehabilitation would improve their condition.	<i>‘To be able to access medical help nurse or doctor when needed’ (male, 60s)</i> <i>‘Having regular follow ups after PR and then maybe another course’ (Female, 60s)</i>
Subtheme: increased access to clinical and diagnostic testing, as well as greater provision for mental healthcare.	<i>‘Having at least yearly spirometry tests’ (Gender not stated, 50s).</i>
Subtheme: participants wanted support more frequently and on a regular basis	<i>‘More regular checks. They are not really being offered annually, as first suggested’ (Female, 70s)</i>
Subtheme: More empathetic understanding from healthcare workers and healthcare system	<i>‘How frightening it was for me to be diagnosed with COPD, and the stigma attached to the disease because of smoking. On the day of diagnosis, my GP simply said ‘..... but don’t panic’ and just went on to prescribe my medication. The lack of empathy was devastating and has hindered my coming to terms with my diagnosis.’ (Female, 50s)</i>
Theme 2: treatment effectiveness	
Subtheme: pharmacotherapy treatments and options	<i>‘Effective inhalers which didn’t create side effects’ (Female, 60s)</i>
Subtheme: novel interventional and or surgical interventions	<i>‘Being given options other than rehab and inhalers, such as latest info on new lung surgery’ (Gender undisclosed, 60s)</i>
Subtheme: investment and research into novel medications by government.	<i>‘More research of the new drugs that are available’ (Gender undisclosed, 50s)</i> <i>‘More funding from the government into new drugs and treatments’ (Gender undisclosed, 70s)</i>
Theme 3: interaction between respiratory health and social, cultural and environmental factors.	
Subtheme: how increases in social security and support would drastically improve their quality of life	<i>‘Enough money to live’ (Gender undisclosed, 50s)</i> <i>‘A Blue Badge so that I don’t have to walk far from my car’ (Female, 80s)</i>
Subtheme: outdoor air pollution and the need for legislation	<i>Ban wood burners’ (Male, 60s)</i> <i>‘No air pollution and second-hand smoke’ (Gender undisclosed, 70s)</i>
Subtheme: indoor air pollution and the need for legislation	<i>‘Get rid of the damp in the house and the mould’ (Female, 60s)</i>
Subtheme: better understanding and more public awareness of COPD and what living with COPD is like	<i>‘Better knowledge and understanding by health care professionals’ (Female, 60s)</i> <i>‘Truthfully for people to be more understanding about the condition’ (Female, 40s)</i>

allow clinicians to ensure they are providing annual reviews which meet the British Thoracic Society (BTS) guidelines. The combination of the austerity measures and COVID-19 pandemic has had a huge negative effect on clinical resources and clinical staff time and is likely to contribute to inadequate COPD reviews.^{11 13 16} Another consideration is the risk that the review becomes a ‘tick box’ exercise limiting the benefit to individual patients?^{17 18} An interesting question for future consideration would be to establish which healthcare professionals are conducting the reviews, the training they have received to conduct these, and what impact that has on patient experience and outcomes.

Implications for service delivery

These data highlight the real consequences of a lack of an annual review and/or inadequate reviews, for people with COPD. It is clear that interventions are needed within primary care to enable providers to offer these aspects of basic care.¹² Several studies within the field have used GP targeted educational interventions and blended remote self-management and face-to-face interventions to improve COPD care quality. An RCT in Switzerland used COPD care quality standards to inform and create an educational intervention for GPs. The intervention addressed key factors such as COPD knowledge, patient decision-making, behaviour change and delivery of care. GP practices that were

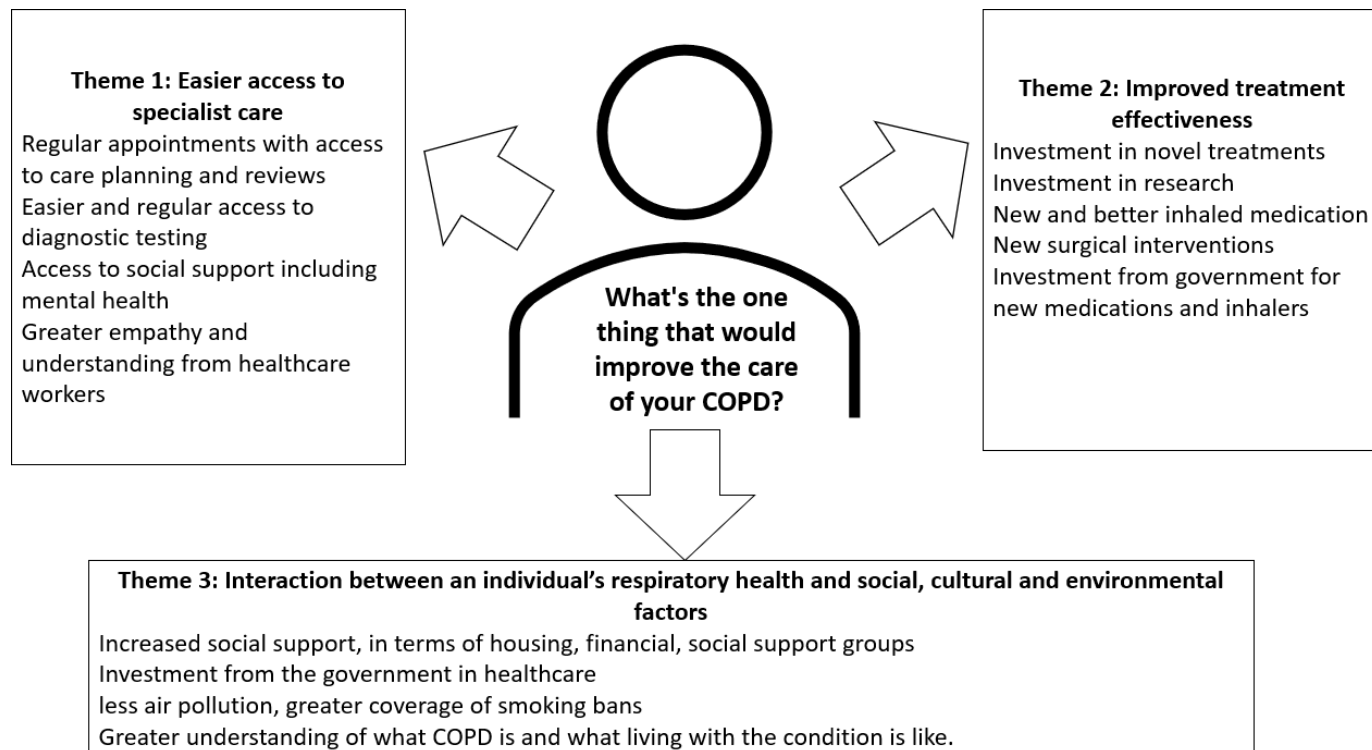


Figure 2 Thematic map—what is the one thing that would improve the care of your COPD, Chronic Obstructive Pulmonary Disease; AECOPD, Acute exacerbation of chronic obstructive pulmonary disease.

enrolled in the education group demonstrated significantly higher implementation scores among COPD care quality domains including smoking cessation, vaccinations and inhaler technique.¹⁹ A 2021 systematic review supported the use of blended remote self-management and in clinic interventions for increasing QOL and reducing admissions within COPD populations.²⁰ Furthermore, within the UK acute respiratory hubs, which have been created as a consequence of the COVID-19 pandemic to improve access and quality of care for patients with acute respiratory infections.²¹ This model of service delivery could be used within chronic respiratory care to improve care quality. Further research is needed to investigate how annual reviews are being conducted, by whom and, how this effects clinical care. As well as evaluating to interventions to improve COPD care quality within primary care.

Study limitations

Both the COPD Patient Passport and the Asthma+Lung UK COPD survey was completed online. Excluding some patients with limited computer access and digital literacy, resulting in potential selection bias and potentially under-reporting the issue. The relationships found may also be associations without direct casual pathways as presented, for example, a patient may not have attended pulmonary rehab after attending an annual review even if it was offered. Only 50.4% of 2021 survey respondents answered the question about improving COPD care that we subjected to thematic

analysis. The COPD Patient Passport does not collect demographic characteristics, so we do not have data including ethnicity, age and socioeconomic status, which would be helpful in obtaining a more comprehensive picture, and are known factors contributing to COPD care quality and QOL.^{6,12} More detail regarding respondent's disease status would have been useful in interpreting quality of care since some clinical recommendations are specific to disease severity.

CONCLUSION

There are substantial gaps in the care received by people with COPD in the UK, and these are much more pronounced in patients who report not receiving an annual review. Improving access, delivery and the quality of annual COPD reviews has the potential to support such patients achieving the fundamental aspects of their care.

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Contributors NSH, PJW, LB, AC and AAL designed the study. PJW and AAL analysed the data and PJW produced the first draft to which all authors NSH, LB, AAL, KEJP and MP contributed. All authors have reviewed and approved the final version. NSH is the guarantor.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

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