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Patient experience of measures to reduce risk of COVID-19: findings from a survey by the Asthma

UK and British Lung Foundation Partnership

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Key Words:

Covid, respiratory, shielding, social distancing, long term condition, anxiety, loneliness

Contribution

KEJP, AC, SM, ML, NSH developed the survey, KEJP performed the data analysis and wrote the first draft. All authors contributed to revisions of this first draft and approved the final version.

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10
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For peer review only

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2
3 **ABSTRACT** (257 words)
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6 **Objectives:** To assess the experience of people with long-term respiratory conditions regarding the
7
8 impact of measures to reduce risk of COVID-19.
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11 **Design:** Analysis of data (n=9,515) from the Asthma UK British Lung Foundation partnership COVID-19
12
13 survey collected between 1st and 8th of April 2020.
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15

16 **Setting:** Community
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19 **Participants:** 9,515 people with self-reported long term respiratory conditions. 81% female, age
20
21 ranges from ≤ 17 years old to 80 and above, from all nations of the UK. Long term respiratory conditions
22
23 reported included asthma (83%), COPD (10%), bronchiectasis (4%), ILD (2%), and 'other' (<1%) (e.g.
24
25 lung cancer and pulmonary endometriosis).
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27

28
29 **Outcome measures:** Study responses related to impacts on key elements of health care, as well as
30
31 practical, psychological and social consequences related to the COVID-19 pandemic and social
32
33 distancing measures.
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35

36 **Results:** 45% reported disruptions to care, including cancellations of appointments, investigations,
37
38 pulmonary rehabilitation, treatment, and monitoring. Other impacts such as difficulty accessing
39
40 healthcare services for other issues, and getting basic necessities such as food, were also common.
41
42 36% did not use online prescriptions and 54% had not accessed online inhaler technique videos. High
43
44 levels of psychosocial stress were reported including anxiety, loneliness and concerns about personal
45
46 health and family were prevalent. 81% reported engaging in physical activity. Among the 11% who
47
48 were smokers, 48% reported they were planning to quit smoking because of COVID-19.
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52 **Conclusions:** COVID-19 and related social distancing measures are having profound impacts on people
53
54 with chronic respiratory conditions. Urgent adaptation and signposting of services is required to
55
56 mitigate the negative health consequences of COVID-19 response for this group.
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Strengths and limitations of this study

- This is one of the first studies in the UK to highlight the impact of COVID-19 related measures on people with long term health conditions.
- The study includes a large sample (n=9515) from broad range of respiratory conditions, age groups, and parts of the UK.
- Key gaps in healthcare provision/access are identified; online prescription and inhaler technique videos; self-management plans; smoking cessation support.
- Although a range of individuals are represented, the sample has a large percentage of people with asthma (83%) and is predominantly female (81%).
- A lack of data regarding disease severity, and further demographic information of interest such as socio-economic status, ethnicity and housing, limits the depth of interpretation possible.

INTRODUCTION

COVID-19 is a particular threat for people with long term respiratory conditions, who are at greater risk of serious disease and death if they become infected¹⁻³. Recommendations for respiratory patients include being especially careful regarding social distancing measures to reduce SARS-CoV-2 transmission. In the UK, for the most vulnerable a period of “social shielding”, avoiding face-to-face contact has been advised^{4 5}, with twin aims of protecting individuals from infection and avoiding a peak of cases in the most vulnerable which might overwhelm the health and social care system. Measures to reduce the immediate impact of COVID-19 are likely to have some adverse consequences for the population’s health and wellbeing^{6 7}, leading to a so called ‘third wave’ of COVID-19 related

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3 morbidity and mortality among people with long-term conditions⁸. This is of particular concern given
4
5 the substantial level of unmet need related to respiratory disease⁹⁻¹³.
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8 Data on the experience of people with long term respiratory conditions regarding the impact of
9
10 COVID-19 prevention measures is currently lacking, but will be important for understanding of the
11
12 impacts on these people, and to help guide current and future provision to where it is required.
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16 17 18 **METHODS**

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21 To assess the impact of measures to address COVID-19 on access to key elements of care^{14 15} as well
22
23 as the practical, psychological and emotional consequences of the current situation, we analysed data
24
25 from an online survey carried out by the Asthma UK (AUK) and British Lung Foundation (BLF)
26
27 Partnership between 1st and 8th of April 2020. The survey was distributed via their mailing lists and
28
29 websites, and advertised on social media (Facebook, Twitter, Instagram and LinkedIn). Social
30
31 distancing measures were announced by the UK Government on 23rd March. The text of the survey is
32
33 available in the online supplement. Furthermore, during the data collection period, Public Health
34
35 England (PHE) recommendations relevant to survey respondents included 1) All members of the public
36
37 were advised to stay at home, only being permitted to leave the house for a small number of specific
38
39 reasons. 2) Shielding of “people with severe respiratory conditions including all cystic fibrosis, severe
40
41 asthma and severe COPD” who were advised to “stay at home at all times and avoid any face-to-face
42
43 contact for a period of at least 12 weeks”.
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49 The analysis presented focuses on questions relating to 1) Impacts on healthcare provision, 2) Social,
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51 psychological and practical responses, and 3) Sources of support and information. Scales are out of
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53 ten unless otherwise specified. These data were collected by AUK-BLF as part of routine information
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55 gathering and marketing activities. All participants consented to their responses being published.
56
57 Anonymised data were shared with the authors for analysis. The Charity's information governance
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3 process supported this, consistent with GDPR, and additional external ethical approval was not
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5 deemed necessary. Analyses were carried out using Stata V.14 (StataCorp). Data used here are not
6
7 being made publicly available.
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10 **Patient and Public Involvement**

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12
13 Patients and members of the public were not specifically involved in the design, conduct or reporting
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15 of this research. However, as the primary focus of this research was to understand the impact of the
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17 COVID-19 risk reduction measures on people living with long-term respiratory conditions.
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23 **RESULTS**

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26 The initial survey data included 9,604 responses. After removing responses from people without a
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28 lung condition (n=25); people who completed the survey twice within the sampling period (n=24 BLF,
29
30 n=21 AUK) and people who completed both surveys (n=19), the sample analysed included 9,515
31
32 individuals, 81% female, with age ranges from ≤ 17 years old to 80 and above. All nations of the UK
33
34 were represented. Reported lung diseases were: 83% asthma, 10% COPD, 4% bronchiectasis, 2% ILD,
35
36 and <1% 'other' for example lung cancer and pulmonary endometriosis (Table 1). Of people who
37
38 completed the AUK survey, 28.25% (2,179) reported having 'difficult' 'severe' or 'brittle' asthma. 32%
39
40 of respondents with non-asthma diagnoses were severely breathless (MRC dyspnoea score ≥ 4). Data
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42 presented are a combination of responses to the BLF and AUK surveys which contributed 1,787 and
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44 7,728 respectively. Where the sum of total answers given is less than 9,515 this is due to non-response
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46 to that specific question.
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52 **Impacts on Healthcare provision**

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55 Despite data collection occurring relatively early in the first wave of the UK pandemic 45% reported
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57 disruptions in healthcare provision, including GP and hospital appointment cancellations effecting 10%
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59 and 8% of respondents respectively, with 31% reporting having appointments conducted remotely
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3 (e.g. by phone) (Table 2). Respondents reported various additional ways in which healthcare provision
4 had been impacted by COVID-19 (under the option 'other'), including cancelled operations,
5 investigations, respiratory nurse appointments, and medication reviews. In addition, finding it difficult
6 to get in contact with relevant care providers for advice and information. Despite being a population
7 with online access, one third did not access online prescriptions and over half had not used online
8 inhaler technique videos. Among the 11% who were smokers, 48% reported they were planning to
9 quit smoking because of COVID-19. A majority of individuals did not have a written self-management
10 plan despite the strong evidence base for this intervention^{15 16}.

11
12 Reassuringly respondents reported high levels of physical activity, with 81% being 'able to keep active
13 or do exercise at home' (Table 2). Frequently reported activities include walks (47%), housework
14 (54%), gardening (29%), Yoga (12%), running (7%) and cycling (6%). In addition to the activities stated
15 684 respondents reported 'other' activities including home exercise bikes, trampolining, tennis,
16 weights, skipping, home PR, Pilates, YouTube exercise videos, Zumba/dance and Wii fit.

17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 **Social and psychological responses**

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39 High levels of anxiety about COVID-19 were reported; mean(SD) anxiety level 8.03(2.07); slightly
40 higher in women than men, 8.13(1.99) vs 7.55(2.28), and decreasing slightly with age (Figure 1). Only
41 34% of men and 24% of women felt that they were 'coping well'. Older age groups were more likely
42 to report coping well with 47% of 70 to 79-year olds, steadily decreasing to 17% in the 18 to 29 years
43 old group. Respondent had various concerns, most commonly reported being 'concern about lung
44 condition' (64%), and concern about family (61%). Interestingly, both showing similar variations
45 related to age and gender as that seen in anxiety and 'coping well', with a higher percentage of
46 females, and younger people reporting concerns.
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3 The majority (87%) of respondents lived with another person; 51% felt they lacked companionship
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5 'some of the time' or 'often', and 52% reported feeling left out of things 'some of the time' or 'often'.
6
7 66% of respondents felt 'isolated from others'. Combining the scores for these three statements
8
9 (modified 3 item UCLA loneliness score),¹⁷ 3 being the lowest score for loneliness and 9 the highest,
10
11 the mean loneliness rating was 5.12(1.80), with broadly similar levels in women and men 5.21(1.81)
12
13 vs 4.74(1.72) and no substantial differences between age groups or disease type (Online Table E1).
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17 Of note, responses in those actively shielding, and not actively shielding were broadly similar. 19.54%
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19 had received the government letter or text message advising them to shield, of whom 98% were doing
20
21 so. Mean perceived preparedness for COVID-19 was 6.41(1.7), with no substantial differences related
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23 to gender, age, or diagnosis.
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26 27 28 29 30 **Sources of support and Information**

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32 Respondents reported having accessed various services to address concerns about coronavirus or its
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34 symptoms. These included NHS 111 online (19%) which was used more commonly by younger adults
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36 (23 to 25% of under 40-year olds, compared with 3 to 9% of over 60 years old, despite the surveys
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38 being online suggesting computer literacy of all respondents. GPs had been used by 26% of
39
40 respondents, again with a trend toward decreasing use in older age groups. The NHS 111 telephone
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42 service had been used by 8% of respondents with a similar decrease in use by older age groups.
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44 Though differences in condition are seen this is likely due to certain conditions being more
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46 represented in certain age groups. For example, the same trends regarding age and NHS 111 online
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48 use were seen when asthma was considered alone. Only 1% of respondents reported using A&E, with
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50 no substantial differences related to gender, age, or diagnosis. 55% of respondents reported not
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52 having used 'any resources due to coronavirus or concerns about its symptoms'. Reporting to not have
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54 used resources was more common in older than younger adults. As might be expected, higher
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3 percentages of respondents in working age groups were concerned about their financial situation due
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5 to missed work.
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8 Respondents made use of various sources for information on coronavirus, the most commonly
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10 reported being television (73%), news websites (50%), and (non-BLF/AUK) social media (25%). Less
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12 commonly reported sources of information on coronavirus include BLF/AUK websites (17%) and social
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14 media (14%), radio (12%) and friends and family (8%) (See Online Table E2 for further responses about
15
16 practical preparedness for COVID-19).
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20 Respondents were particularly interested in having more information about how to manage their lung
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22 condition during in relation to coronavirus (65%), decisions they may need to make if they were to get
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24 ill with COVID-19 (49%), and how to look after their mental health (31%).
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30 **Practical difficulties**

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33 Multiple difficulties were experienced by respondents regarding health impacting practical issues. 22%
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35 reported difficulties accessing groceries, while 7% had difficulties accessing prescriptions (Online Table
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37 E2)
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46 **DISCUSSION**

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49 COVID-19 is having significant impacts on individuals with respiratory disease, generating high levels
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51 of anxiety and concerns about potential impacts on respondents and their families, compounded by
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53 social isolation and loneliness. In addition many aspects of care have been cancelled or deferred,
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55 including pulmonary rehabilitation and severe asthma appointments in secondary and tertiary, care,
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57 on a background of provision that was already failing to meet the needs of many people^{9 10}, with
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3 impacts evident despite relatively recent introduction of distancing measures. Respondents were
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5 clearly making an effort to engage in physical activity despite the challenging nature of the situation.
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8 Despite the requirement for physical distancing, social isolation and loneliness can still be avoided, or
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10 reduced, through targeted support and intervention. There is growing evidence that COVID-19
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12 disproportionately effects more deprived groups¹⁸. Isolation strategies are also likely to impact most
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14 heavily on the most disadvantaged individuals with the least economic and social capital.
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18 A key practical issue is that nearly half the respondents who smoke tobacco reported that they
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20 intended to quit due to COVID-19. It will be important to ensure that there is provision of appropriate
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22 accessible smoking cessation support services, to maximise their chance of success both to reduce the
23
24 occurrence of smoking related disease generally¹⁹ and to reduce individuals' risk from COVID-19
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26 specifically¹²⁰. In addition, encouraging uptake of online prescriptions and directing patients to online
27
28 resources including inhaler technique videos to support self-management, as recommended in the
29
30 NICE COVID-19 COPD Rapid Guideline Update (NG168)²¹, should be prioritised.
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34 The study sample includes representation from a wide age range, a variety of respiratory conditions,
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36 and all countries of the UK, but some limitations exist. More detail about disease severity would have
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38 been useful for interpreting responses, as this impacts government guidance regarding distancing and
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40 shielding measures. The study was online so results may not be representative for digitally excluded
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42 individuals.
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45 46 **CONCLUSION**

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48 Measures to reduce the risk of COVID-19 are having profound impacts on people with lung disease
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50 including widespread disruption to fundamental components of healthcare services, high levels of
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52 anxiety and loneliness. There is an urgent need to adapt services to address these needs and improve
53
54 signposting of individuals to existing resources, in order to mitigate negative health consequences,
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56 and provide appropriate care to this vulnerable group.
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Transparency statement

Dr Keir Philip affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Table 1: Participant Characteristics

	Asthma n=7975	Chronic respiratory disease (non-asthma) n=1541
Age group		
17 and under	5.54 % (439)	0.33 % (5)
18 to 29	12.11 % (959)	0.59 % (9)
30 to 39	24.68 % (1,955)	1.90 % (29)
40 to 49	30.60 % (2,424)	8.93 % (136)
50 to 59	18.67 % (1,479)	21.47 % (327)
60 to 69	6.26 % (496)	37.82 % (576)
70 to 79	1.94 % (154)	25.21 % (384)
80 and above	0.19 % (15)	3.74 % (57)
Gender (%Female)	82.92 % (6,562)	74.67 % (1,141)
Country		
England	75.35 % (5,981)	83.33 % (1,275)
Scotland	13.03 % (1,034)	9.54 % (146)
Wales	7.19 % (571)	5.23 % (80)
Northern Ireland	4.43 % (352)	1.90 % (29)
Influenza immunisation 2019/20		
Yes	77.10 % (6,139)	89.96 % (1,380)
No	22.54 % (1,795)	9.97 % (153)
Don't know	0.35 % (28)	0.07 % (1)
Current smoking		
Non-smoker	89.41 % (7,115)	86.07 % (1,322)
Smoker	10.59 % (843)	13.93 % (214)
Of smokers -		
Intending to quit smoking due to COVID-19	49.11 % (414)	64.48 % (138)
Not intending quit smoking due to COVID-19	50.89 % (429)	35.51 % (76)
Shielding		
Actively shielding	68.66 % (5,461)	89.97 % (1,381)
Not actively shielding	31.34 % (2,493)	10.30 % (154)
Self-isolating		
Currently self-isolating	67.81 % (5,403)	88.01 % (1,350)
Not currently self-isolating	32.19 % (2,565)	11.99 % (184)
Current COVID-19 Symptoms 'Yes'	6.89 % (549)	3.07 % (47)
Current COVID-19 Symptoms 'Not sure'	3.99 % (318)	3.78 % (58)
Following self-isolation advice due to symptoms	92.81 % (800)	98.04 % (100)
Not following self-isolation advice	7.19 % (62)	1.96 % (2)
Diagnosis		

Asthma	83.81 % (7,975)
COPD	10.12 % (963)
Bronchiectasis	3.81 % (363)
ILD	1.78 % (169)
Other	0.48 % (46)

Table 2: Impact of COVID-19 related measures on chronic disease healthcare provision and self-management

Component of disease management	Percentage	Number of observations
Health service provision		
GP appointment cancelled	9.69 %	922
Hospital appointment cancelled	7.83 %	745
GP phone/remote appointment	30.93 %	2,944
Some form of cancellation or change in service delivery	44.86 %	4,270
Of those who do PR (n=553)		
Doing PR at home	24.77 %	137
PR cancelled	24.23 %	134
Have enough medications	93.41 %	8,871
Have online prescriptions	64.38 %	6,112
Have a written self-management plan for their condition	39.56 %	3,756
Have watched online inhaler videos		
Yes	44.11 %	4,190
No	53.57 %	5,089
Don't use inhalers	2.33 %	221
Physical activity		
Able to 'keep active' or do exercise at home	81.02 %	7,682
Not able to 'keep active' or do exercise at home	18.92 %	1,800
Type of activity		
Walks	47.05 %	4,478
Cycling	6.43 %	612
Run	7.17 %	682
Yoga	12.03 %	1,145
Gardening	29.06 %	2,817
Housework	54.16 %	5,155

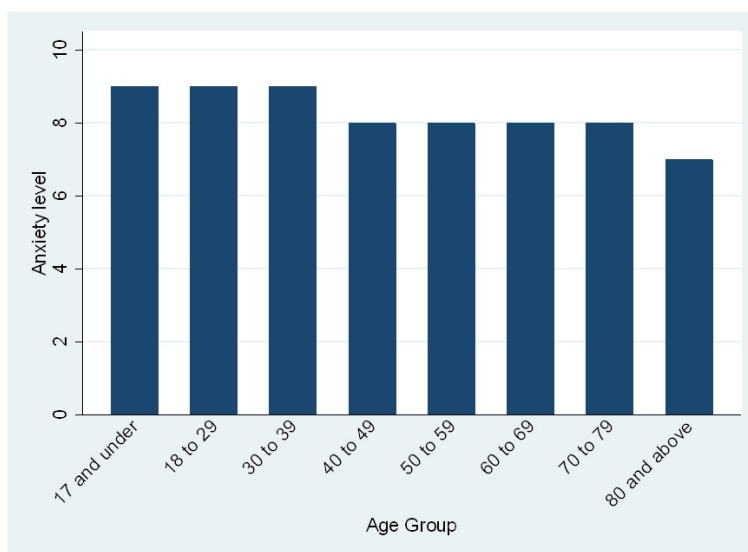
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Figure 1: A bar chart of median anxiety level by age group



We conducted the Kruskal-Wallis H test to determine if there is a statistically significant difference between anxiety levels in different age groups. This test was selected due to the marked left shift in the data. Sample sizes in each group are reported in table 2. This test demonstrated statistically significant differences between groups (chi-squared = 158.895 with 7 d.f., probability = 0.0001).

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3 **Patient experience of measures to reduce risk of COVID-19: findings from a survey by the Asthma**

4
5 **UK and British Lung Foundation Partnership – ONLINE SUPPLEMENT**

6
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8 Authors: Keir EJ Philip¹, Andrew Cumella², Sarah MacFadyen², Michael Laffan², Nicholas S

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10 Hopkinson^{1,2},

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SURVEY QUESTIONS:

1
2
3
4
5 What is your age?

6
7 What is your gender?

8
9 What nation do you live in?

10
11 Have you ever been told that you have 'difficult', 'brittle' or 'severe' asthma? (AUK survey only)

12
13 What is your main lung diagnosis?

14
15 Do you receive pulmonary rehabilitation as part of your care?

16
17 When do you get out of breath? (MRC dyspnoea scale options) (BLF survey only)

18
19 Are you currently following the government's 'shielding' advice?

20
21 Have you received a letter or text message advising you to shield?

22
23 Did you have the flu jab this winter?

24
25 Have you seen guidance or advice on coronavirus from Asthma UK or the British Lung Foundation?

26
27 How did you see this advice?

28
29 Where do you mainly get your information about coronavirus?

30
31 the NHS?

32
33 What was it about the advice you saw that wasn't helpful?

34
35 healthcare professionals?

36
37 What was it about the advice you saw that wasn't helpful?

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39 charities?

40
41 What was it about the advice you saw that wasn't helpful?

42
43 the Government?

44
45 What was it about the advice you saw that wasn't helpful?

46
47 Would you like more information on any of the following during the coronavirus outbreak?

48
49 Are you currently suffering from any coronavirus symptoms?

50
51 Are you following isolation advice?

52
53 How confident are you about following advice to self-isolate or shield?

54
55 How confident are you that you will be able to access food and other provisions if you have to self-isolate or shield?

56
57 Do you have enough medicines for your needs at the moment?

58
59 Are you registered to order prescriptions online from your GP?

60
Have you had a look at online inhaler technique videos to check that you are using your inhalers properly?

1
2
3 Do you have a written self-management plan for your condition?
4

5 In general, how well prepared do you feel for coronavirus?
6

7 In general, how anxious do you feel about coronavirus?
8

9 Which of the following apply to you?

- 10
11 - I'm concerned about my lung condition
12 - I'm concerned about the health of my family members
13 - I'm coping well
14 - I'm having trouble getting groceries
15 - I'm worried about my financial situation due to missed work
16 - I can't get the prescriptions I need
17 - None of the above
18 - Other
19
20

21 Have you used any of these services due to coronavirus, or concerns about its symptoms?
22

- 23 - NHS 111 (online checker)
24 - NHS 111 (telephone advice)
25 - GP
26 - Pharmacy
27 - A&E
28 - BLF or AUK nurse phone
29 - Other
30
31

32 Has any of the following happened to you because of the way the NHS is working at the moment?
33

- 34 - I have had to have a GP appointment conducted over the phone / remotely
35 - My regular care for my lung condition at the hospital has been cancelled
36 - My regular care for my lung condition at the GP has been cancelled
37 - Pulmonary rehabilitation classes were cancelled
38 - I have had to do pulmonary rehabilitation exercises at home
39 - None of the above
40 - Other
41
42

43 Are you able to perform your job at home?
44

45 How supportive have your workplace been during the coronavirus outbreak?
46

47 Are you keeping physically active, or are able to do any exercise at home?
48

49 Which of the following are you doing to stay active while at home?

- 50 - Housework
51 - Gardening
52 - Going on walks
53 - Yoga
54 - Cycling
55 - Running
56 - Other
57
58

59 If you smoke, are you planning to try to quit smoking to protect yourself from coronavirus?
60

1
2
3 Are you actively self-isolating due to coronavirus?
4

5 Do you live alone?
6

7 How often do you feel you lack companionship?
8

9 How often do you feel left out of things?
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11 How often do you feel isolated from others?
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For peer review only

Table E1: Loneliness, Isolation, Anxiety, and Concerns

	Percentage	Number of observations
Domestic Isolation		
Live alone	13.06 %	1,241
Does not live alone	86.94 %	8,260
Loneliness		
Feels lacks companionship		
Hardly ever	48.91 %	4,643
Some of the time	39.84 %	3,782
Often	11.25 %	1,068
Feels left out of things		
Hardly ever	46.73 %	4,434
Some of the time	40.84 %	3,875
Often	12.43 %	1,179
Feels isolated from others		
Hardly ever	34.34 %	3,261
Some of the time	47.21 %	4,483
Often	18.45 %	1,752
	Mean (SD)	N
Overall loneliness score (all respondents)		
	5.12 (1.80)	9,458
Loneliness by gender		
Male	4.74 (1.72)	1,728
Female	5.21 (1.81)	7,652
Loneliness by age		
17 and under	4.81 (1.68)	441
18 to 29	5.65 (1.84)	962
30 to 39	5.20 (1.82)	1,978
40 to 49	4.96(1.78)	2,550
50 to 59	5.00 (1.75)	1,794
60 to 69	5.24 (1.83)	1,064
70 to 79	5.03 (1.74)	532
80 and above	5.26 (1.79)	69
Loneliness by main diagnosis		
Asthma	5.06 (1.79)	7,936
COPD	5.56 (1.85)	957
Bronchiectasis	5.18(1.71)	357
ILD	5.54 (1.92)	163
Other	5.40 (1.84)	45
Loneliness by shielding		
Actively shielding	5.23 (1.81)	6,804
Not actively shielding	4.85 (1.74)	2,654
Anxiety		
How anxious do you feel? (1-10)	8.03 (2.07)	9,495
Anxiety by gender		

	Male	7.55 (2.28)	1,728
	Female	8.13 (1.99)	7,691
Anxiety by age			
	17 and under	8.14 (2.11)	442
	18 to 29	8.23 (1.90)	967
	30 to 39	8.24 (1.97)	1,981
	40 to 49	8.14 (1.96)	2,558
	50 to 59	8.00 (2.11)	1,803
	60 to 69	7.60 (2.27)	1,066
	70 to 79	7.32 (2.18)	536
	80 and above	7.03 (2.33)	72
Anxiety by diagnosis			
	Asthma	8.11 (2.01)	7,959
	COPD	7.57 (2.31)	960
	Bronchiectasis	7.64 (2.14)	362
	ILD	7.51 (2.24)	168
	Other	7.76 (2.23)	46
	Actively shielding	8.06 (2.08)	6,829
	Not actively shielding	7.94 (2.03)	2,666
Feels coping well		25.90 %	2,465
By Gender			
	Male	34.39 %	596
	Female	23.96 %	1,844
By Age			
	17 and under	22.97 %	102
	18 to 29	17.46 %	169
	30 to 39	19.20 %	381
	40 to 49	24.38 %	624
	50 to 59	26.74 %	483
	60 to 69	37.50 %	402
	70 to 79	47.21 %	254
	80 and above	45.83 %	33
By diagnosis			
	Asthma	24.33 %	1,940
	COPD	34.79 %	335
	Bronchiectasis	31.96 %	116
	ILD	34.91 %	59
	Other	32.61 %	15
	Bronchiectasis	8.26 %	30
	ILD	12.43 %	21
	Other	13 %	6
Concerns			
	Concerned about lung condition	64.25 %	6,115

By Gender		
Male	57.24 %	992
Female	65.88 %	5075
By Age		
17 and under	41.22 %	183
18 to 29	73.14 %	708
30 to 39	71.47 %	1,418
40 to 49	68.71 %	1,759
50 to 59	62.24 %	1,124
60 to 69	54.76 %	587
70 to 79	48.14 %	259
80 and above	50.00 %	36
By diagnosis		
Asthma	64.94 %	5,179
COPD	56.80 %	547
Bronchiectasis	67.77 %	246
ILD	66.86 %	113
Other	65.22 %	30
Concerned about family	61.50 %	5,854
By Gender		
Male	54.99 %	953
Female	63.03 %	4,855
By Age		
17 and under	60.36 %	268
18 to 29	65.91 %	638
30 to 39	66.33 %	1,316
40 to 49	64.02 %	1,639
50 to 59	60.24 %	1,088
60 to 69	53.82 %	1,072
70 to 79	47.21 %	538
80 and above	38.89 %	72
By diagnosis		
Asthma	63.32 %	5,050
COPD	51.40 %	495
Bronchiectasis	53.72 %	195
ILD	49.11 %	83
Other	67.39 %	31
Concerned about financial situation due to missed work	18.61 %	1,771
By Gender		
Male	18.58 %	322
Female	18.64 %	1,436
By Age		

	17 and under	13.51 %	60
	18 to 29	26.96 %	261
	30 to 39	22.73 %	451
	40 to 49	22.50 %	576
	50 to 59	18.72 %	338
	60 to 69	6.62 %	71
	70 to 79	0.74 %	4
	80 and above	1.39 %	1
	By diagnosis		
	Asthma	20.43 %	1,629
	COPD	8.83 %	85
	Bronchiectasis	8.26 %	30
	ILD	12.43 %	21
	Other	13 %	6

Table E2: Practical Preparedness

	Percentage	Number of observations
Sources of Information		
Government Letter		
Has received	19.54 %	1,855
Has not received	78.98 %	7,498
Does not know	1.49 %	141
Actively shielding of those who have received government letter	97.83 %	1,804
Main sources of COVID info		
TV	72.98 %	6,946
Radio	11.56 %	1,100
New websites	50.34 %	4,791
AUK/BLF website	17.49 %	1,665
AUK/BLF social media	14.36 %	1,367
Other social media	24.85 %	2,365
Friends and Family	8.34 %	794
Would like more information on:		
Symptoms	35.26 %	3,356
How to help their community	6.60 %	628
Financial help	14.57 %	1,387
Decisions possibly required if a person I care for gets ill	28.20 %	2,684
Decisions possibly required if I get ill	48.95 %	4,659
How to manage my lung condition during coronavirus	65.26 %	6,211
How to look after my mental health	31.14 %	2,964
How to manage being at home for so long	26.79 %	2,550
I do not need more information on coronavirus	13.05 %	1,242
Confidence		
How well prepared do you feel? (1-10)	Mean (SD)	Observations
	6.41 (1.7)	9,490
By Gender		
Male	6.63 (1.75)	1,729
Female	6.36 (1.80)	1,683
By Age		
17 and under	6.41 (1.70)	444
18 to 29	5.94 (1.71)	967
30 to 39	6.07 (1.74)	1,982
40 to 49	6.36 (1.75)	2,555
50 to 59	6.60 (1.78)	1,803
60 to 69	6.89 (1.85)	1,067
70 to 79	7.12 (1.76)	533
80 and above	6.92 (1.90)	70
By diagnosis		

	Asthma	6.36 (1.76)	7,958
	COPD	6.68 (2.00)	657
	Bronchiectasis	6.63 (1.88)	361
	ILD	6.79 (1.89)	168
	Other	6.50 (1.80)	46
	Confidence following government advice (1-10)	4.17 (0.85)	9,480
	By Gender		
	Male	4.15 (0.86)	1,727
	Female	4.17(0.86)	7,675
	By Age		
	17 and under	4.27 (0.75)	440
	18 to 29	4.06 (0.84)	965
	30 to 39	4.05 (0.92)	1,975
	40 to 49	4.12 (0.87)	2,552
	50 to 59	4.19 (0.85)	1,802
	60 to 69	4.36 (0.79)	1,068
	70 to 79	4.47 (0.67)	537
	80 and above	4.30 (0.80)	71
	By diagnosis		
	Asthma	4.14 (0.87)	7,944
	COPD	4.34 (0.81)	959
	Bronchiectasis	4.31 (0.78)	362
	ILD	4.42 (0.72)	169
	Other	4.26 (0.80)	46
	Problems accessing groceries	21.95 %	2,089
	By Gender		
	Male	18.29 %	317
	Female	22.74 %	1,752
	By Age		
	17 and under	18.47 %	82
	18 to 29	23.35 %	226
	30 to 39	24.80 %	492
	40 to 49	22.30 %	571
	50 to 59	19.16 %	346
	60 to 69	22.39 %	240
	70 to 79	18.22 %	98
	80 and above	19.44 %	14
	By diagnosis		
	Asthma	21.23 %	1,693
	COPD	22.53 %	217
	Bronchiectasis	30.58 %	111
	ILD	31.36 %	53
	Other	32.61 %	15

Problems accessing prescriptions		7.28 %	693
By Gender			
	Male	6.52 %	113
	Female	7.46 %	575
By Age			
	17 and under	8.33 %	37
	18 to 29	10.23 %	99
	30 to 39	8.62 %	171
	40 to 49	7.93 %	203
	50 to 59	5.43 %	98
	60 to 69	4.76 %	51
	70 to 79	5.39 %	29
	80 and above	2.78 %	2
By diagnosis			
	Asthma	7.72 %	616
	COPD	4.78 %	46
	Bronchiectasis	6.06 %	22
	ILD	2.96 %	5
	Other	8.70 %	4
Have you used any of these services due to coronavirus, or concerns about its symptoms?			
Used 111 Online		19.23 %	1,830
By Gender			
	Male	17.57 %	304
	Female	19.64 %	1,513
By Age			
	17 and under	24.32 %	444
	18 to 29	23.35 %	968
	30 to 39	26.41 %	1,984
	40 to 49	21.80 %	558
	50 to 59	16.06 %	290
	60 to 69	8.68 %	93
	70 to 79	2.79 %	15
	80 and above	2.78 %	2
By diagnosis			
	Asthma	21.45 %	1,711
	COPD	6.65 %	64
	Bronchiectasis	10.19 %	37
	ILD	7.10 %	12
	Other	13.04 %	6
Used 111 Phone		8.01 %	762
By Gender			
	Male	8.02 %	139

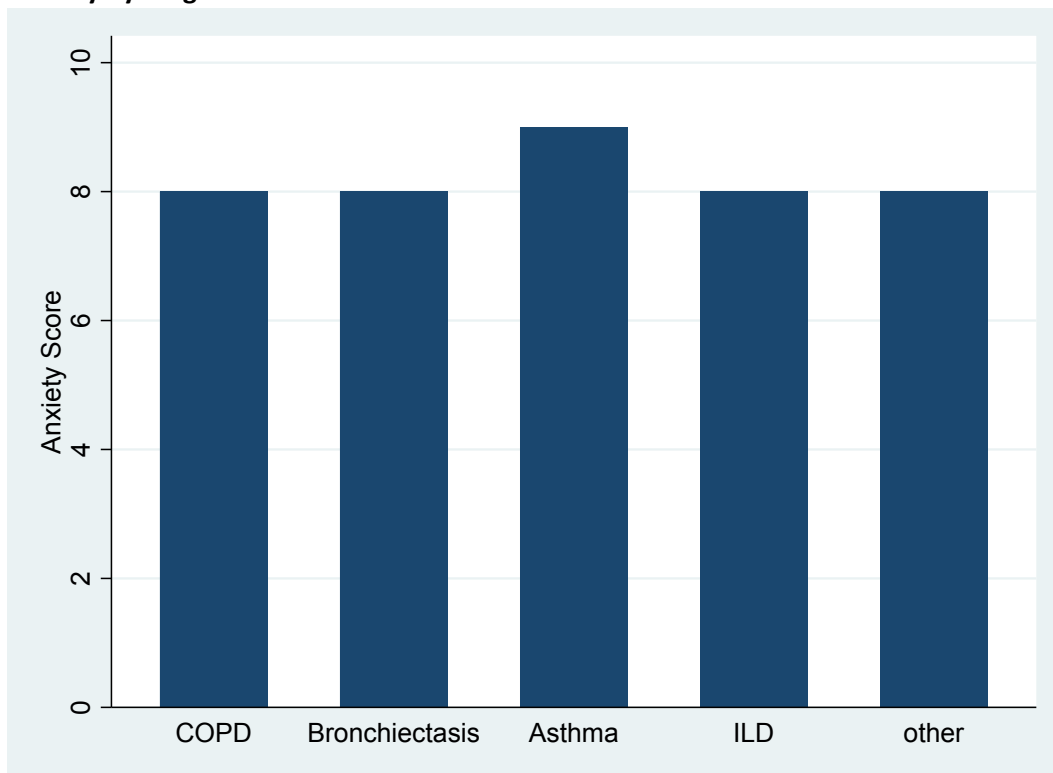
	Female	8.00 %	616
By Age			
	17 and under	9.68 %	43
	18 to 29	10.12 %	98
	30 to 39	11.19 %	222
	40 to 49	8.67 %	222
	50 to 59	6.76 %	122
	60 to 69	3.26 %	35
	70 to 79	2.79 %	15
	80 and above	0.00 %	0
By diagnosis			
	Asthma	8.80 %	702
	COPD	3.53 %	34
	Bronchiectasis	3.86 %	14
	ILD	5.33 %	9
	Other	6.52 %	3
Used A&E			
		1.11 %	106
By Gender			
	Male	1.15 %	20
	Female	1.10 %	85
By Age			
	17 and under	0.90 %	4
	18 to 29	1.14 %	11
	30 to 39	1.14 %	35
	40 to 49	1.45 %	37
	50 to 59	0.78 %	14
	60 to 69	0.28 %	3
	70 to 79	0.00 %	0
	80 and above	1.39 %	1
By diagnosis			
	Asthma	1.24 %	99
	COPD	0.42 %	4
	Bronchiectasis	0.55 %	2
	ILD	0.59 %	1
	Other	0.00 %	0
Used GP			
		25.63 %	2,439
By Gender			
	Male	23.43 %	406
	Female	26.20 %	7,703
By Age			
	17 and under	26.58 %	118
	18 to 29	29.65 %	287
	30 to 39	29.74 %	590

	40 to 49	28.83 %	738
	50 to 59	24.97 %	451
	60 to 69	16.60 %	178
	70 to 79	10.97 %	59
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	27.18 %	2,168
	COPD	14.75 %	142
	Bronchiectasis	22.31 %	81
	ILD	22.49 %	38
	Other	21.74 %	10
	Used the pharmacy	8.95 %	852
	By Gender		
	Male	10.91 %	189
	Female	8.54 %	658
	By Age		
	17 and under	11.71 %	52
	18 to 29	10.64 %	103
	30 to 39	8.87 %	174
	40 to 49	9.49 %	243
	50 to 59	8.42 %	152
	60 to 69	7.46 %	80
	70 to 79	7.06 %	38
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	9.19 %	733
	COPD	8.20 %	79
	Bronchiectasis	7.44 %	27
	ILD	6.51 %	11
	Other	4.35 %	2
	Used BLF or AUK nurse phone	7.19 %	684
	By Gender		
	Male	6.29 %	109
	Female	7.40 %	570
	By Age		
	17 and under	9.23 %	41
	18 to 29	8.06 %	78
	30 to 39	8.87 %	176
	40 to 49	8.36 %	214
	50 to 59	7.14 %	129
	60 to 69	2.89 %	31
	70 to 79	2.23 %	12
	80 and above	0	0

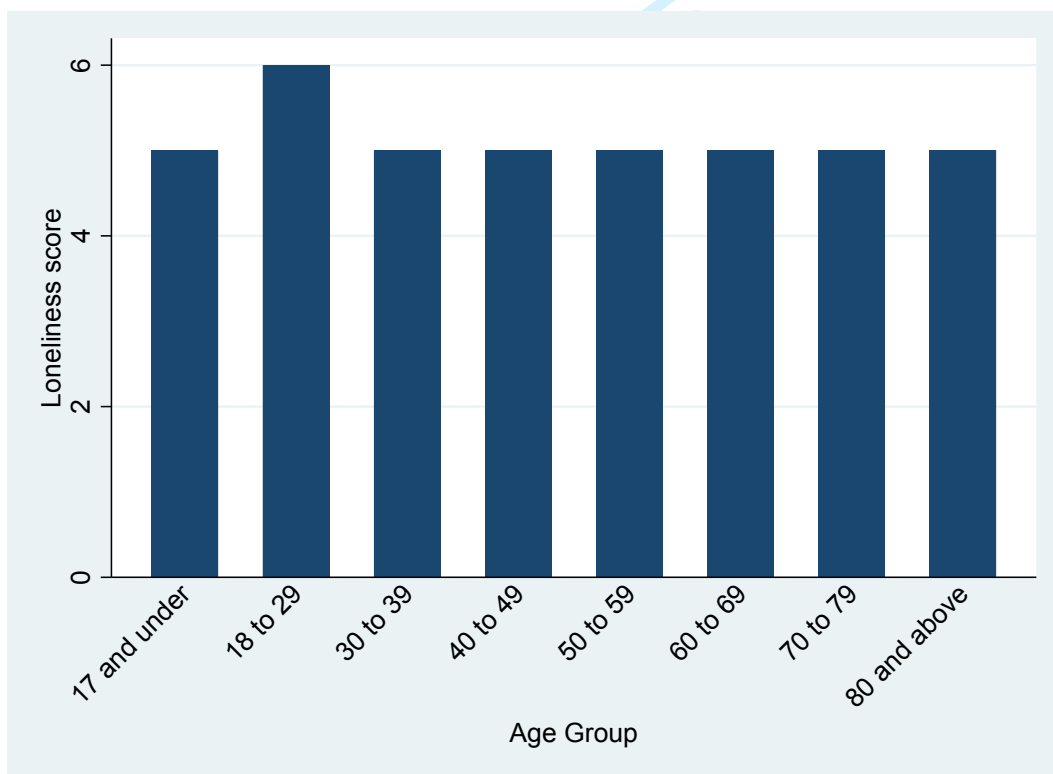
By diagnosis		
Asthma	8.13 %	648
COPD	1.56 %	15
Bronchiectasis	3.86 %	14
ILD	2.96 %	5
Other	4.35 %	2
Used none of these	55.45 %	5,278
By Gender		
Male	57.11 %	1,007
Female	54.85 %	4,225
By Age		
17 and under	48.65 %	216
18 to 29	50.52 %	489
30 to 39	47.33 %	939
40 to 49	52.19 %	1,336
50 to 59	56.92 %	1,028
60 to 69	69.50 %	745
70 to 79	78.44 %	422
80 and above	83.33 %	60
By diagnosis		
Asthma	52.69 %	4,202
COPD	73.00 %	703
Bronchiectasis	65.84 %	239
ILD	62.72 %	106
Other	60.87 %	28

Additional Graphs of Anxiety and Loneliness by Age and Diagnosis

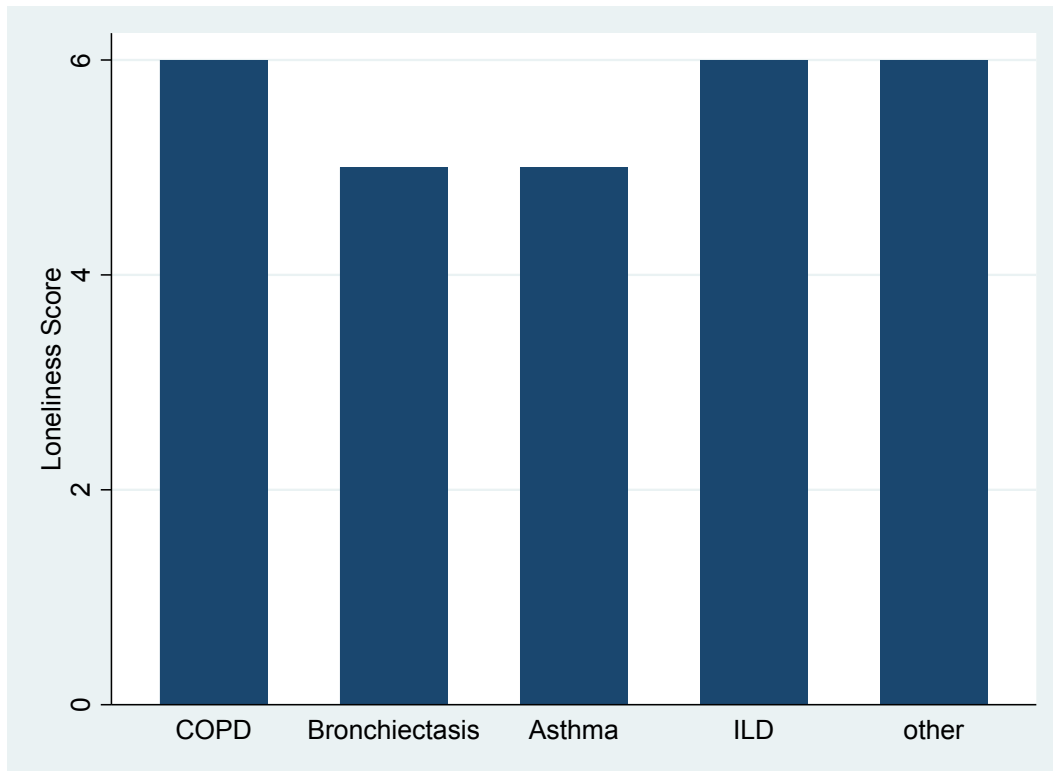
Anxiety by Diagnosis



Loneliness by Age Group



Loneliness by Diagnosis



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Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectional reporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

	Reporting Item	Page Number
Title and abstract		
Title	#1a Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction		
Background / rationale	#2 Explain the scientific background and rationale for the investigation being reported	4
Objectives	#3 State specific objectives, including any prespecified hypotheses	5
Methods		
Study design	#4 Present key elements of study design early in the paper	5
Setting	#5 Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5

1	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	5
2				
3				
4				
5		#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
6				
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10	Data sources /	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
11	measurement			
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18	Bias	#9	Describe any efforts to address potential sources of bias	10
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21	Study size	#10	Explain how the study size was arrived at	6
22				
23	Quantitative	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	6-9
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27	Statistical	#12a	Describe all statistical methods, including those used to control for confounding	6-9, Figure 1 and Tables
28	methods			
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31	Statistical	#12b	Describe any methods used to examine subgroups and interactions	Figure 1
32	methods			
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35	Statistical	#12c	Explain how missing data were addressed	n/a
36	methods			
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38	Statistical	#12d	If applicable, describe analytical methods taking account of sampling strategy	n/a
39	methods			
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42	Statistical	#12e	Describe any sensitivity analyses	n/a
43	methods			
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46	Results			
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48	Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	6
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56	Participants	#13b	Give reasons for non-participation at each stage	n/a
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1	Participants	#13c	Consider use of a flow diagram	6
2				
3	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	6 and Table 1
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10	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	Tables 1, 2, E1 and E2 (online supp)
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15	Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
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21	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	6
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27	Main results	#16b	Report category boundaries when continuous variables were categorized	6
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31	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
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35	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	6-9
36				
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39	Discussion			
40				
41	Key results	#18	Summarise key results with reference to study objectives	9-10
42				
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44	Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	10
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49	Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	9-10
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54	Generalisability	#21	Discuss the generalisability (external validity) of the study results	9-10
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57	Other			
58	Information			
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1 Funding [#22](#) Give the source of funding and the role of the funders for the 1
2 present study and, if applicable, for the original study on which the
3 present article is based
4
5

6 Notes:
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- 8 • 12a: 6-9, Figure 1 and Tables
- 9 • 14a: 6 and Table 1
- 10 • 14b: Tables 1, 2, E1 and E2 (online supp) The STROBE checklist is distributed under the terms of the
11 Creative Commons Attribution License CC-BY. This checklist was completed on 26. May 2020 using
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Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive cross-sectional UK wide survey

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3 **Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive**
4 **cross-sectional UK wide survey**
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38 **Key Words:**
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40 COVID-19, respiratory, shielding, social distancing, long term condition, anxiety, loneliness
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44 **Contribution**
45

46 KEJP, AC, JFD, ML, NSH developed the survey, KEJP performed the data analysis and wrote the first
47
48 draft. All authors contributed to revisions of this first draft and approved the final version.
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50
51

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53

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58 no say in the design and conduct of the study; collection, management, analysis, and interpretation
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3 of the data; preparation, review, or approval of the manuscript; and decision to submit the
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5 manuscript for publication.
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8 **Data availability statement** 9

10 All data relevant to the study are included in the article or uploaded as supplementary information
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14 **Conflicts of interest** 15

16
17 The authors report no conflicts of interest.
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3 **ABSTRACT** (262 words)
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6 **Objectives:** To assess the experience of people with long-term respiratory conditions regarding the
7
8 impact of measures to reduce risk of COVID-19.
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11 **Design:** Analysis of data (n=9,515) from the Asthma UK and British Lung Foundation partnership
12
13 COVID-19 survey collected online between 1st and 8th of April 2020.
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16 **Setting:** Community
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19 **Participants:** 9,515 people with self-reported long term respiratory conditions. 81% female, age
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21 ranges from ≤ 17 years to 80 and above, from all nations of the UK. Long term respiratory conditions
22
23 reported included asthma (83%), Chronic Obstructive Pulmonary Disease (COPD) (10%),
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25 bronchiectasis (4%), Interstitial Lung Disease (ILD) (2%), and 'other' (<1%) (e.g. lung cancer and
26
27 pulmonary endometriosis).
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31 **Outcome measures:** Study responses related to impacts on key elements of health care, as well as
32
33 practical, psychological and social consequences related to the COVID-19 pandemic and social
34
35 distancing measures.
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38 **Results:** 45% reported disruptions to care, including cancellations of appointments, investigations,
39
40 pulmonary rehabilitation, treatment, and monitoring. Other practical impacts such as difficulty
41
42 accessing healthcare services for other issues, and getting basic necessities such as food, were also
43
44 common. 36% did not use online prescriptions and 54% had not accessed online inhaler technique
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46 videos. Psycho-social impacts including anxiety, loneliness and concerns about personal health and
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48 family were prevalent. 81% reported engaging in physical activity. Among the 11% who were smokers,
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50 48% reported they were planning to quit smoking because of COVID-19.
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54 **Conclusions:** COVID-19 and related social distancing measures are having profound impacts on people
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56 with chronic respiratory conditions. Urgent adaptation and signposting of services is required to
57
58 mitigate the negative health consequences of the COVID-19 response for this group.
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Strengths and limitations of this study

- This is one of the first studies in the UK to highlight the impact of COVID-19 related measures on people with long term health conditions.
- The study includes a large sample (n=9515) from broad range of respiratory conditions, age groups, and parts of the UK.
- Key gaps in healthcare provision/access are identified including online prescription and inhaler technique videos; self-management plans; smoking cessation support.
- Although a range of individuals are represented, the sample has a large percentage of people with asthma (83%) and is predominantly female (81%).
- A lack of data regarding disease severity, and further demographic information of interest such as socio-economic status, ethnicity and housing, limits the depth of interpretation possible.

INTRODUCTION

COVID-19 is a particular threat for people with long term respiratory conditions, who are at greater risk of serious disease and death if they become infected^{1,2}. Recommendations for respiratory patients include being especially careful regarding social distancing measures to reduce SARS-CoV-2 transmission. In the UK, for the most vulnerable a period of “social shielding”, avoiding face-to-face contact has been advised^{3,4}, with twin aims of protecting individuals from infection and avoiding a peak of cases in the most vulnerable which might overwhelm the health and social care system. Measures to reduce the immediate impact of COVID-19 are likely to have some adverse consequences for the population’s health and wellbeing⁵⁻⁸, leading to a so called ‘third wave’ of COVID-19 related

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3 morbidity and mortality in which detrimental health impacts for people with long-term conditions
4 result from interruptions to care provision and health seeking behaviours⁹. This is of particular concern
5 given the substantial level of unmet need related to respiratory disease¹⁰⁻¹⁵. Identification of health
6 and wellbeing impacts is required to facilitate mitigation interventions, of which examples of
7 successful approaches are being reported¹⁶.

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10 Data on the experience of people with long term respiratory conditions regarding the impact of
11 COVID-19 prevention measures is currently lacking¹⁷, but will be important for understanding of the
12 impacts on these people, and to help guide current and future provision to where it is required.
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15 16 17 18 19 20 21 22 23 24 25 **METHODS**

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28 To assess the impact of measures to address COVID-19 on access to key elements of care^{18 19} as well
29 as the practical, psychological and emotional consequences of the current situation, we analysed data
30 from an online survey carried out by the Asthma UK (AUK) and British Lung Foundation (BLF)
31 Partnership between 1st and 8th of April 2020. The survey was developed by the authors, and other
32 colleagues at the Asthma UK and British Lung Foundation (AUK-BLF) partnership, to improve
33 understanding of the experiences of lockdown and coronavirus on people with lung conditions in the
34 UK, and to find out how AUK-BLF can best support them. The topics were based on areas raised by
35 patients and healthcare professionals as being of particularly vulnerable to disruption, and those
36 having potentially important implications for disease management. The core survey was developed
37 by both AUK and the BLF in partnership, with each adding a couple of questions specific to their patient
38 group. In the Online Supplement the questions that only feature in the AUK or BLF versions are
39 highlighted. The survey results for the core questions were then combined. Any single survey question
40 responses are highlighted as such. The survey was promoted to supporters of both Asthma UK and
41 the British Lung Foundation, and was conducted on Typeform. Initial response targets for the survey
42 were 3,000 (AUK) and 1,000 (BLF). The survey was distributed to individuals on their mailing
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3 lists, placed on the charities' websites, and advertised on social media (Facebook, Twitter, Instagram
4 and LinkedIn). Social distancing measures were announced by the UK Government on 23rd March. The
5 text of the survey is available in the online supplement. Furthermore, during the data collection
6 period, Public Health England (PHE) recommendations relevant to survey respondents included 1) All
7 members of the public were advised to stay at home, only being permitted to leave the house for a
8 small number of specific reasons. 2) Shielding of "people with severe respiratory conditions including
9 all cystic fibrosis, severe asthma and severe COPD" who were advised to "stay at home at all times
10 and avoid any face-to-face contact for a period of at least 12 weeks".

11
12 The analysis presented focuses on questions relating to 1) Impacts on healthcare provision, 2) Social,
13 psychological and practical responses, and 3) Sources of support and information. Rating scales are
14 from zero (lowest) to ten (highest) unless otherwise specified, for questions relating to how well
15 prepared they felt, and levels of anxiety experienced. The survey questions and response options are
16 provided in the Online Supplement. Data are presented using descriptive statistics. Where a between
17 group difference was of a potentially clinically significant magnitude, this was tested using t-test or
18 Kruskal-Wallis tests as appropriate. Data were grouped into 'Asthma' and Chronic respiratory disease
19 (non-asthma) in table 1 so that the composition of the sample was clearer for readers. These data
20 were collected by AUK-BLF as part of routine information gathering and marketing activities, which
21 often relate to topical issues for people with respiratory conditions, in this case COVID-19. All
22 participants consented to their responses being used for research, analysis and publication.
23 Anonymised data were shared with the authors for analysis. The Charity's information governance
24 process supported this, consistent with GDPR the General Data Protection Regulation (GDPR, the
25 primary legislation regarding data protection and privacy in the European Union), and additional
26 external ethical approval was not deemed necessary. Analyses were carried out using Stata V.14
27 (StataCorp). Data used here are not being made publicly available.

58 **Patient and Public Involvement**

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3 Patients and members of the public were not specifically involved in the design, conduct or reporting
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5 of this research. However, the primary focus of this research was to understand the impact of the
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7 COVID-19 risk reduction measures on people living with long-term respiratory conditions, and
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9 questions were shaped around issues being raised by patients and the public with AUK, BLF and the
10
11 clinical staff involved in developing the survey.
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18 RESULTS

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21 11,124 people started the AUK survey, of which 7,748 completed it, while 2,518 people started the
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23 BLF survey, of which 1,856 provided completed responses. Hence, the initial survey data included
24
25 9,604 full responses. Responses were then removed from people without a lung condition (n=25);
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27 people who completed the survey twice within the sampling period (n=24 BLF, n=21 AUK) and people
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29 who completed both surveys (n=19), which left 9,515 individuals' responses for analysis.. Data
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31 presented here are the combined responses to the core questions which were the same in the BLF
32
33 and AUK hosted surveys. The BLF hosted version contributed 1,787 responses, while the AUK hosted
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35 survey contributed 7,728 responses. Where the sum of total answers given is less than 9,515 this is
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37 due to non-response to that specific question. The surveys took respondents an average of (AUK)
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39 8:36(m/s) and (BLF) 11:35(m/s) to complete. The exact response rate is not possible to establish given
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41 the method by which the survey was publicised including via social media. This final sample was 81%
42
43 female, with age ranges from ≤ 17 years to 80 and above, and all nations of the UK represented.
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45 Reported lung diseases were 83% asthma, 10% COPD, 4% bronchiectasis, 2% Interstitial Lung Disease
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47 (ILD), and <1% 'other' for example lung cancer and pulmonary endometriosis (Table 1). Of people who
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49 completed the AUK hosted version of the survey which asked about severity of asthma, 28.25% (2,179)
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51 reported having 'difficult' 'severe' or 'brittle' asthma. The BLF hosted version of the survey included
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53 an additional question on breathlessness, to which 32% of respondents with non-asthma diagnoses
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55 reported being severely breathless (MRC dyspnoea score ≥ 4).
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Impacts on Healthcare provision

Despite data collection occurring relatively early in the first wave of the UK pandemic, 45% reported disruptions in healthcare provision, including GP and hospital appointment cancellations affecting 10% and 8% of respondents respectively, with 31% reporting having appointments conducted remotely (e.g. by phone) (Table 2). Respondents reported various additional ways in which healthcare provision had been impacted by COVID-19 (under the freetext option 'other'), including cancelled operations, investigations, respiratory nurse appointments, and medication reviews. In addition, finding it difficult to get in contact with relevant care providers for advice and information. Despite being a population by definition with online access, one third did not access online prescription services and over half had not made use of online inhaler technique videos. Among the 11% who were smokers, 48% reported they were planning to quit smoking because of COVID-19. A majority of individuals did not have a written self-management plan despite the strong evidence base for this intervention^{19 20}.

Reassuringly, respondents reported high levels of physical activity, with 81% being 'able to keep active or do exercise at home' (Table 2). Most frequently reported activities include walks (47%), housework (54%), and gardening (29%)(Table 2). In addition to the activities listed in table 2, 7% of respondents reported 'other' activities including home exercise bikes, trampolining, tennis, weights, skipping, home PR, Pilates, YouTube exercise videos, Zumba/dance and Wii fit.

Social and psychological responses

High levels of anxiety about COVID-19 were reported; mean(SD) anxiety level 8.03(2.07); slightly higher in women than men, 8.13(1.99) vs 7.55(2.28)(t-test $p < 0.001$), and decreasing slightly with age (Figure 1, Kruskal-Wallis $p < 0.001$). Only 34% of men and 24% of women felt that they were 'coping well' (t-test for between group difference $p < 0.001$). Older age groups were more likely to report

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3 coping well with 47% of 70 to 79-year olds, steadily decreasing to 17% in the 18 to 29 years old group
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5 (Kruskal-Wallis $p < 0.001$). Respondent had various concerns, most commonly reported being 'concern
6
7 about lung condition' (64%), and concern about family (61%). Interestingly, both showing similar
8
9 variations related to age and gender as that seen in anxiety and 'coping well', with a higher percentage
10
11 of females, and younger people reporting concerns.
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15 The majority (87%) of respondents lived with another person; 51% felt they lacked companionship
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17 'some of the time' or 'often', and 52% reported feeling left out of things 'some of the time' or 'often'.
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19 66% of respondents felt 'isolated from others'. Combining the scores for these three statements
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21 (modified 3 item UCLA loneliness score),²¹ 3 being the lowest score for loneliness and 9 the highest,
22
23 the mean loneliness rating was 5.12(1.80), with broadly similar levels in women and men 5.21(1.81)
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25 vs 4.74(1.72), although the difference was statistically significant (t-test $p < 0.001$). Similarly, although
26
27 in this large sample the Kruskal-Wallis test showed values were not equal for age groups ($p < 0.001$)
28
29 and disease types ($p < 0.001$), the differences in loneliness ratings between them were relatively small
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31 (Online Table E1).
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35 Of note, responses in those who reported that they were actively shielding suggested only slightly
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37 higher levels of loneliness to those who were not, at 5.23 and 4.85 (t-test $p < 0.001$) respectively (Table
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39 E1). 19.54% of respondents had received the government letter or text message advising them to
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41 shield, of whom 98% were doing so. Mean perceived preparedness for COVID-19 was 6.41(1.7) out of
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43 10. Again, although there were statistically significant differences related to gender (t-test $p < 0.001$),
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45 age (Kruskal-Wallis $p < 0.001$), and diagnosis (Kruskal-Wallis $p < 0.001$) these were small in absolute
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47 terms, and as such unlikely to be of importance (Online Table E2).
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54 55 **Sources of support and Information** 56 57 58 59 60

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3 Respondents reported having accessed various services to address concerns about coronavirus or its
4 symptoms. These included NHS 111 online (19%) (an interactive website for the National Health
5 Service that provides information, guidance and self-management support) which was used more
6 commonly by younger adults (23 to 25% of under 40-year olds, compared with 3 to 9% of over 60
7 years old, Kruskal-Wallis <0.001, Online Table E2) , despite the surveys being online which imply at
8 least some level of digital literacy in all respondents. GPs had been used by 26% of respondents, again
9 with a trend toward decreasing use in older (>60) age groups (Online Table E2). The NHS 111
10 telephone service (a telephone service for non-emergency health advice and guidance) had been used
11 by 8% of respondents with a similar decrease in use by older age groups. Though differences between
12 conditions are seen this is likely due to certain conditions being more represented in certain age
13 groups. For example, the same trends regarding age and NHS 111 online use were seen when asthma
14 was considered alone. Only 1% of respondents reported using A&E, with no substantial differences in
15 absolute values related to gender, age, or diagnosis. 55% of respondents reported not having used
16 'any resources due to coronavirus or concerns about its symptoms'. Reporting not having used
17 resources was more common in older than younger adults (Kruskal-Wallis <0.001, Online Table E2).
18 As might be expected, higher percentages of respondents in working age groups were concerned
19 about their financial situation due to missed work.
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42 Respondents made use of various sources for information on coronavirus, the most commonly
43 reported being television (73%), news websites (50%), and (non-BLF/AUK) social media (25%). Less
44 commonly reported sources of information on coronavirus include BLF/AUK websites (17%) and social
45 media (14%), radio (12%) and friends and family (8%) (See Online Table E2 for further responses about
46 practical preparedness for COVID-19).
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53 Respondents were particularly interested in having more information about how to manage their lung
54 condition in relation to coronavirus (65%), decisions they may need to make if they were to get ill with
55 COVID-19 (49%), and how to look after their mental health (31%).
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Practical difficulties

Multiple difficulties were experienced by respondents regarding health impacting practical issues. 22% reported difficulties accessing groceries, while 7% had difficulties accessing prescriptions (Online Table E2)

DISCUSSION

COVID-19 is having significant impacts on individuals with respiratory disease, generating high levels of anxiety and concerns about potential impacts on respondents and their families, compounded by social isolation and loneliness. In addition, many aspects of care have been cancelled or deferred, including pulmonary rehabilitation and severe asthma appointments in secondary and tertiary, care, on a background of provision that was already failing to meet the needs of many people^{10 11}, with impacts evident despite relatively recent introduction of distancing measures. Respondents were clearly making an effort to engage in physical activity despite the challenging nature of the situation.

Despite the requirement for physical distancing, social isolation and loneliness can still be avoided, or reduced, through targeted support and intervention. There is growing evidence that COVID-19 disproportionately effects more deprived groups²². Isolation strategies are also likely to impact most heavily on the most disadvantaged individuals with the least economic and social capital.

A key practical issue is that nearly half the respondents who smoke tobacco reported that they intended to quit due to COVID-19. It will be important to ensure that there is provision of appropriate accessible smoking cessation support services, to maximise their chance of success both to reduce the occurrence of smoking related disease generally²³ and to reduce individuals' risk from COVID-19 specifically²⁴. In addition, encouraging uptake of online prescriptions and directing patients to online

resources including inhaler technique videos to support self-management, as recommended in the NICE COVID-19 COPD Rapid Guideline Update (NG168)²⁵, should be prioritised.

The study sample includes representation from a wide age range, a variety of respiratory conditions, and all countries of the UK, but some limitations exist. More detail about disease severity would have been useful for interpreting responses, as this impacts government guidance regarding distancing and shielding measures. The study was online so results may not be representative for digitally excluded individuals. In addition, this study did not assess the views on the use of facemasks which has been found to be protective, to some extent, for mental health in China²⁶. This would be of interest to explore further in the UK population. Finally, the cross-sectional nature of this study does not allow for longitudinal change of the level of psychiatric comorbidity, which in patients with respiratory disorders may have a higher baseline prevalence than the general population even prior to the COVID-19 pandemic²⁷.

CONCLUSION

Measures to reduce the risk of COVID-19 are having profound impacts on people with lung disease including widespread disruption to fundamental components of healthcare services, high levels of anxiety and loneliness. There is an urgent need to adapt services to address these needs and improve signposting of individuals to existing resources, in order to mitigate negative health consequences, and provide appropriate care to this vulnerable group.

Acknowledgements

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Transparency statement

Dr Keir Philip affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

For peer review only

Table 1: Participant Characteristics

	Asthma n=7975	Chronic respiratory disease (non-asthma) n=1541
Age group		
17 and under	5.54 % (439)	0.33 % (5)
18 to 29	12.11 % (959)	0.59 % (9)
30 to 39	24.68 % (1,955)	1.90 % (29)
40 to 49	30.60 % (2,424)	8.93 % (136)
50 to 59	18.67 % (1,479)	21.47 % (327)
60 to 69	6.26 % (496)	37.82 % (576)
70 to 79	1.94 % (154)	25.21 % (384)
80 and above	0.19 % (15)	3.74 % (57)
Gender (%Female)	82.92 % (6,562)	74.67 % (1,141)
Country		
England	75.35 % (5,981)	83.33 % (1,275)
Scotland	13.03 % (1,034)	9.54 % (146)
Wales	7.19 % (571)	5.23 % (80)
Northern Ireland	4.43 % (352)	1.90 % (29)
Influenza immunisation 2019/20		
Yes	77.10 % (6,139)	89.96 % (1,380)
No	22.54 % (1,795)	9.97 % (153)
Don't know	0.35 % (28)	0.07 % (1)
Current smoking		
Non-smoker	89.41 % (7,115)	86.07 % (1,322)
Smoker	10.59 % (843)	13.93 % (214)
Of smokers -		
Intending to quit smoking due to COVID-19	49.11 % (414)	64.48 % (138)
Not intending quit smoking due to COVID-19	50.89 % (429)	35.51 % (76)
Shielding		
Actively shielding	68.66 % (5,461)	89.97 % (1,381)
Not actively shielding	31.34 % (2,493)	10.30 % (154)
Self-isolating		
Currently self-isolating	67.81 % (5,403)	88.01 % (1,350)
Not currently self-isolating	32.19 % (2,565)	11.99 % (184)
Current COVID-19 Symptoms 'Yes'	6.89 % (549)	3.07 % (47)
Current COVID-19 Symptoms 'Not sure'	3.99 % (318)	3.78 % (58)
Following self-isolation advice due to symptoms	92.81 % (800)	98.04 % (100)
Not following self-isolation advice	7.19 % (62)	1.96 % (2)
Diagnosis		

Asthma	83.81 % (7,975)
COPD	10.12 % (963)
Bronchiectasis	3.81 % (363)
ILD	1.78 % (169)
Other	0.48 % (46)

Table 2: Impact of COVID-19 related measures on chronic disease healthcare provision and self-management

Component of disease management	Percentage	Number of observations
Health service provision		
GP appointment cancelled	9.69 %	922
Hospital appointment cancelled	7.83 %	745
GP phone/remote appointment	30.93 %	2,944
Some form of cancellation or change in service delivery	44.86 %	4,270
Of those who do PR (n=553)		
Doing PR at home	24.77 %	137
PR cancelled	24.23 %	134
Have enough medications	93.41 %	8,871
Have online prescriptions	64.38 %	6,112
Have a written self-management plan for their condition	39.56 %	3,756
Have watched online inhaler videos		
Yes	44.11 %	4,190
No	53.57 %	5,089
Don't use inhalers	2.33 %	221
Physical activity		
Able to 'keep active' or do exercise at home	81.02 %	7,682
Not able to 'keep active' or do exercise at home	18.92 %	1,800
Type of activity		
Walks	47.05 %	4,478
Cycling	6.43 %	612
Run	7.17 %	682
Yoga	12.03 %	1,145
Gardening	29.06 %	2,817
Housework	54.16 %	5,155

Figure 1: legend A bar chart of median anxiety level by age group

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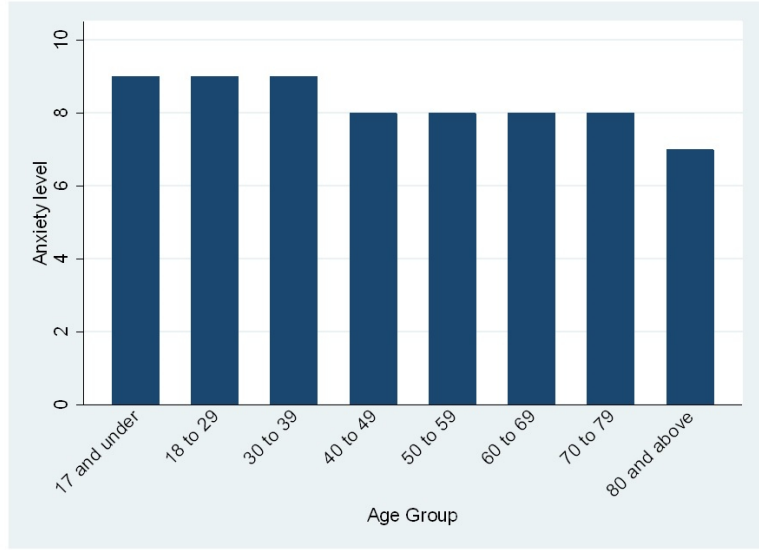
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Figure 1: A bar chart of median anxiety level by age group



We conducted the Kruskal-Wallis H test to determine if there is a statistically significant difference between anxiety levels in different age groups. This test was selected due to the marked left shift in the data. Sample sizes in each group are reported in table 2. This test demonstrated statistically significant differences between groups (chi-squared = 158.895 with 7 d.f., probability = 0.0001).

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3 **Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive**
4 **cross-sectional UK wide survey**
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8 **– ONLINE SUPPLEMENT**
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SURVEY QUESTIONS AND POSSIBLE RESPONSES:

What is your age? 17 and under; 18-29; 30-39; 40-49; 50-59; 60-69; 70-79; 80+ What is your gender? Male; Female; Other

What nation do you live in? England; Northern Ireland; Scotland; Wales

Have you ever been told that you have 'difficult', 'brittle' or 'severe' asthma? (AUK survey only) Yes; No; Not sure

What is your main lung diagnosis? Asthma; COPD (chronic obstructive pulmonary disease); Bronchiectasis; ILD (interstitial lung disease); I do not have a lung condition; Other

Do you receive pulmonary rehabilitation as part of your care? Yes; No.

When do you get out of breath? (MRC dyspnoea scale options) (BLF survey only)

- I'm not troubled by being out of breath, except on strenuous exercise
- I'm short of breath when hurrying on the level or walking up a slight hill
- I walk slower than most people on the level, stop after a mile or so, or stop after 15 minutes of walking at my own pace
- I stop for breath after walking about 100 yards or after a few minutes on level ground
- I'm too breathless to leave the house, or breathless when dressing and undressing

Are you currently following the government's 'shielding' advice? Yes; No.

Have you received a letter or text message advising you to shield? Yes; No; Don't know.

Did you have the flu jab this winter? Yes; No; Don't know.

Have you seen guidance or advice on coronavirus from Asthma UK or the British Lung Foundation? Yes; No.

How did you see this advice? Via email; On Twitter; On Facebook; On the AUK and/or BLF websites.

Where do you mainly get your information about coronavirus? TV; Radio; News websites; AUK / BLF websites; AUK /BLF social media; Other social media; Friends and family.

What was it about the advice you saw that wasn't helpful? It was too complicated; There was not enough detail; I didn't trust it; It was badly presented; It couldn't answer my query.

The Government? Very helpful; Helpful; Neither helpful nor unhelpful; Not helpful; Not helpful at all; I have not seen their advice.

What was it about the advice you saw that wasn't helpful? It was too complicated; There was not enough detail; I didn't trust it; It was badly presented; It couldn't answer my query

Would you like more information on any of the following during the coronavirus outbreak? Yes, No.

Are you currently suffering from any coronavirus symptoms? Yes; No; Not sure.

Are you following isolation advice? Yes; No.

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3 How confident are you about following advice to self-isolate or shield? Very confident; Somewhat
4 confident; Neither confident nor not confident; Not very confident; Not confident at all.
5

6 How confident are you that you will be able to access food and other provisions if you have to self-
7 isolate or shield? Very confident; Somewhat confident; Neither confident nor not confident; Not
8 very confident; Not confident at all.
9

10 Do you have enough medicines for your needs at the moment? Yes; No.

11 Are you registered to order prescriptions online from your GP? Yes; No.

12 Have you had a look at online inhaler technique videos to check that you are using your inhalers
13 properly? Yes; No; I don't use inhalers.

14 Do you have a written self-management plan for your condition? Yes; No.

15 In general, how well prepared do you feel for coronavirus? 1-10, with 10 being most prepared

16 In general, how anxious do you feel about coronavirus? 1-10, with 10 being most anxious

17 Which of the following apply to you?

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25 - I'm concerned about my lung condition
26 - I'm concerned about the health of my family members
27 - I'm coping well
28 - I'm having trouble getting groceries
29 - I'm worried about my financial situation due to missed work
30 - I can't get the prescriptions I need
31 - None of the above
32 - Other
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35 Have you used any of these services due to coronavirus, or concerns about its symptoms?

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37 - NHS 111 (online checker)
38 - NHS 111 (telephone advice)
39 - GP
40 - Pharmacy
41 - A&E
42 - BLF or AUK nurse phone
43 - Other
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46 Has any of the following happened to you because of the way the NHS is working at the moment?

- 47
48 - I have had to have a GP appointment conducted over the phone / remotely
49 - My regular care for my lung condition at the hospital has been cancelled
50 - My regular care for my lung condition at the GP has been cancelled
51 - Pulmonary rehabilitation classes were cancelled
52 - I have had to do pulmonary rehabilitation exercises at home
53 - None of the above
54 - Other
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57 Are you able to perform your job at home? Yes; No; I'm not in work.
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3 How supportive have your workplace been during the coronavirus outbreak? Very supportive;
4 Supportive; Somewhat supportive; Not supportive; Not supportive at all.
5

6 Are you keeping physically active, or are able to do any exercise at home? Yes; No.
7

8 Which of the following are you doing to stay active while at home?
9

- 10 - Housework
- 11 - Gardening
- 12 - Going on walks
- 13 - Yoga
- 14 - Cycling
- 15 - Running
- 16 - Other
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19 If you smoke, are you planning to try to quit smoking to protect yourself from coronavirus? Yes; No; I
20 don't smoke.
21

22 Are you actively self-isolating due to coronavirus? Yes; No.
23

24 Do you live alone? Yes; No.
25

26 How often do you feel you lack companionship? Hardly ever; Some of the time; Often.
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28 How often do you feel left out of things? Hardly ever; Some of the time; Often.
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30 How often do you feel isolated from others? Hardly ever; Some of the time; Often.
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Table E1: Loneliness, Isolation, Anxiety, and Concerns

	Percentage	Number of observations
Domestic Isolation		
Live alone	13.06 %	1,241
Does not live alone	86.94 %	8,260
Loneliness		
Feels lacks companionship		
Hardly ever	48.91 %	4,643
Some of the time	39.84 %	3,782
Often	11.25 %	1,068
Feels left out of things		
Hardly ever	46.73 %	4,434
Some of the time	40.84 %	3,875
Often	12.43 %	1,179
Feels isolated from others		
Hardly ever	34.34 %	3,261
Some of the time	47.21 %	4,483
Often	18.45 %	1,752
	Mean (SD)	N
Overall loneliness score (all respondents)		
	5.12 (1.80)	9,458
Loneliness by gender		
Male	4.74 (1.72)	1,728
Female	5.21 (1.81)	7,652
Loneliness by age		
17 and under	4.81 (1.68)	441
18 to 29	5.65 (1.84)	962
30 to 39	5.20 (1.82)	1,978
40 to 49	4.96(1.78)	2,550
50 to 59	5.00 (1.75)	1,794
60 to 69	5.24 (1.83)	1,064
70 to 79	5.03 (1.74)	532
80 and above	5.26 (1.79)	69
Loneliness by main diagnosis		
Asthma	5.06 (1.79)	7,936
COPD	5.56 (1.85)	957
Bronchiectasis	5.18(1.71)	357
ILD	5.54 (1.92)	163
Other	5.40 (1.84)	45
Loneliness by shielding		
Actively shielding	5.23 (1.81)	6,804
Not actively shielding	4.85 (1.74)	2,654
Anxiety		
How anxious do you feel? (1-10)	8.03 (2.07)	9,495
Anxiety by gender		

	Male	7.55 (2.28)	1,728
	Female	8.13 (1.99)	7,691
Anxiety by age			
	17 and under	8.14 (2.11)	442
	18 to 29	8.23 (1.90)	967
	30 to 39	8.24 (1.97)	1,981
	40 to 49	8.14 (1.96)	2,558
	50 to 59	8.00 (2.11)	1,803
	60 to 69	7.60 (2.27)	1,066
	70 to 79	7.32 (2.18)	536
	80 and above	7.03 (2.33)	72
Anxiety by diagnosis			
	Asthma	8.11 (2.01)	7,959
	COPD	7.57 (2.31)	960
	Bronchiectasis	7.64 (2.14)	362
	ILD	7.51 (2.24)	168
	Other	7.76 (2.23)	46
	Actively shielding	8.06 (2.08)	6,829
	Not actively shielding	7.94 (2.03)	2,666
Feels coping well		25.90 %	2,465
By Gender			
	Male	34.39 %	596
	Female	23.96 %	1,844
By Age			
	17 and under	22.97 %	102
	18 to 29	17.46 %	169
	30 to 39	19.20 %	381
	40 to 49	24.38 %	624
	50 to 59	26.74 %	483
	60 to 69	37.50 %	402
	70 to 79	47.21 %	254
	80 and above	45.83 %	33
By diagnosis			
	Asthma	24.33 %	1,940
	COPD	34.79 %	335
	Bronchiectasis	31.96 %	116
	ILD	34.91 %	59
	Other	32.61 %	15
	Bronchiectasis	8.26 %	30
	ILD	12.43 %	21
	Other	13 %	6
Concerns			
	Concerned about lung condition	64.25 %	6,115

By Gender		
Male	57.24 %	992
Female	65.88 %	5075
By Age		
17 and under	41.22 %	183
18 to 29	73.14 %	708
30 to 39	71.47 %	1,418
40 to 49	68.71 %	1,759
50 to 59	62.24 %	1,124
60 to 69	54.76 %	587
70 to 79	48.14 %	259
80 and above	50.00 %	36
By diagnosis		
Asthma	64.94 %	5,179
COPD	56.80 %	547
Bronchiectasis	67.77 %	246
ILD	66.86 %	113
Other	65.22 %	30
Concerned about family	61.50 %	5,854
By Gender		
Male	54.99 %	953
Female	63.03 %	4,855
By Age		
17 and under	60.36 %	268
18 to 29	65.91 %	638
30 to 39	66.33 %	1,316
40 to 49	64.02 %	1,639
50 to 59	60.24 %	1,088
60 to 69	53.82 %	1,072
70 to 79	47.21 %	538
80 and above	38.89 %	72
By diagnosis		
Asthma	63.32 %	5,050
COPD	51.40 %	495
Bronchiectasis	53.72 %	195
ILD	49.11 %	83
Other	67.39 %	31
Concerned about financial situation due to missed work	18.61 %	1,771
By Gender		
Male	18.58 %	322
Female	18.64 %	1,436
By Age		

17 and under	13.51 %	60
18 to 29	26.96 %	261
30 to 39	22.73 %	451
40 to 49	22.50 %	576
50 to 59	18.72 %	338
60 to 69	6.62 %	71
70 to 79	0.74 %	4
80 and above	1.39 %	1
By diagnosis		
Asthma	20.43 %	1,629
COPD	8.83 %	85
Bronchiectasis	8.26 %	30
ILD	12.43 %	21
Other	13 %	6

Table E2: Practical Preparedness

	Percentage	Number of observations
Sources of Information		
Government Letter		
Has received	19.54 %	1,855
Has not received	78.98 %	7,498
Does not know	1.49 %	141
Actively shielding of those who have received government letter	97.83 %	1,804
Main sources of COVID info		
TV	72.98 %	6,946
Radio	11.56 %	1,100
New websites	50.34 %	4,791
AUK/BLF website	17.49 %	1,665
AUK/BLF social media	14.36 %	1,367
Other social media	24.85 %	2,365
Friends and Family	8.34 %	794
Would like more information on:		
Symptoms	35.26 %	3,356
How to help their community	6.60 %	628
Financial help	14.57 %	1,387
Decisions possibly required if a person I care for gets ill	28.20 %	2,684
Decisions possibly required if I get ill	48.95 %	4,659
How to manage my lung condition during coronavirus	65.26 %	6,211
How to look after my mental health	31.14 %	2,964
How to manage being at home for so long	26.79 %	2,550
I do not need more information on coronavirus	13.05 %	1,242
Confidence		
How well prepared do you feel? (1-10)	Mean (SD)	Observations
	6.41 (1.7)	9,490
By Gender		
Male	6.63 (1.75)	1,729
Female	6.36 (1.80)	1,683
By Age		
17 and under	6.41 (1.70)	444
18 to 29	5.94 (1.71)	967
30 to 39	6.07 (1.74)	1,982
40 to 49	6.36 (1.75)	2,555
50 to 59	6.60 (1.78)	1,803
60 to 69	6.89 (1.85)	1,067
70 to 79	7.12 (1.76)	533
80 and above	6.92 (1.90)	70
By diagnosis		

	Asthma	6.36 (1.76)	7,958
	COPD	6.68 (2.00)	657
	Bronchiectasis	6.63 (1.88)	361
	ILD	6.79 (1.89)	168
	Other	6.50 (1.80)	46
	Confidence following government advice (1-10)	4.17 (0.85)	9,480
	By Gender		
	Male	4.15 (0.86)	1,727
	Female	4.17(0.86)	7,675
	By Age		
	17 and under	4.27 (0.75)	440
	18 to 29	4.06 (0.84)	965
	30 to 39	4.05 (0.92)	1,975
	40 to 49	4.12 (0.87)	2,552
	50 to 59	4.19 (0.85)	1,802
	60 to 69	4.36 (0.79)	1,068
	70 to 79	4.47 (0.67)	537
	80 and above	4.30 (0.80)	71
	By diagnosis		
	Asthma	4.14 (0.87)	7,944
	COPD	4.34 (0.81)	959
	Bronchiectasis	4.31 (0.78)	362
	ILD	4.42 (0.72)	169
	Other	4.26 (0.80)	46
	Problems accessing groceries	21.95 %	2,089
	By Gender		
	Male	18.29 %	317
	Female	22.74 %	1,752
	By Age		
	17 and under	18.47 %	82
	18 to 29	23.35 %	226
	30 to 39	24.80 %	492
	40 to 49	22.30 %	571
	50 to 59	19.16 %	346
	60 to 69	22.39 %	240
	70 to 79	18.22 %	98
	80 and above	19.44 %	14
	By diagnosis		
	Asthma	21.23 %	1,693
	COPD	22.53 %	217
	Bronchiectasis	30.58 %	111
	ILD	31.36 %	53
	Other	32.61 %	15

Problems accessing prescriptions		7.28 %	693
By Gender			
	Male	6.52 %	113
	Female	7.46 %	575
By Age			
	17 and under	8.33 %	37
	18 to 29	10.23 %	99
	30 to 39	8.62 %	171
	40 to 49	7.93 %	203
	50 to 59	5.43 %	98
	60 to 69	4.76 %	51
	70 to 79	5.39 %	29
	80 and above	2.78 %	2
By diagnosis			
	Asthma	7.72 %	616
	COPD	4.78 %	46
	Bronchiectasis	6.06 %	22
	ILD	2.96 %	5
	Other	8.70 %	4
Have you used any of these services due to coronavirus, or concerns about its symptoms?			
Used 111 Online		19.23 %	1,830
By Gender			
	Male	17.57 %	304
	Female	19.64 %	1,513
By Age			
	17 and under	24.32 %	444
	18 to 29	23.35 %	968
	30 to 39	26.41 %	1,984
	40 to 49	21.80 %	558
	50 to 59	16.06 %	290
	60 to 69	8.68 %	93
	70 to 79	2.79 %	15
	80 and above	2.78 %	2
By diagnosis			
	Asthma	21.45 %	1,711
	COPD	6.65 %	64
	Bronchiectasis	10.19 %	37
	ILD	7.10 %	12
	Other	13.04 %	6
Used 111 Phone		8.01 %	762
By Gender			
	Male	8.02 %	139

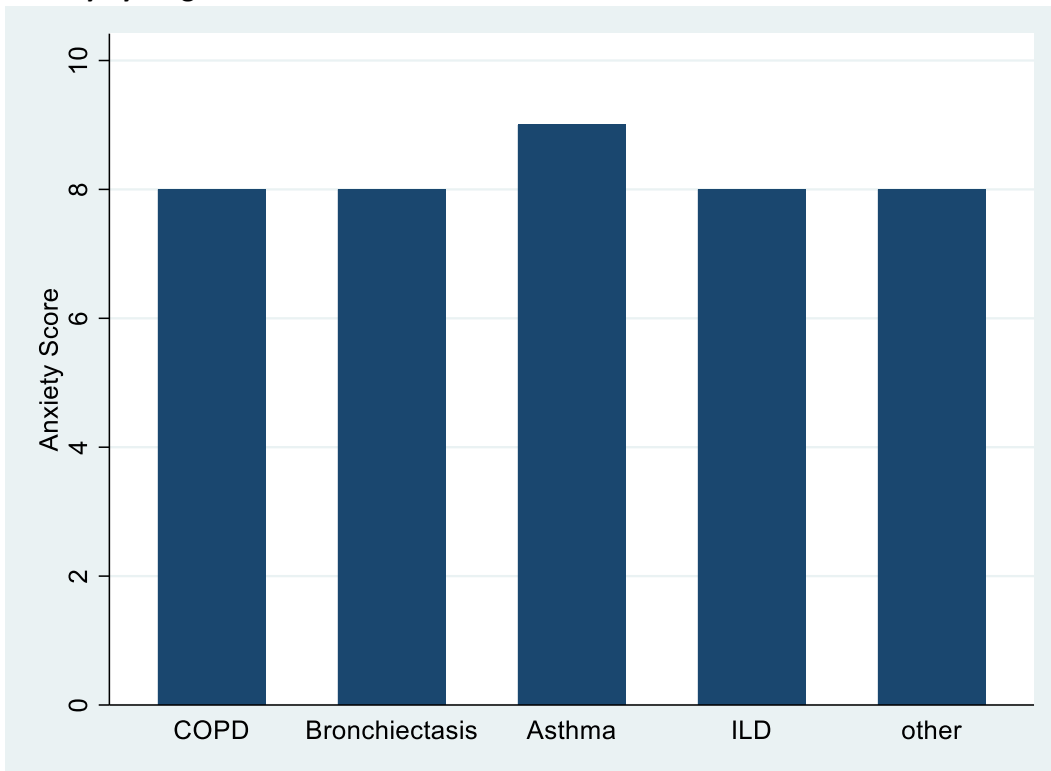
	Female	8.00 %	616
By Age			
	17 and under	9.68 %	43
	18 to 29	10.12 %	98
	30 to 39	11.19 %	222
	40 to 49	8.67 %	222
	50 to 59	6.76 %	122
	60 to 69	3.26 %	35
	70 to 79	2.79 %	15
	80 and above	0.00 %	0
By diagnosis			
	Asthma	8.80 %	702
	COPD	3.53 %	34
	Bronchiectasis	3.86 %	14
	ILD	5.33 %	9
	Other	6.52 %	3
Used A&E			
		1.11 %	106
By Gender			
	Male	1.15 %	20
	Female	1.10 %	85
By Age			
	17 and under	0.90 %	4
	18 to 29	1.14 %	11
	30 to 39	1.14 %	35
	40 to 49	1.45 %	37
	50 to 59	0.78 %	14
	60 to 69	0.28 %	3
	70 to 79	0.00 %	0
	80 and above	1.39 %	1
By diagnosis			
	Asthma	1.24 %	99
	COPD	0.42 %	4
	Bronchiectasis	0.55 %	2
	ILD	0.59 %	1
	Other	0.00 %	0
Used GP			
		25.63 %	2,439
By Gender			
	Male	23.43 %	406
	Female	26.20 %	7,703
By Age			
	17 and under	26.58 %	118
	18 to 29	29.65 %	287
	30 to 39	29.74 %	590

	40 to 49	28.83 %	738
	50 to 59	24.97 %	451
	60 to 69	16.60 %	178
	70 to 79	10.97 %	59
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	27.18 %	2,168
	COPD	14.75 %	142
	Bronchiectasis	22.31 %	81
	ILD	22.49 %	38
	Other	21.74 %	10
	Used the pharmacy	8.95 %	852
	By Gender		
	Male	10.91 %	189
	Female	8.54 %	658
	By Age		
	17 and under	11.71 %	52
	18 to 29	10.64 %	103
	30 to 39	8.87 %	174
	40 to 49	9.49 %	243
	50 to 59	8.42 %	152
	60 to 69	7.46 %	80
	70 to 79	7.06 %	38
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	9.19 %	733
	COPD	8.20 %	79
	Bronchiectasis	7.44 %	27
	ILD	6.51 %	11
	Other	4.35 %	2
	Used BLF or AUK nurse phone	7.19 %	684
	By Gender		
	Male	6.29 %	109
	Female	7.40 %	570
	By Age		
	17 and under	9.23 %	41
	18 to 29	8.06 %	78
	30 to 39	8.87 %	176
	40 to 49	8.36 %	214
	50 to 59	7.14 %	129
	60 to 69	2.89 %	31
	70 to 79	2.23 %	12
	80 and above	0	0

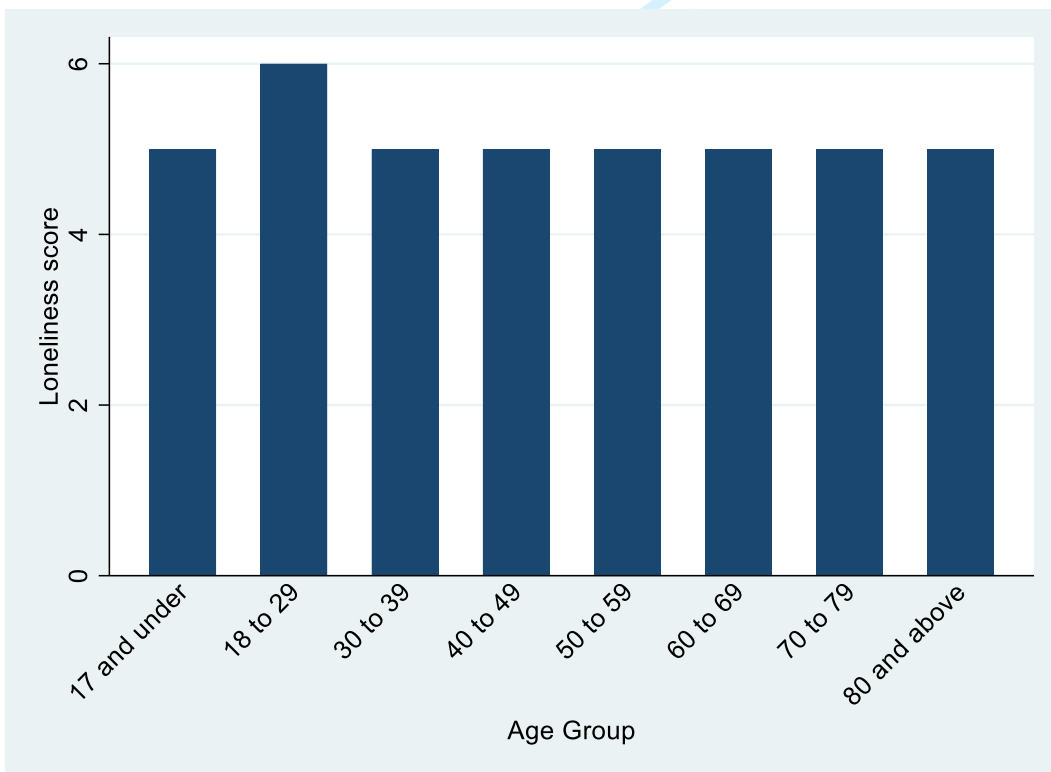
By diagnosis		
Asthma	8.13 %	648
COPD	1.56 %	15
Bronchiectasis	3.86 %	14
ILD	2.96 %	5
Other	4.35 %	2
Used none of these	55.45 %	5,278
By Gender		
Male	57.11 %	1,007
Female	54.85 %	4,225
By Age		
17 and under	48.65 %	216
18 to 29	50.52 %	489
30 to 39	47.33 %	939
40 to 49	52.19 %	1,336
50 to 59	56.92 %	1,028
60 to 69	69.50 %	745
70 to 79	78.44 %	422
80 and above	83.33 %	60
By diagnosis		
Asthma	52.69 %	4,202
COPD	73.00 %	703
Bronchiectasis	65.84 %	239
ILD	62.72 %	106
Other	60.87 %	28

Additional Graphs of Anxiety and Loneliness by Age and Diagnosis

Anxiety by Diagnosis

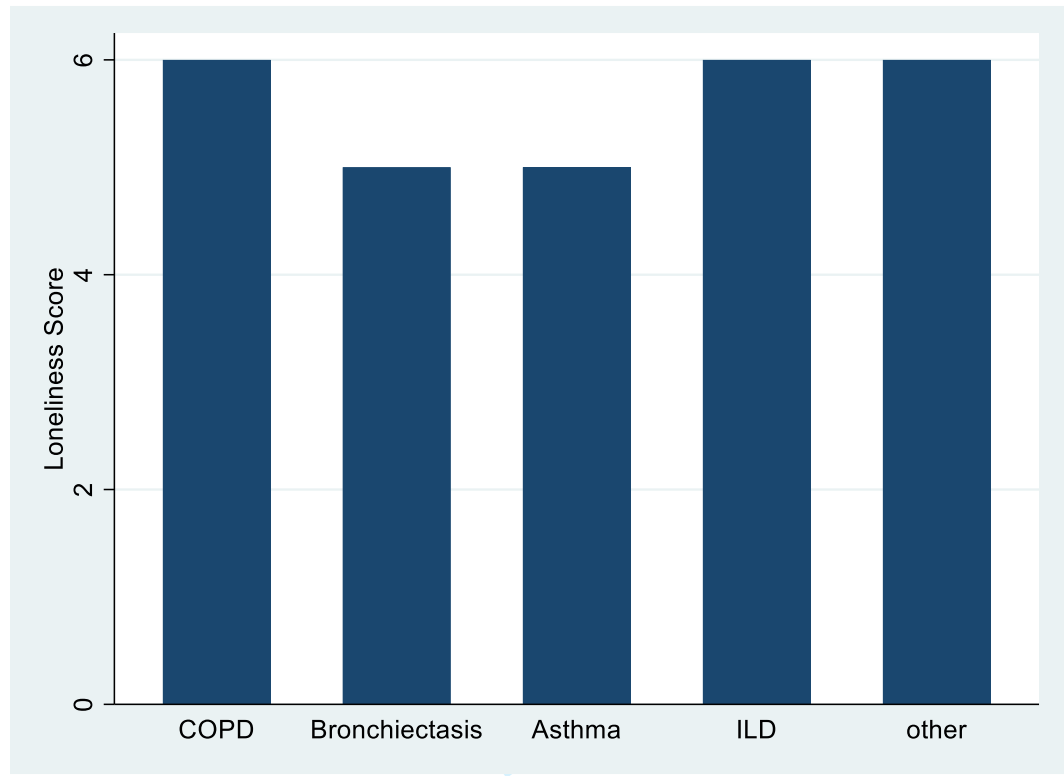


Loneliness by Age Group



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Loneliness by Diagnosis



review only

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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In your methods section, say that you used the STROBE cross sectional reporting guidelines, and cite them as:

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	Reporting Item	Page Number
Title and abstract		
Title	#1a Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction		
Background / rationale	#2 Explain the scientific background and rationale for the investigation being reported	4
Objectives	#3 State specific objectives, including any prespecified hypotheses	5
Methods		
Study design	#4 Present key elements of study design early in the paper	5
Setting	#5 Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5

1	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	5
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5		#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
6				
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10	Data sources /	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
11	measurement			
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18	Bias	#9	Describe any efforts to address potential sources of bias	10
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20				
21	Study size	#10	Explain how the study size was arrived at	6
22				
23	Quantitative	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	6-9
24	variables			
25				
26				
27	Statistical	#12a	Describe all statistical methods, including those used to control for confounding	6-9, Figure 1 and Tables
28	methods			
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31	Statistical	#12b	Describe any methods used to examine subgroups and interactions	Figure 1
32	methods			
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35	Statistical	#12c	Explain how missing data were addressed	n/a
36	methods			
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39	Statistical	#12d	If applicable, describe analytical methods taking account of sampling strategy	n/a
40	methods			
41				
42				
43	Statistical	#12e	Describe any sensitivity analyses	n/a
44	methods			
45				
46	Results			
47				
48	Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	6
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56	Participants	#13b	Give reasons for non-participation at each stage	n/a
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1	Participants	#13c	Consider use of a flow diagram	6
2				
3	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	6 and Table 1
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10	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	Tables 1, 2, E1 and E2 (online supp)
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15	Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
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21	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	6
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27	Main results	#16b	Report category boundaries when continuous variables were categorized	6
28				
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31	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
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35	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	6-9
36				
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39	Discussion			
40				
41	Key results	#18	Summarise key results with reference to study objectives	9-10
42				
43	Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	10
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49	Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	9-10
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54	Generalisability	#21	Discuss the generalisability (external validity) of the study results	9-10
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57	Other			
58	Information			
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60				

1 Funding [#22](#) Give the source of funding and the role of the funders for the 1
2 present study and, if applicable, for the original study on which the
3 present article is based
4
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6 Notes:
7

- 8 • 12a: 6-9, Figure 1 and Tables
- 9
- 10 • 14a: 6 and Table 1
- 11
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- 13 • 14b: Tables 1, 2, E1 and E2 (online supp) The STROBE checklist is distributed under the terms of the
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15 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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BMJ Open

Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive cross-sectional UK wide survey

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-040951.R2
Article Type:	Original research
Date Submitted by the Author:	25-Aug-2020
Complete List of Authors:	Philip, Keir; National Heart and Lung Institute Cumella, Andrew; Asthma UK and British Lung Foundation Partnership Farrington-Douglas, Joe; Asthma UK and British Lung Foundation Partnership Laffan, Michael; Asthma UK and British Lung Foundation Partnership Hopkinson, Nicholas; National Heart and Lung Institute; Asthma UK and British Lung Foundation Partnership
Primary Subject Heading:	Respiratory medicine
Secondary Subject Heading:	Medical management, Mental health, Patient-centred medicine
Keywords:	Public health < INFECTIOUS DISEASES, MENTAL HEALTH, RESPIRATORY MEDICINE (see Thoracic Medicine), Respiratory infections < THORACIC MEDICINE

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3 **Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive**
4 **cross-sectional UK wide survey**
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7

8 Authors: Keir EJ Philip¹, Andrew Cumella², Joe Farrington-Douglas², Michael Laffan², Nicholas S
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10 Hopkinson^{1,2},
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38 **Key Words:**
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40 COVID-19, respiratory, shielding, social distancing, long term condition, anxiety, loneliness
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43

44 **Contribution**
45

46 KEJP, AC, JFD, ML, NSH developed the survey, KEJP performed the data analysis and wrote the first
47
48 draft. All authors contributed to revisions of this first draft and approved the final version.
49
50
51

52 **Funding**
53

54 KEJP was supported by the Imperial College Clinician Investigator Scholarship, which is managed
55
56 within Imperial College London, and does not have a specific award/grant number. The funders had
57
58 no say in the design and conduct of the study; collection, management, analysis, and interpretation
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2
3 of the data; preparation, review, or approval of the manuscript; and decision to submit the
4
5 manuscript for publication.
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8 **Data availability statement** 9

10 All data relevant to the study are included in the article or uploaded as supplementary information
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14 **Conflicts of interest** 15

16
17 The authors report no conflicts of interest.
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20 **Word Count:** 2584
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3 **ABSTRACT** (262 words)
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6 **Objectives:** To assess the experience of people with long-term respiratory conditions regarding the
7
8 impact of measures to reduce risk of COVID-19.
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10
11 **Design:** Analysis of data (n=9,515) from the Asthma UK and British Lung Foundation partnership
12
13 COVID-19 survey collected online between 1st and 8th of April 2020.
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15

16 **Setting:** Community
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19 **Participants:** 9,515 people with self-reported long term respiratory conditions. 81% female, age
20
21 ranges from ≤ 17 years to 80 and above, from all nations of the UK. Long term respiratory conditions
22
23 reported included asthma (83%), Chronic Obstructive Pulmonary Disease (COPD) (10%),
24
25 bronchiectasis (4%), Interstitial Lung Disease (ILD) (2%), and 'other' (<1%) (e.g. lung cancer and
26
27 pulmonary endometriosis).
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31 **Outcome measures:** Study responses related to impacts on key elements of health care, as well as
32
33 practical, psychological and social consequences related to the COVID-19 pandemic and social
34
35 distancing measures.
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37

38 **Results:** 45% reported disruptions to care, including cancellations of appointments, investigations,
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40 pulmonary rehabilitation, treatment, and monitoring. Other practical impacts such as difficulty
41
42 accessing healthcare services for other issues, and getting basic necessities such as food, were also
43
44 common. 36% did not use online prescriptions and 54% had not accessed online inhaler technique
45
46 videos. Psycho-social impacts including anxiety, loneliness and concerns about personal health and
47
48 family were prevalent. 81% reported engaging in physical activity. Among the 11% who were smokers,
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50 48% reported they were planning to quit smoking because of COVID-19.
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54 **Conclusions:** COVID-19 and related social distancing measures are having profound impacts on people
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56 with chronic respiratory conditions. Urgent adaptation and signposting of services is required to
57
58 mitigate the negative health consequences of the COVID-19 response for this group.
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60

Strengths and limitations of this study

- This is one of the first studies in the UK to highlight the impact of COVID-19 related measures on people with long term health conditions.
- The study includes a large sample (n=9515) from broad range of respiratory conditions, age groups, and parts of the UK.
- Key gaps in healthcare provision/access are identified including online prescription and inhaler technique videos; self-management plans; smoking cessation support.
- Although a range of individuals are represented, the sample has a large percentage of people with asthma (83%) and is predominantly female (81%).
- A lack of data regarding disease severity, and further demographic information of interest such as socio-economic status, ethnicity and housing, limits the depth of interpretation possible.

INTRODUCTION

COVID-19 is a particular threat for people with long term respiratory conditions, who are at greater risk of serious disease and death if they become infected^{1,2}. Recommendations for respiratory patients include being especially careful regarding social distancing measures to reduce SARS-CoV-2 transmission. In the UK, for the most vulnerable a period of “social shielding”, avoiding face-to-face contact has been advised^{3,4}, with twin aims of protecting individuals from infection and avoiding a peak of cases in the most vulnerable which might overwhelm the health and social care system. Measures to reduce the immediate impact of COVID-19 are likely to have some adverse consequences for the population’s health and wellbeing⁵⁻⁸, leading to a so called ‘third wave’ of COVID-19 related

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3 morbidity and mortality in which detrimental health impacts for people with long-term conditions
4 result from interruptions to care provision and health seeking behaviours⁹. This is of particular concern
5 given the substantial level of unmet need related to respiratory disease¹⁰⁻¹⁵. Identification of health
6 and wellbeing impacts is required to facilitate mitigation interventions, of which examples of
7 successful approaches are being reported¹⁶.

8
9
10 Data on the experience of people with long term respiratory conditions regarding the impact of
11 COVID-19 prevention measures is currently lacking¹⁷, but will be important for understanding of the
12 impacts on these people, and to help guide current and future provision to where it is required.
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14

15 16 17 18 19 20 21 22 23 24 25 **METHODS**

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28 To assess the impact of measures to address COVID-19 on access to key elements of care^{18 19} as well
29 as the practical, psychological and emotional consequences of the current situation, we analysed data
30 from an online survey carried out by the Asthma UK (AUK) and British Lung Foundation (BLF)
31 Partnership between 1st and 8th of April 2020. The survey was developed by the authors, and other
32 colleagues at the Asthma UK and British Lung Foundation (AUK-BLF) partnership, to improve
33 understanding of the experiences of lockdown and coronavirus on people with lung conditions in the
34 UK, and to find out how AUK-BLF can best support them. The topics were based on areas raised by
35 patients and healthcare professionals as being of particularly vulnerable to disruption, and those
36 having potentially important implications for disease management. The core survey was developed
37 by both AUK and the BLF in partnership, with each adding a couple of questions specific to their patient
38 group. In the Online Supplement the questions that only feature in the AUK or BLF versions are
39 highlighted. The survey results for the core questions were then combined. Any single survey question
40 responses are highlighted as such. The survey was promoted to supporters of both Asthma UK and
41 the British Lung Foundation, and was conducted on Typeform. Initial response targets for the survey
42 were 3,000 (AUK) and 1,000 (BLF). The survey was distributed to individuals on their mailing lists,
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3 placed on the charities' websites, and advertised on social media (Facebook, Twitter, Instagram and
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5 LinkedIn). Social distancing measures were announced by the UK Government on 23rd March. The text
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7 of the survey is available in the online supplement. Furthermore, during the data collection period,
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9 Public Health England (PHE) recommendations relevant to survey respondents included 1) All
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11 members of the public were advised to stay at home, only being permitted to leave the house for a
12
13 small number of specific reasons. 2) Shielding of "people with severe respiratory conditions including
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15 all cystic fibrosis, severe asthma and severe COPD" who were advised to "stay at home at all times
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17 and avoid any face-to-face contact for a period of at least 12 weeks".
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21 The analysis presented focuses on questions relating to 1) Impacts on healthcare provision, 2) Social,
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23 psychological and practical responses, and 3) Sources of support and information. Rating scales are
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25 from zero (lowest) to ten (highest) unless otherwise specified, for questions relating to how well
26
27 prepared they felt, and levels of anxiety experienced. The 3 item UCLA Loneliness scale was used to
28
29 assess loneliness²⁰. The survey questions and response options are provided in the Online Supplement.
30
31 Data are presented using descriptive statistics. Where a between group difference was of a potentially
32
33 clinically significant magnitude, this was tested using t-test or Kruskal-Wallis tests as appropriate.
34
35 Respiratory conditions were grouped into 'Asthma' and 'Chronic respiratory disease' (non-asthma) in
36
37 table 1 so that the composition of the sample was clearer for readers. These data were collected by
38
39 AUK-BLF as part of routine information gathering and marketing activities, which often relate to
40
41 topical issues for people with respiratory conditions, in this case COVID-19. All participants consented
42
43 to their responses being used for research, analysis and publication. Anonymised data were shared
44
45 with the authors for analysis. The Charity's information governance process supported this, consistent
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47 with GDPR the General Data Protection Regulation (GDPR, the primary legislation regarding data
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49 protection and privacy in the European Union), and additional external ethical approval was not
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51 deemed necessary. Analyses were carried out using Stata V.14 (StataCorp). Data used here are not
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53 being made publicly available.
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Patient and Public Involvement

Patients and members of the public were not specifically involved in the design, conduct or reporting of this research. However, the primary focus of this research was to understand the impact of the COVID-19 risk reduction measures on people living with long-term respiratory conditions, and questions were shaped around issues being raised by patients and the public with AUK, BLF and the clinical staff involved in developing the survey.

RESULTS

11,124 people started the AUK survey, of which 7,748 completed it, while 2,518 people started the BLF survey, of which 1,856 provided completed responses. Hence, the initial survey data included 9,604 full responses. Responses were then removed from people without a lung condition (n=25); people who completed the survey twice within the sampling period (n=24 BLF, n=21 AUK) and people who completed both surveys (n=19), which left 9,515 individuals' responses for analysis. Data presented here are the combined responses to the core questions which were the same in the BLF and AUK hosted surveys. The BLF hosted version contributed 1,787 responses, while the AUK hosted survey contributed 7,728 responses. Where the sum of total answers given is less than 9,515 this is due to non-response to that specific question. The surveys took respondents an average of (AUK) 8:36(m/s) and (BLF) 11:35(m/s) to complete. The exact response rate is not possible to establish given the method by which the survey was publicised including via social media. This final sample was 81% female, with age ranges from ≤ 17 years to 80 and above, and all nations of the UK represented. Reported lung diseases were 83% asthma, 10% COPD, 4% bronchiectasis, 2% Interstitial Lung Disease (ILD), and <1% 'other' for example lung cancer and pulmonary endometriosis (Table 1). Of people who completed the AUK hosted version of the survey which asked about severity of asthma, 28.25% (2,179) reported having 'difficult' 'severe' or 'brittle' asthma. The BLF hosted version of the survey included

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3 an additional question on breathlessness, to which 32% of respondents with non-asthma diagnoses
4 reported being severely breathless (MRC dyspnoea score ≥ 4).
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10 11 **Impacts on Healthcare provision**

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14 Despite data collection occurring relatively early in the first wave of the UK pandemic, 45% reported
15 disruptions in healthcare provision, including GP and hospital appointment cancellations affecting 10%
16 and 8% of respondents respectively, with 31% reporting having appointments conducted remotely
17 (e.g. by phone) (Table 2). Respondents reported various additional ways in which healthcare provision
18 had been impacted by COVID-19 (under the freetext option 'other'), including cancelled operations,
19 investigations, respiratory nurse appointments, and medication reviews. In addition, finding it difficult
20 to get in contact with relevant care providers for advice and information. Despite being a population
21 by definition with online access, one third did not access online prescription services and over half had
22 not made use of online inhaler technique videos. Among the 11% who were smokers, 48% reported
23 they were planning to quit smoking because of COVID-19. A majority of individuals did not have a
24 written self-management plan despite the strong evidence base for this intervention^{19 21}.
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39 Reassuringly, respondents reported high levels of physical activity, with 81% being 'able to keep active
40 or do exercise at home' (Table 2). Most frequently reported activities include walks (47%), housework
41 (54%), and gardening (29%)(Table 2). In addition to the activities listed in table 2, 7% of respondents
42 reported 'other' activities including home exercise bikes, trampolining, tennis, weights, skipping,
43 home PR, Pilates, YouTube exercise videos, Zumba/dance and Wii fit.
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54 **Social and psychological responses**

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57 High levels of anxiety about COVID-19 were reported; mean(SD) anxiety level 8.03(2.07); slightly
58 higher in women than men, 8.13(1.99) vs 7.55(2.28)(t-test $p < 0.001$), and decreasing slightly with age
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3 (Figure 1, Kruskal-Wallis $p < 0.001$). Only 34% of men and 24% of women felt that they were 'coping
4 well' (t-test for between group difference $p < 0.001$). Older age groups were more likely to report
5 coping well with 47% of 70 to 79-year olds, steadily decreasing to 17% in the 18 to 29 years old group
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7 (Kruskal-Wallis $p < 0.001$). Respondent had various concerns, most commonly reported being 'concern
8 about lung condition' (64%), and concern about family (61%). Interestingly, both showing similar
9 variations related to age and gender as that seen in anxiety and 'coping well', with a higher percentage
10 of females, and younger people reporting concerns.
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19 The majority (87%) of respondents lived with another person; 51% felt they lacked companionship
20 'some of the time' or 'often', and 52% reported feeling left out of things 'some of the time' or 'often'.
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22 66% of respondents felt 'isolated from others'. Combining the scores for these three statements
23 (modified 3 item UCLA loneliness score),²⁰ 3 being the lowest score for loneliness and 9 the highest,
24 the mean loneliness rating was 5.12(1.80), with broadly similar levels in women and men 5.21(1.81)
25 vs 4.74(1.72), although the difference was statistically significant (t-test $p < 0.001$). Similarly, although
26 in this large sample the Kruskal-Wallis test showed values were not equal for age groups ($p < 0.001$)
27 and disease types ($p < 0.001$), the differences in loneliness ratings between them were relatively small
28 (Online Table E1).
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40 Of note, responses in those who reported that they were actively shielding suggested only slightly
41 higher levels of loneliness to those who were not, at 5.23 and 4.85 (t-test $p < 0.001$) respectively (Table
42 E1). 19.54% of respondents had received the government letter or text message advising them to
43 shield, of whom 98% were doing so. Mean perceived preparedness for COVID-19 was 6.41(1.7) out of
44 10. Again, although there were statistically significant differences related to gender (t-test $p < 0.001$),
45 age (Kruskal-Wallis $p < 0.001$), and diagnosis (Kruskal-Wallis $p < 0.001$) these were small in absolute
46 terms, and as such unlikely to be of importance (Online Table E2).
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Sources of support and Information

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3 Respondents reported having accessed various services to address concerns about coronavirus or its
4 symptoms. These included NHS 111 online (19%) (an interactive website for the National Health
5 Service that provides information, guidance and self-management support) which was used more
6 commonly by younger adults (23 to 25% of under 40-year olds, compared with 3 to 9% of over 60
7 years old, Kruskal-Wallis <0.001, Online Table E2) , despite the surveys being online which imply at
8 least some level of digital literacy in all respondents. GPs had been used by 26% of respondents, again
9 with a trend toward decreasing use in older (>60) age groups (Online Table E2). The NHS 111
10 telephone service (a telephone service for non-emergency health advice and guidance) had been used
11 by 8% of respondents with a similar decrease in use by older age groups. Though differences between
12 conditions are seen this is likely due to certain conditions being more represented in certain age
13 groups. For example, the same trends regarding age and NHS 111 online use were seen when asthma
14 was considered alone. Only 1% of respondents reported using A&E, with no substantial differences in
15 absolute values related to gender, age, or diagnosis. 55% of respondents reported not having used
16 'any resources due to coronavirus or concerns about its symptoms'. Reporting not having used
17 resources was more common in older than younger adults (Kruskal-Wallis <0.001, Online Table E2).
18 As might be expected, higher percentages of respondents in working age groups were concerned
19 about their financial situation due to missed work.
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42 Respondents made use of various sources for information on coronavirus, the most commonly
43 reported being television (73%), news websites (50%), and (non-BLF/AUK) social media (25%). Less
44 commonly reported sources of information on coronavirus include BLF/AUK websites (17%) and social
45 media (14%), radio (12%) and friends and family (8%) (See Online Table E2 for further responses about
46 practical preparedness for COVID-19).
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53 Respondents were particularly interested in having more information about how to manage their lung
54 condition in relation to coronavirus (65%), decisions they may need to make if they were to get ill with
55 COVID-19 (49%), and how to look after their mental health (31%).
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Practical difficulties

Multiple difficulties were experienced by respondents regarding health impacting practical issues. 22% reported difficulties accessing groceries, while 7% had difficulties accessing prescriptions (Online Table E2)

DISCUSSION

COVID-19 is having significant impacts on individuals with respiratory disease, generating high levels of anxiety and concerns about potential impacts on respondents and their families, compounded by social isolation and loneliness. In addition, many aspects of care have been cancelled or deferred, including pulmonary rehabilitation and severe asthma appointments in secondary and tertiary, care, on a background of provision that was already failing to meet the needs of many people^{10 11}, with impacts evident despite relatively recent introduction of distancing measures. Respondents were clearly making an effort to engage in physical activity despite the challenging nature of the situation.

Despite the requirement for physical distancing, social isolation and loneliness can still be avoided, or reduced, through targeted support and intervention. There is growing evidence that COVID-19 disproportionately effects more deprived groups²². Isolation strategies are also likely to impact most heavily on the most disadvantaged individuals with the least economic and social capital.

A key practical issue is that nearly half the respondents who smoke tobacco reported that they intended to quit due to COVID-19. It will be important to ensure that there is provision of appropriate accessible smoking cessation support services, to maximise their chance of success both to reduce the occurrence of smoking related disease generally²³ and to reduce individuals' risk from COVID-19 specifically²⁴. In addition, encouraging uptake of online prescriptions and directing patients to online

resources including inhaler technique videos to support self-management, as recommended in the NICE COVID-19 COPD Rapid Guideline Update (NG168)²⁵, should be prioritised.

The study sample includes representation from a wide age range, a variety of respiratory conditions, and all countries of the UK, but some limitations exist. More detail about disease severity would have been useful for interpreting responses, as this impacts government guidance regarding distancing and shielding measures. The study was online so results may not be representative for digitally excluded individuals. In addition, this study did not assess the views on the use of facemasks which has been found to be protective, to some extent, for mental health in China²⁶. This would be of interest to explore further in the UK population. Finally, the cross-sectional nature of this study does not allow for longitudinal change of the level of psychiatric comorbidity, which in patients with respiratory disorders may have a higher baseline prevalence than the general population even prior to the COVID-19 pandemic²⁷.

CONCLUSION

Measures to reduce the risk of COVID-19 are having profound impacts on people with lung disease including widespread disruption to fundamental components of healthcare services, high levels of anxiety and loneliness. There is an urgent need to adapt services to address these needs and improve signposting of individuals to existing resources, in order to mitigate negative health consequences, and provide appropriate care to this vulnerable group.

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Transparency statement

Dr Keir Philip affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

For peer review only

Table 1: Participant Characteristics

	Asthma n=7975	Chronic respiratory disease (non-asthma) n=1541
Age group		
17 and under	5.54 % (439)	0.33 % (5)
18 to 29	12.11 % (959)	0.59 % (9)
30 to 39	24.68 % (1,955)	1.90 % (29)
40 to 49	30.60 % (2,424)	8.93 % (136)
50 to 59	18.67 % (1,479)	21.47 % (327)
60 to 69	6.26 % (496)	37.82 % (576)
70 to 79	1.94 % (154)	25.21 % (384)
80 and above	0.19 % (15)	3.74 % (57)
Gender (%Female)	82.92 % (6,562)	74.67 % (1,141)
Country		
England	75.35 % (5,981)	83.33 % (1,275)
Scotland	13.03 % (1,034)	9.54 % (146)
Wales	7.19 % (571)	5.23 % (80)
Northern Ireland	4.43 % (352)	1.90 % (29)
Influenza immunisation 2019/20		
Yes	77.10 % (6,139)	89.96 % (1,380)
No	22.54 % (1,795)	9.97 % (153)
Don't know	0.35 % (28)	0.07 % (1)
Current smoking		
Non-smoker	89.41 % (7,115)	86.07 % (1,322)
Smoker	10.59 % (843)	13.93 % (214)
Of smokers -		
Intending to quit smoking due to COVID-19	49.11 % (414)	64.48 % (138)
Not intending quit smoking due to COVID-19	50.89 % (429)	35.51 % (76)
Shielding		
Actively shielding	68.66 % (5,461)	89.97 % (1,381)
Not actively shielding	31.34 % (2,493)	10.30 % (154)
Self-isolating		
Currently self-isolating	67.81 % (5,403)	88.01 % (1,350)
Not currently self-isolating	32.19 % (2,565)	11.99 % (184)
Current COVID-19 Symptoms 'Yes'	6.89 % (549)	3.07 % (47)
Current COVID-19 Symptoms 'Not sure'	3.99 % (318)	3.78 % (58)
Following self-isolation advice due to symptoms	92.81 % (800)	98.04 % (100)
Not following self-isolation advice	7.19 % (62)	1.96 % (2)
Diagnosis		

Asthma	83.81 % (7,975)
COPD	10.12 % (963)
Bronchiectasis	3.81 % (363)
ILD	1.78 % (169)
Other	0.48 % (46)

Table 2: Impact of COVID-19 related measures on chronic disease healthcare provision and self-management

Component of disease management	Percentage	Number of observations
Health service provision		
GP appointment cancelled	9.69 %	922
Hospital appointment cancelled	7.83 %	745
GP phone/remote appointment	30.93 %	2,944
Some form of cancellation or change in service delivery	44.86 %	4,270
Of those who do PR (n=553)		
Doing PR at home	24.77 %	137
PR cancelled	24.23 %	134
Have enough medications	93.41 %	8,871
Have online prescriptions	64.38 %	6,112
Have a written self-management plan for their condition	39.56 %	3,756
Have watched online inhaler videos		
Yes	44.11 %	4,190
No	53.57 %	5,089
Don't use inhalers	2.33 %	221
Physical activity		
Able to 'keep active' or do exercise at home	81.02 %	7,682
Not able to 'keep active' or do exercise at home	18.92 %	1,800
Type of activity		
Walks	47.05 %	4,478
Cycling	6.43 %	612
Run	7.17 %	682
Yoga	12.03 %	1,145
Gardening	29.06 %	2,817
Housework	54.16 %	5,155

Figure 1: legend A bar chart of median anxiety level by age group

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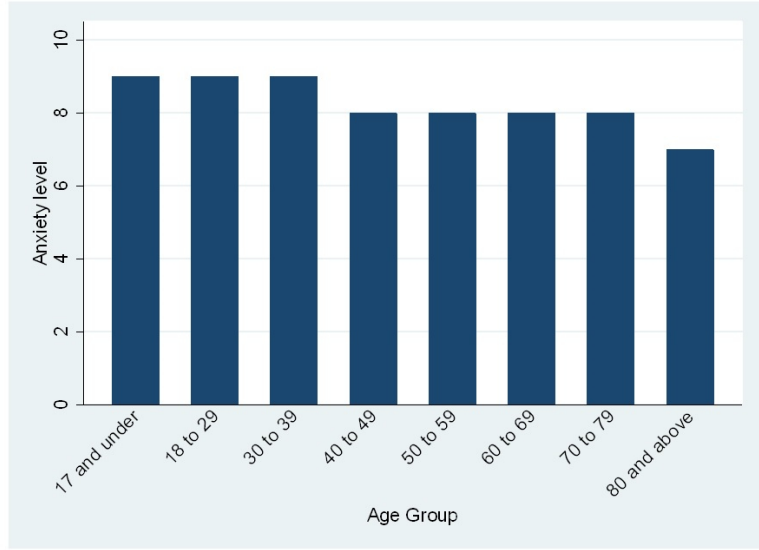
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Figure 1: A bar chart of median anxiety level by age group



We conducted the Kruskal-Wallis H test to determine if there is a statistically significant difference between anxiety levels in different age groups. This test was selected due to the marked left shift in the data. Sample sizes in each group are reported in table 2. This test demonstrated statistically significant differences between groups (chi-squared = 158.895 with 7 d.f., probability = 0.0001).

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3 **Respiratory patient experience of measures to reduce risk of COVID-19: findings from a descriptive**
4 **cross-sectional UK wide survey**
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8 **– ONLINE SUPPLEMENT**
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SURVEY QUESTIONS AND POSSIBLE RESPONSES:

What is your age? 17 and under; 18-29; 30-39; 40-49; 50-59; 60-69; 70-79; 80+ What is your gender? Male; Female; Other

What nation do you live in? England; Northern Ireland; Scotland; Wales

Have you ever been told that you have 'difficult', 'brittle' or 'severe' asthma? (AUK survey only) Yes; No; Not sure

What is your main lung diagnosis? Asthma; COPD (chronic obstructive pulmonary disease); Bronchiectasis; ILD (interstitial lung disease); I do not have a lung condition; Other

Do you receive pulmonary rehabilitation as part of your care? Yes; No.

When do you get out of breath? (MRC dyspnoea scale options) (BLF survey only)

- I'm not troubled by being out of breath, except on strenuous exercise
- I'm short of breath when hurrying on the level or walking up a slight hill
- I walk slower than most people on the level, stop after a mile or so, or stop after 15 minutes of walking at my own pace
- I stop for breath after walking about 100 yards or after a few minutes on level ground
- I'm too breathless to leave the house, or breathless when dressing and undressing

Are you currently following the government's 'shielding' advice? Yes; No.

Have you received a letter or text message advising you to shield? Yes; No; Don't know.

Did you have the flu jab this winter? Yes; No; Don't know.

Have you seen guidance or advice on coronavirus from Asthma UK or the British Lung Foundation? Yes; No.

How did you see this advice? Via email; On Twitter; On Facebook; On the AUK and/or BLF websites.

Where do you mainly get your information about coronavirus? TV; Radio; News websites; AUK / BLF websites; AUK /BLF social media; Other social media; Friends and family.

What was it about the advice you saw that wasn't helpful? It was too complicated; There was not enough detail; I didn't trust it; It was badly presented; It couldn't answer my query.

The Government? Very helpful; Helpful; Neither helpful nor unhelpful; Not helpful; Not helpful at all; I have not seen their advice.

What was it about the advice you saw that wasn't helpful? It was too complicated; There was not enough detail; I didn't trust it; It was badly presented; It couldn't answer my query

Would you like more information on any of the following during the coronavirus outbreak? Yes, No.

Are you currently suffering from any coronavirus symptoms? Yes; No; Not sure.

Are you following isolation advice? Yes; No.

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2
3 How confident are you about following advice to self-isolate or shield? Very confident; Somewhat
4 confident; Neither confident nor not confident; Not very confident; Not confident at all.
5

6 How confident are you that you will be able to access food and other provisions if you have to self-
7 isolate or shield? Very confident; Somewhat confident; Neither confident nor not confident; Not
8 very confident; Not confident at all.
9

10 Do you have enough medicines for your needs at the moment? Yes; No.

11 Are you registered to order prescriptions online from your GP? Yes; No.

12 Have you had a look at online inhaler technique videos to check that you are using your inhalers
13 properly? Yes; No; I don't use inhalers.

14 Do you have a written self-management plan for your condition? Yes; No.

15 In general, how well prepared do you feel for coronavirus? 1-10, with 10 being most prepared

16 In general, how anxious do you feel about coronavirus? 1-10, with 10 being most anxious

17 Which of the following apply to you?

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25 - I'm concerned about my lung condition
26 - I'm concerned about the health of my family members
27 - I'm coping well
28 - I'm having trouble getting groceries
29 - I'm worried about my financial situation due to missed work
30 - I can't get the prescriptions I need
31 - None of the above
32 - Other
33
34

35 Have you used any of these services due to coronavirus, or concerns about its symptoms?

- 36
37 - NHS 111 (online checker)
38 - NHS 111 (telephone advice)
39 - GP
40 - Pharmacy
41 - A&E
42 - BLF or AUK nurse phone
43 - Other
44
45

46 Has any of the following happened to you because of the way the NHS is working at the moment?

- 47
48 - I have had to have a GP appointment conducted over the phone / remotely
49 - My regular care for my lung condition at the hospital has been cancelled
50 - My regular care for my lung condition at the GP has been cancelled
51 - Pulmonary rehabilitation classes were cancelled
52 - I have had to do pulmonary rehabilitation exercises at home
53 - None of the above
54 - Other
55
56

57 Are you able to perform your job at home? Yes; No; I'm not in work.
58
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60

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2
3 How supportive have your workplace been during the coronavirus outbreak? Very supportive;
4 Supportive; Somewhat supportive; Not supportive; Not supportive at all.
5

6 Are you keeping physically active, or are able to do any exercise at home? Yes; No.
7

8 Which of the following are you doing to stay active while at home?
9

- 10 - Housework
- 11 - Gardening
- 12 - Going on walks
- 13 - Yoga
- 14 - Cycling
- 15 - Running
- 16 - Other
- 17
- 18

19 If you smoke, are you planning to try to quit smoking to protect yourself from coronavirus? Yes; No; I
20 don't smoke.
21

22 Are you actively self-isolating due to coronavirus? Yes; No.
23

24 Do you live alone? Yes; No.
25

26 How often do you feel you lack companionship? Hardly ever; Some of the time; Often.
27

28 How often do you feel left out of things? Hardly ever; Some of the time; Often.
29

30 How often do you feel isolated from others? Hardly ever; Some of the time; Often.
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Table E1: Loneliness, Isolation, Anxiety, and Concerns

	Percentage	Number of observations
Domestic Isolation		
Live alone	13.06 %	1,241
Does not live alone	86.94 %	8,260
Loneliness		
Feels lacks companionship		
Hardly ever	48.91 %	4,643
Some of the time	39.84 %	3,782
Often	11.25 %	1,068
Feels left out of things		
Hardly ever	46.73 %	4,434
Some of the time	40.84 %	3,875
Often	12.43 %	1,179
Feels isolated from others		
Hardly ever	34.34 %	3,261
Some of the time	47.21 %	4,483
Often	18.45 %	1,752
	Mean (SD)	N
Overall loneliness score (all respondents)		
	5.12 (1.80)	9,458
Loneliness by gender		
Male	4.74 (1.72)	1,728
Female	5.21 (1.81)	7,652
Loneliness by age		
17 and under	4.81 (1.68)	441
18 to 29	5.65 (1.84)	962
30 to 39	5.20 (1.82)	1,978
40 to 49	4.96(1.78)	2,550
50 to 59	5.00 (1.75)	1,794
60 to 69	5.24 (1.83)	1,064
70 to 79	5.03 (1.74)	532
80 and above	5.26 (1.79)	69
Loneliness by main diagnosis		
Asthma	5.06 (1.79)	7,936
COPD	5.56 (1.85)	957
Bronchiectasis	5.18(1.71)	357
ILD	5.54 (1.92)	163
Other	5.40 (1.84)	45
Loneliness by shielding		
Actively shielding	5.23 (1.81)	6,804
Not actively shielding	4.85 (1.74)	2,654
Anxiety		
How anxious do you feel? (1-10)	8.03 (2.07)	9,495
Anxiety by gender		

	Male	7.55 (2.28)	1,728
	Female	8.13 (1.99)	7,691
Anxiety by age			
	17 and under	8.14 (2.11)	442
	18 to 29	8.23 (1.90)	967
	30 to 39	8.24 (1.97)	1,981
	40 to 49	8.14 (1.96)	2,558
	50 to 59	8.00 (2.11)	1,803
	60 to 69	7.60 (2.27)	1,066
	70 to 79	7.32 (2.18)	536
	80 and above	7.03 (2.33)	72
Anxiety by diagnosis			
	Asthma	8.11 (2.01)	7,959
	COPD	7.57 (2.31)	960
	Bronchiectasis	7.64 (2.14)	362
	ILD	7.51 (2.24)	168
	Other	7.76 (2.23)	46
	Actively shielding	8.06 (2.08)	6,829
	Not actively shielding	7.94 (2.03)	2,666
Feels coping well		25.90 %	2,465
By Gender			
	Male	34.39 %	596
	Female	23.96 %	1,844
By Age			
	17 and under	22.97 %	102
	18 to 29	17.46 %	169
	30 to 39	19.20 %	381
	40 to 49	24.38 %	624
	50 to 59	26.74 %	483
	60 to 69	37.50 %	402
	70 to 79	47.21 %	254
	80 and above	45.83 %	33
By diagnosis			
	Asthma	24.33 %	1,940
	COPD	34.79 %	335
	Bronchiectasis	31.96 %	116
	ILD	34.91 %	59
	Other	32.61 %	15
	Bronchiectasis	8.26 %	30
	ILD	12.43 %	21
	Other	13 %	6
Concerns			
	Concerned about lung condition	64.25 %	6,115

By Gender		
Male	57.24 %	992
Female	65.88 %	5075
By Age		
17 and under	41.22 %	183
18 to 29	73.14 %	708
30 to 39	71.47 %	1,418
40 to 49	68.71 %	1,759
50 to 59	62.24 %	1,124
60 to 69	54.76 %	587
70 to 79	48.14 %	259
80 and above	50.00 %	36
By diagnosis		
Asthma	64.94 %	5,179
COPD	56.80 %	547
Bronchiectasis	67.77 %	246
ILD	66.86 %	113
Other	65.22 %	30
Concerned about family	61.50 %	5,854
By Gender		
Male	54.99 %	953
Female	63.03 %	4,855
By Age		
17 and under	60.36 %	268
18 to 29	65.91 %	638
30 to 39	66.33 %	1,316
40 to 49	64.02 %	1,639
50 to 59	60.24 %	1,088
60 to 69	53.82 %	1,072
70 to 79	47.21 %	538
80 and above	38.89 %	72
By diagnosis		
Asthma	63.32 %	5,050
COPD	51.40 %	495
Bronchiectasis	53.72 %	195
ILD	49.11 %	83
Other	67.39 %	31
Concerned about financial situation due to missed work	18.61 %	1,771
By Gender		
Male	18.58 %	322
Female	18.64 %	1,436
By Age		

17 and under	13.51 %	60
18 to 29	26.96 %	261
30 to 39	22.73 %	451
40 to 49	22.50 %	576
50 to 59	18.72 %	338
60 to 69	6.62 %	71
70 to 79	0.74 %	4
80 and above	1.39 %	1
By diagnosis		
Asthma	20.43 %	1,629
COPD	8.83 %	85
Bronchiectasis	8.26 %	30
ILD	12.43 %	21
Other	13 %	6

Table E2: Practical Preparedness

	Percentage	Number of observations
Sources of Information		
Government Letter		
Has received	19.54 %	1,855
Has not received	78.98 %	7,498
Does not know	1.49 %	141
Actively shielding of those who have received government letter	97.83 %	1,804
Main sources of COVID info		
TV	72.98 %	6,946
Radio	11.56 %	1,100
New websites	50.34 %	4,791
AUK/BLF website	17.49 %	1,665
AUK/BLF social media	14.36 %	1,367
Other social media	24.85 %	2,365
Friends and Family	8.34 %	794
Would like more information on:		
Symptoms	35.26 %	3,356
How to help their community	6.60 %	628
Financial help	14.57 %	1,387
Decisions possibly required if a person I care for gets ill	28.20 %	2,684
Decisions possibly required if I get ill	48.95 %	4,659
How to manage my lung condition during coronavirus	65.26 %	6,211
How to look after my mental health	31.14 %	2,964
How to manage being at home for so long	26.79 %	2,550
I do not need more information on coronavirus	13.05 %	1,242
Confidence		
How well prepared do you feel? (1-10)	Mean (SD)	Observations
	6.41 (1.7)	9,490
By Gender		
Male	6.63 (1.75)	1,729
Female	6.36 (1.80)	1,683
By Age		
17 and under	6.41 (1.70)	444
18 to 29	5.94 (1.71)	967
30 to 39	6.07 (1.74)	1,982
40 to 49	6.36 (1.75)	2,555
50 to 59	6.60 (1.78)	1,803
60 to 69	6.89 (1.85)	1,067
70 to 79	7.12 (1.76)	533
80 and above	6.92 (1.90)	70
By diagnosis		

	Asthma	6.36 (1.76)	7,958
	COPD	6.68 (2.00)	657
	Bronchiectasis	6.63 (1.88)	361
	ILD	6.79 (1.89)	168
	Other	6.50 (1.80)	46
	Confidence following government advice (1-10)	4.17 (0.85)	9,480
	By Gender		
	Male	4.15 (0.86)	1,727
	Female	4.17(0.86)	7,675
	By Age		
	17 and under	4.27 (0.75)	440
	18 to 29	4.06 (0.84)	965
	30 to 39	4.05 (0.92)	1,975
	40 to 49	4.12 (0.87)	2,552
	50 to 59	4.19 (0.85)	1,802
	60 to 69	4.36 (0.79)	1,068
	70 to 79	4.47 (0.67)	537
	80 and above	4.30 (0.80)	71
	By diagnosis		
	Asthma	4.14 (0.87)	7,944
	COPD	4.34 (0.81)	959
	Bronchiectasis	4.31 (0.78)	362
	ILD	4.42 (0.72)	169
	Other	4.26 (0.80)	46
	Problems accessing groceries	21.95 %	2,089
	By Gender		
	Male	18.29 %	317
	Female	22.74 %	1,752
	By Age		
	17 and under	18.47 %	82
	18 to 29	23.35 %	226
	30 to 39	24.80 %	492
	40 to 49	22.30 %	571
	50 to 59	19.16 %	346
	60 to 69	22.39 %	240
	70 to 79	18.22 %	98
	80 and above	19.44 %	14
	By diagnosis		
	Asthma	21.23 %	1,693
	COPD	22.53 %	217
	Bronchiectasis	30.58 %	111
	ILD	31.36 %	53
	Other	32.61 %	15

Problems accessing prescriptions		7.28 %	693
By Gender			
	Male	6.52 %	113
	Female	7.46 %	575
By Age			
	17 and under	8.33 %	37
	18 to 29	10.23 %	99
	30 to 39	8.62 %	171
	40 to 49	7.93 %	203
	50 to 59	5.43 %	98
	60 to 69	4.76 %	51
	70 to 79	5.39 %	29
	80 and above	2.78 %	2
By diagnosis			
	Asthma	7.72 %	616
	COPD	4.78 %	46
	Bronchiectasis	6.06 %	22
	ILD	2.96 %	5
	Other	8.70 %	4
Have you used any of these services due to coronavirus, or concerns about its symptoms?			
Used 111 Online		19.23 %	1,830
By Gender			
	Male	17.57 %	304
	Female	19.64 %	1,513
By Age			
	17 and under	24.32 %	444
	18 to 29	23.35 %	968
	30 to 39	26.41 %	1,984
	40 to 49	21.80 %	558
	50 to 59	16.06 %	290
	60 to 69	8.68 %	93
	70 to 79	2.79 %	15
	80 and above	2.78 %	2
By diagnosis			
	Asthma	21.45 %	1,711
	COPD	6.65 %	64
	Bronchiectasis	10.19 %	37
	ILD	7.10 %	12
	Other	13.04 %	6
Used 111 Phone		8.01 %	762
By Gender			
	Male	8.02 %	139

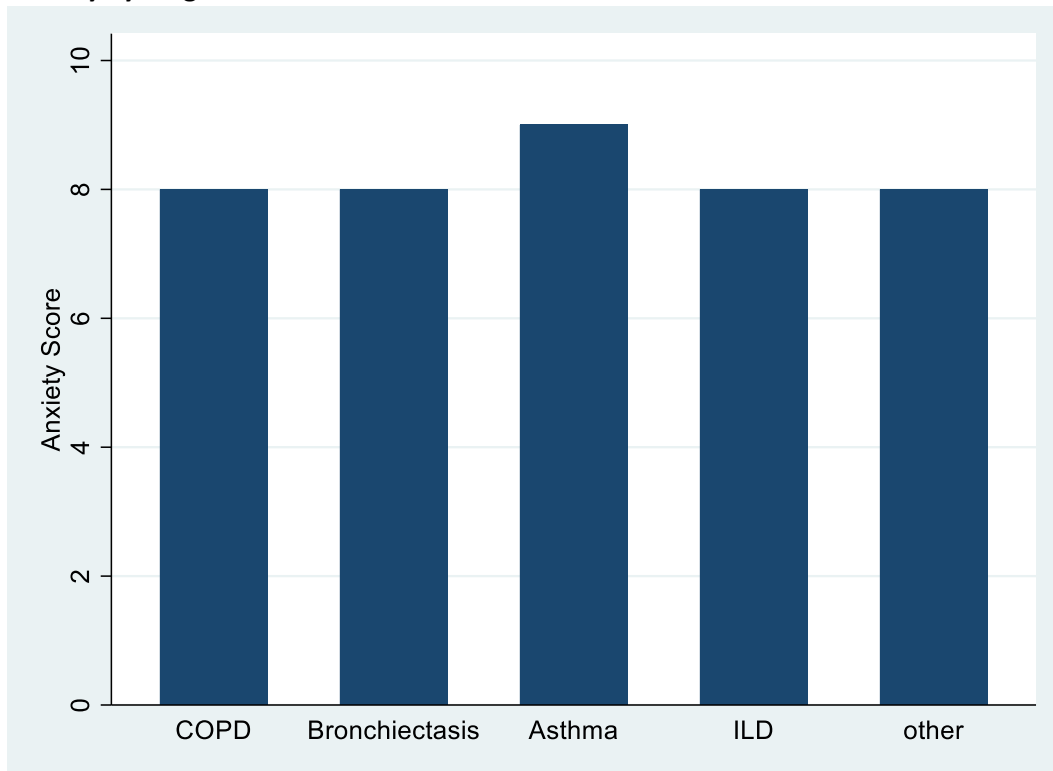
	Female	8.00 %	616
By Age			
	17 and under	9.68 %	43
	18 to 29	10.12 %	98
	30 to 39	11.19 %	222
	40 to 49	8.67 %	222
	50 to 59	6.76 %	122
	60 to 69	3.26 %	35
	70 to 79	2.79 %	15
	80 and above	0.00 %	0
By diagnosis			
	Asthma	8.80 %	702
	COPD	3.53 %	34
	Bronchiectasis	3.86 %	14
	ILD	5.33 %	9
	Other	6.52 %	3
Used A&E			
		1.11 %	106
By Gender			
	Male	1.15 %	20
	Female	1.10 %	85
By Age			
	17 and under	0.90 %	4
	18 to 29	1.14 %	11
	30 to 39	1.14 %	35
	40 to 49	1.45 %	37
	50 to 59	0.78 %	14
	60 to 69	0.28 %	3
	70 to 79	0.00 %	0
	80 and above	1.39 %	1
By diagnosis			
	Asthma	1.24 %	99
	COPD	0.42 %	4
	Bronchiectasis	0.55 %	2
	ILD	0.59 %	1
	Other	0.00 %	0
Used GP			
		25.63 %	2,439
By Gender			
	Male	23.43 %	406
	Female	26.20 %	7,703
By Age			
	17 and under	26.58 %	118
	18 to 29	29.65 %	287
	30 to 39	29.74 %	590

	40 to 49	28.83 %	738
	50 to 59	24.97 %	451
	60 to 69	16.60 %	178
	70 to 79	10.97 %	59
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	27.18 %	2,168
	COPD	14.75 %	142
	Bronchiectasis	22.31 %	81
	ILD	22.49 %	38
	Other	21.74 %	10
	Used the pharmacy	8.95 %	852
	By Gender		
	Male	10.91 %	189
	Female	8.54 %	658
	By Age		
	17 and under	11.71 %	52
	18 to 29	10.64 %	103
	30 to 39	8.87 %	174
	40 to 49	9.49 %	243
	50 to 59	8.42 %	152
	60 to 69	7.46 %	80
	70 to 79	7.06 %	38
	80 and above	6.94 %	5
	By diagnosis		
	Asthma	9.19 %	733
	COPD	8.20 %	79
	Bronchiectasis	7.44 %	27
	ILD	6.51 %	11
	Other	4.35 %	2
	Used BLF or AUK nurse phone	7.19 %	684
	By Gender		
	Male	6.29 %	109
	Female	7.40 %	570
	By Age		
	17 and under	9.23 %	41
	18 to 29	8.06 %	78
	30 to 39	8.87 %	176
	40 to 49	8.36 %	214
	50 to 59	7.14 %	129
	60 to 69	2.89 %	31
	70 to 79	2.23 %	12
	80 and above	0	0

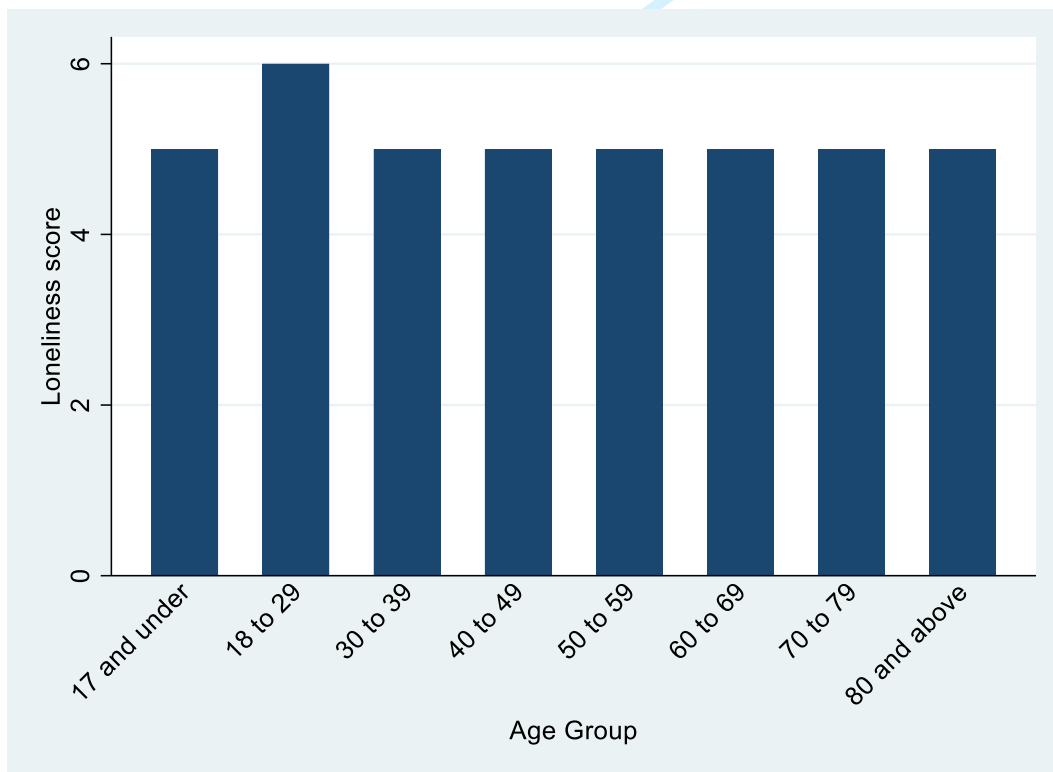
By diagnosis		
Asthma	8.13 %	648
COPD	1.56 %	15
Bronchiectasis	3.86 %	14
ILD	2.96 %	5
Other	4.35 %	2
Used none of these	55.45 %	5,278
By Gender		
Male	57.11 %	1,007
Female	54.85 %	4,225
By Age		
17 and under	48.65 %	216
18 to 29	50.52 %	489
30 to 39	47.33 %	939
40 to 49	52.19 %	1,336
50 to 59	56.92 %	1,028
60 to 69	69.50 %	745
70 to 79	78.44 %	422
80 and above	83.33 %	60
By diagnosis		
Asthma	52.69 %	4,202
COPD	73.00 %	703
Bronchiectasis	65.84 %	239
ILD	62.72 %	106
Other	60.87 %	28

Additional Graphs of Anxiety and Loneliness by Age and Diagnosis

Anxiety by Diagnosis

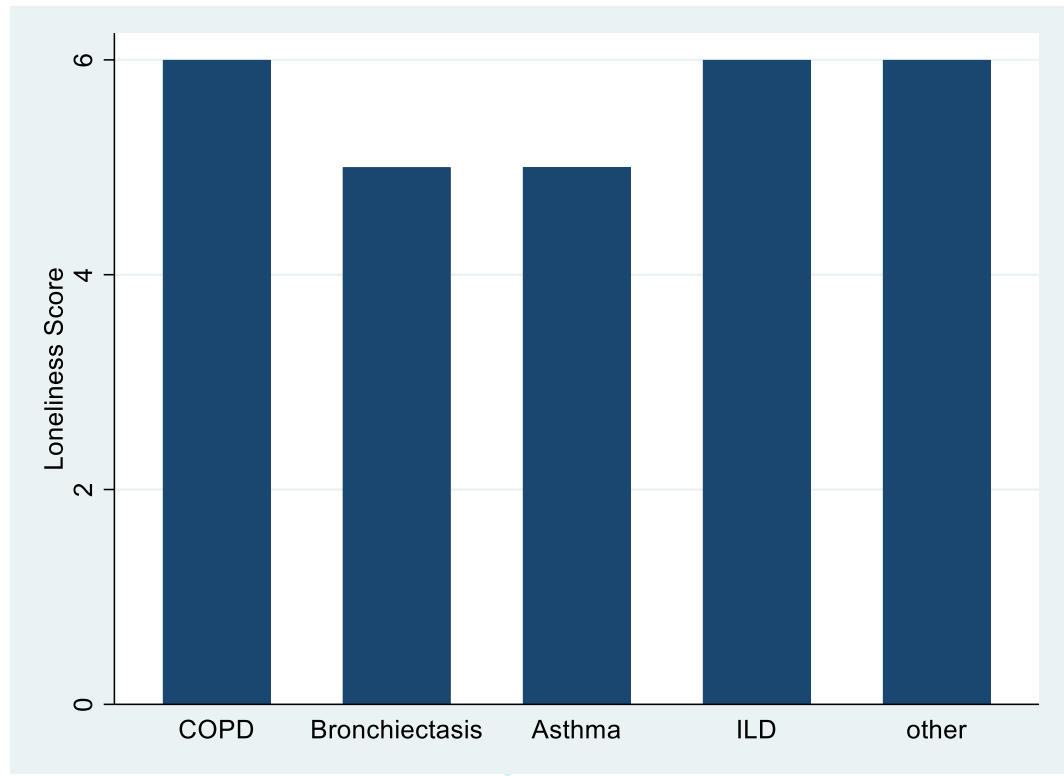


Loneliness by Age Group



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Loneliness by Diagnosis



review only

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectional reporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

	Reporting Item	Page Number
Title and abstract		
Title	#1a Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction		
Background / rationale	#2 Explain the scientific background and rationale for the investigation being reported	4
Objectives	#3 State specific objectives, including any prespecified hypotheses	5
Methods		
Study design	#4 Present key elements of study design early in the paper	5
Setting	#5 Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5

1	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	5
2				
3				
4				
5		#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
6				
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9				
10	Data sources /	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
11	measurement			
12				
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18	Bias	#9	Describe any efforts to address potential sources of bias	10
19				
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21	Study size	#10	Explain how the study size was arrived at	6
22				
23	Quantitative	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	6-9
24	variables			
25				
26				
27	Statistical	#12a	Describe all statistical methods, including those used to control for confounding	6-9, Figure 1 and Tables
28	methods			
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31	Statistical	#12b	Describe any methods used to examine subgroups and interactions	Figure 1
32	methods			
33				
34				
35	Statistical	#12c	Explain how missing data were addressed	n/a
36	methods			
37				
38	Statistical	#12d	If applicable, describe analytical methods taking account of sampling strategy	n/a
39	methods			
40				
41				
42	Statistical	#12e	Describe any sensitivity analyses	n/a
43	methods			
44				
45				
46	Results			
47				
48	Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	6
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56	Participants	#13b	Give reasons for non-participation at each stage	n/a
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1	Participants	#13c	Consider use of a flow diagram	6
2				
3	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	6 and Table 1
4				
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10	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	Tables 1, 2, E1 and E2 (online supp)
11				
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15	Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
16				
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21	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	6
22				
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27	Main results	#16b	Report category boundaries when continuous variables were categorized	6
28				
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31	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
32				
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35	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	6-9
36				
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39	Discussion			
40				
41	Key results	#18	Summarise key results with reference to study objectives	9-10
42				
43	Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	10
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49	Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	9-10
50				
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54	Generalisability	#21	Discuss the generalisability (external validity) of the study results	9-10
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57	Other			
58	Information			
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60				

1 Funding [#22](#) Give the source of funding and the role of the funders for the 1
2 present study and, if applicable, for the original study on which the
3 present article is based
4
5

6 Notes:
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- 8 • 12a: 6-9, Figure 1 and Tables
- 9 • 14a: 6 and Table 1
- 10 • 14b: Tables 1, 2, E1 and E2 (online supp) The STROBE checklist is distributed under the terms of the
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