

1 **COPD in Heroin smokers: A patient perspective**

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3 Nightingale R<sup>1</sup>, Griffiths, P<sup>2</sup>, Mortimer K<sup>1</sup>, Walker PP<sup>3</sup>, Byrne T<sup>4</sup>, Marwood K<sup>4</sup>, Morrison-Griffiths S<sup>4</sup>,  
4 Renwick S<sup>5</sup>, Rylance J\*<sup>1, 6</sup>, Burhan H\*<sup>2</sup>

5 \* Rylance J and Burhan H are joint last name authors

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7 Corresponding author Mrs Rebecca Nightingale (Rebecca.Nightingale@lstm.ac.uk)

8 *1 Liverpool School of Tropical Medicine, Liverpool, UK*

9 *2 Royal Liverpool and Broadgreen University Hospitals, Liverpool, UK*

10 *3 University Hospital Aintree, Liverpool, UK*

11 *4 Addaction, Liverpool, UK*

12 *5 Liverpool Clinical Commissioning Group, Liverpool, UK*

13 *6 Malawi-Liverpool-Wellcome Trust Clinical Research Programme, Blantyre, Malawi.*

14 **Author contributions**

15 Design: RN,PG,KM, TB, SMG, SR, JR,PW, HB

16 Acquisition of data: RN, PG, KM, TB, SMG, HB

17 Analysis of data: RN, PG, JR

18 Interpretation of data: RN, PG, PW, JR, HB

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## 1 Abstract

## 2 Background

3 Smoking rather than injecting heroin has become more common over the last twenty years.  
4 Although there is an increasing body of evidence describing high levels of COPD in heroin smokers,  
5 there is limited evidence documenting the impact this has on this population group.

## 6 Aim

7 We aimed to describe the experiences of heroin smokers with COPD in Liverpool, UK

## 8 Design and Setting

9 Participants were purposefully sampled for this qualitative study. Participants included were adults  
10 enrolled in an opioid replacement clinic run by Addaction in Liverpool, UK and whom had already  
11 engaged with spirometry testing for COPD as part of a previous study.

## 12 Methods

13 We performed semi-structured interviews with participants with spirometrically-confirmed COPD in  
14 opioid replacement clinics in Liverpool, UK. Data were analysed using a framework analysis  
15 approach.

## 16 Results

17 We invited 16 potential participants of whom 10 agreed to take part and were interviewed. Three  
18 themes common to all interviews were identified: functional measures of lung health that impacted  
19 on their activities of daily living, inhaler and medication perceptions with erratic use that was not  
20 concordant with their prescription, and the impact of difficulties accessing care.

## 21 Conclusion

22 These findings, along with previous studies highlighting the prevalence of COPD in this population,  
23 warrant efforts to integrate community COPD and opioid replacement services to improve outcomes  
24 for this vulnerable population.

## 25 “How this fits in”

26 There is a growing body of evidence of high levels of COPD in the heroin smoking population. This  
27 appears to happen at an earlier age than the general population. This qualitative study investigates  
28 the experiences of these patients and provides clinicians a new insight into the challenges facing this  
29 population. These results can be used to help guide the planning of future primary care service for  
30 this group of patients.

## 1 Introduction

2 Over the last two decades, heroin users have increasingly smoked rather than injected the drug,  
3 understanding this to be a method of harm reduction [1, 2]. This has, however, led many heroin  
4 smokers to develop chronic obstructive pulmonary disease (COPD) at an earlier age than typically  
5 seen in exclusive tobacco smokers [3, 4]. A recent study in Liverpool, UK, demonstrated that  
6 approximately 50% of heroin smokers have COPD or its overlap syndrome with asthma [3]. Those  
7 with COPD reported extensive respiratory symptoms - shortness of breath, cough and wheeze [5-7] -  
8 which are likely to lead to increased hospital admissions [8-10]. Screening heroin users for COPD  
9 may be an important part of providing care early in the course of the disease and limiting the burden  
10 of acute hospital care [4, 11].

11 There is limited evidence regarding patient experience among heroin users. We therefore sought  
12 insight into the experience and challenges faced by heroin smokers with COPD in order to shape  
13 future screening and treatment services. This qualitative study examines the lived experience of  
14 those with symptoms and a diagnosis of chronic lung disease, and of their experience of interfacing  
15 with healthcare services to access treatment.

16

## 1 Methods

2 We conducted semi-structured interviews with heroin smokers diagnosed with COPD as part of a  
3 screening programme between December 2017 and April 2018.

### 4 Study context

5 The interviews were carried out in Addaction community opioid replacement clinics as part of a  
6 COPD screening programme. Addaction is a large independent charity commissioned by the local city  
7 council public health department. The screening programme has been previously reported[3, 12].  
8 Between December 2015 and June 2016, participants had been evaluated using respiratory-  
9 symptom-specific questionnaires, and spirometry to test their lung function. Follow-up screening  
10 took place between December 2017 and April 2018[3, 12].

### 11 Recruitment

12 Within Addaction clinics for opioid replacement therapy, we asked key workers to identify potential  
13 participants for the qualitative study. All had been diagnosed with COPD during baseline screening  
14 and were current or previous smokers of heroin. Potential participants were given study information  
15 prior to their appointment, and if they agreed to being interviewed, a key worker who knew them  
16 notified the study team. The key worker was not present during the interviews, but was available for  
17 support as necessary. Written informed consent was obtained from all participants.

### 18 Data collection

19 Interviews were led by a researcher (PG) independent of the quantitative screening study with  
20 experience of qualitative research and extensive medical knowledge of COPD. The researcher was  
21 aware the participant had COPD but knew no further clinical details. The interviews took place  
22 within the two large Addaction clinic sites in Liverpool, in rooms separate from the clinics to remove  
23 the participants from the clinical environment, and with refreshments provided. The researcher  
24 followed the topic guide which included: reported symptoms or problems, understanding of COPD,  
25 understanding of medications and experience of access to care. Open questions were asked with pre  
26 prepared probing questions to gain further information (Supplement one).

27 All interviews were digitally recorded and identified by participant number only.

### 28 Analysis

29 We used a framework analysis approach, taking five steps to results: familiarisation, coding,  
30 developing and applying a framework, charting and interpretation [13]. Each interview was  
31 transcribed verbatim, and the transcripts were read through by two researchers (RN and PG) for

1 familiarisation. Following this, RN and PG agreed on the major coded themes based on the topic  
2 guide. The data were coded separately in Microsoft Excel, with the transcripts coloured coded for  
3 each theme in Microsoft Word. These codes were then shared with the wider research team (RN,  
4 PG, JR, HB) and a thematic framework was developed through discussion until a consensus was  
5 reached on the mapping of the codes. The themes were shared with Addaction staff members who  
6 were part of the research team to ensure they were accurate to the setting and true to the original  
7 topic guides (TB and KM).

## 8 Ethics

9 Ethical approval was gained from Health Research Authority (HRA) via the integrated Research  
10 Application System (IRAS) number: 235151.

11

## 1 Results

2 We invited 16 potential participants of whom 10 agreed to take part and were interviewed. The age  
3 range of those interviewed was 47-59 years, with eight males and two females taking part, all were  
4 Caucasian. The participants had a range of COPD severity measure by the GOLD classifications (mild  
5 n=4, moderate n=3, severe n=3)[14]. All were taking opioid replacement therapy with seven  
6 reporting they still smoke heroin. Following the interview framework, three themes common to all  
7 interviews were identified: functional measures of lung health that impacted on their activities of  
8 daily living, inhaler and medication perceptions with erratic use that was not concordant with their  
9 prescription, and the impact of difficulties accessing care.

### 10 Functional measures of lung health

11 All participants described their COPD in relation to the degree of functional limitation imposed by  
12 their symptoms. None of the participants described their COPD or lung disease in terms of medical  
13 outcomes such as spirometry results or breathlessness scores. Every participant had concerns about  
14 how COPD was affecting their everyday activities of daily life:

15 *“You know every day I get up in the morning, I go to make a cup of coffee and I come back in and sit  
16 down and I’m gasping for breath and I can’t catch my breath, I just can’t get it, you know what I  
17 mean?”* (Interview 5)

18 *“I mean I often don’t go out, I struggle carrying shopping, I use one of them now, a bag over your  
19 shoulder, with the string, they help me to walk, a lot better. One time, I was putting the bags down,  
20 walk a bit, get my breath, again and again, oh God it was horrendous.”* (Interview 10)

21 Participants described how their functional capacity had deteriorated over time. Eight participants  
22 recognised a worsening over a period of months or years. COPD was not explicitly mentioned in  
23 these cases, rather the participants described problems with their “lungs” or “chest” but did not  
24 necessarily attribute their problems to or label their condition as COPD:

25 *“I was just speedy me. I was just one of them people, but now, now I just can’t even, even when my  
26 son was 7, I mean he’s 15 now, I was still doing the garden but I couldn’t breathe. I’ve stopped trying  
27 to do the garden I mean coz that nearly killed me, I mean it, bad palpitations, I think it would have  
28 killed me that day, my neighbour came out and said ‘go in, get in now!’ and stayed with me and  
29 everything.”* (Interview 9)

30 *“I can’t any more, I was quite active say 10 years ago, but now I can’t run, can go slow on a bike but  
31 that’s it, couldn’t run if I wanted to...yeah, just from walking, or as I’ve said just getting out of bed, I*

1 *can walk to the landing to look out the window and be standing panting, thinking 'where's the*  
2 *inhalers' and it's only when I have the inhalers that it seems to calm me down a bit."* (Interview 3)

3 Two participants did not perceive their chest to be a significant problem; both described functional  
4 limitation, but reported it as normal for them:

5 *"I did run for the bus the other day and feel a bit out of breath, but most people would wouldn't*  
6 *they? Running for the bus and exerting themselves, you know, at 8 o'clock in the morning.... I've got*  
7 *to be very fit and active every single day... So my chest isn't too bad considering what I've put into it*  
8 *over the years, at least from my perspective it's not."* (Interview 2)

9 *"No...no it doesn't stop me, and the inhalers I don't use them every day, only when I need to, only*  
10 *when I'm coughing and short of breath I'll use them then.....yeah but only when I'm coughing,*  
11 *sometimes I cough and I'm nearly puking... maybe 2 or 3 times a week."* (Interview 4)

## 12 Inhalers and Medication perceptions

13 All participants reported taking at least one inhaler and talked about them consistently during the  
14 interviews. Of the ten participants interviewed, seven reported that they had recently borrowed  
15 other people's inhalers or medication to help their chest. The reasons for this were not always  
16 identifiable, but access to medication was a frequent difficulty:

17 *"well the last one I needed I got off me cousin coz she had a spare"* (Interview 4)

18 *"My girlfriend has one of those nebuliser things so I just throw myself on that, and erm, that kind of*  
19 *makes me feel ok."* (Interview 6)

20 *"If there's antibiotics in the house then I'll use them instead [of going to a Doctor]....it's like, I've been*  
21 *around drugs most of my life, so I'm not afraid to try an antibiotic or something if I think it might help*  
22 *me... well the wife has got asthma there, so err she got inhalers, a brown one and a blue one, and I'll*  
23 *use them every now and again....They've told me COPD is different to asthma so instead of using the*  
24 *wife's stuff, I might need something else, a different one for my condition might be better."*  
25 (Interview 7)

26  
27 Participants also reported the use of metered dose inhalers (MDI) as drug pipes, either by  
28 themselves or others:

29 *"We used to make bongs out them, the blue one [salbutamol MDI], years ago, but God I couldn't*  
30 *even look at doing that now it knocks me sick."* (Interview 9)

31 *"You just take the tube out and put a bit of foil on the bottom part, put holes in that, and use the*  
32 *mouth piece part...Yeah yeah the blue ones, the hollow tube, the mouth piece is where the cannister*  
33 *goes in to it. Just bang a bit of foil on the top and some in it, I've seen a lot of people use them like*

1 *that, like 'rock pipes' we called them...So it's a common thing to do...It sounds mad that people are*  
2 *using things meant to help you breathe for that stuff doesn't it?" (Interview 4)*

3 There was generally poor knowledge and understanding surrounding inhalers, with participants  
4 confused between the name of the inhaler and the colour, for example describing a "blue inhaler"  
5 but pointing to a purple (Seretide) inhaler (Interview one). In general, participants described high  
6 usage of the "blue inhaler" (salbutamol) and inconsistent use of long acting medication such as  
7 tiotropium or formoterol. Participants reported that they used inhalers as and when they need  
8 them, and there appeared to be a lack of understanding of using longer term inhalers as prevention  
9 for some of the functional problems they described:

10 *"I use the inhalers carefully, don't waste them you know, use them as and when I feel I really need*  
11 *them, I don't use them for the fun of it, I'll only use them when I feel as though I'm struggling."*  
12 (Interview 8)

13 *"Talking about the "blue and pink"? Nah I don't use any of them regularly, only when I get bouts of*  
14 *it." (Interview 4)*

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## 16 [Impact of access to care](#)

17 The difficulty in accessing both primary care appointments and hospital appointments was a  
18 recurring theme. The participants described travel to and from appointments as a barrier to  
19 attending both the GP surgery and the hospital. In some circumstances the cost of travel was  
20 prohibitive and in others it was the practicalities of getting out of the house while being unwell. The  
21 participants suggested that they may attend more often if access to care was easier:

22 *"well it's 2 buses away, and it kills me to get there, but I love that doctor so I make the effort if I need*  
23 *to." (Interview 1)*

24

25 *"It can be a bit of a task though, with the breathing and that, sometimes I only have to walk around*  
26 *the corner and I'm having a bad time... yeah well I have to walk here as well so that can be hard in*  
27 *itself, stop and rest about 20 times... you'd see me sat down on the road and all that, you know what*  
28 *I mean?" (Interview 6)*

29

30 *"I just can't get there, even if I phone a taxi to come and take me, I just can't get up and down the*  
31 *stairs." (Interview 8)*

32

33 The experience that participants had of their GPs and hospital doctors varied throughout the  
34 interviews, with participants describing their GP as "marvellous" (interview 1) and "I can't fault him"  
35 (interview 10). All participants reported that seeing their own GP was difficult, either they saw a  
36 locum which they reported as a negative experience, or that getting an appointment via reception  
37 was difficult:

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*“well it’s hard to get an appointment at the doctors, to get my script, and God did I feel it when I ran out, really bad” (Interview 1)*

*“you know the credit on your phone to ring up, and you know when they say to ring at 8 o’clock in the morning, well try using somebody else’s phone, like I’ve had to use before, at 8 in the morning. That’s no good to me.” (Interview 10)*

*“maybe receptionists, when you phone up you’ve got to phone at certain times, waiting to get through to the receptionists, you see it’s like you wait for the phones to turn over at 8:20am and you might not get through ‘til 0920am and they’ve all gone, so, that’s not good....like I could have a problem like today, and I’ll go in or ring up and they’ll say ‘yeah we can fit you in in 2 weeks’ time’, well hang on, you know?” (Interview 8)*

The participants generally reported that they did not attend hospital appointments. There were a variety of reasons for this including the feeling of stigma or that because chest problems were self-inflicted. Several participants avoided secondary care environments due to negative associations with for example, a dying relative, or a negative experience with the hospital staff:

*“I think they’re rushed off their feet, so you know, I think there’s sicker people than me to be seen to.... coz mine are self-inflicted, like they see sick children and it just shows you that I’ve done this to myself, you know?... because it’s self-inflicted isn’t it? I just feel embarrassed wasting the national health money...” (Interview 1)*

*“well they can’t do nothing can they, the doctors can’t do nothing for my chest the way it is, I have inhalers, I asked them about nebulisers, they said I don’t need a nebuliser, so, but I think I do like...I don’t know, I feel like they just look at you and think ‘ah its self-inflicted’ and that...” (Interview 5)*

[when admitted with chest problem] *“I’m on certain medication that they just won’t give you, like the methadone, they just won’t give you that, so I’ve got to lie there, like if I go in on a Friday I’ve got to lie there until Monday, with no nothin’. So you’re in bits by Monday, they sort your dose out, I know people might try and cheat the system, but you know, it goes on, I’m not going to abuse it and as doctors and nurses you’ve got to think ‘is this man on this?’. For one time in the hospital I was on 360ml a day, so when the doctors read that they thought ‘F\*ck off no way’, you’d say as well. I mean I’m not on that now. They say to you get a stat dose of 20ml, but what that’s gonna do for me when I’m on 360? It doesn’t help. It’s experiences like that, the last thing I’d want to do is ring an ambulance if I can help it.” (Interview 8)*

## 1 Discussion

### 2 Summary

3 Using qualitative interviews we have shown the key challenges to this cohort are lung health  
4 symptoms that impacted on their activities of daily living, inhaler and medication perceptions with  
5 erratic use that was not concordant with their prescription, and the impacts of difficulties accessing  
6 care. These themes occurred throughout the interviews and could help inform and develop  
7 respiratory services in this group of patients.

### 8 Comparison with exciting literature

9 The participants' main focus was the functional limitation that they experienced in their activities of  
10 daily living as a result of their COPD. No participant discussed the details of their medical diagnosis,  
11 the staging of their COPD or used medical scoring such as MRC and CAT to describe their COPD. To  
12 the best of our knowledge there are no studies that specifically describe the impact and functional  
13 limitations of COPD in heroin smokers, however the themes identified in this study are similar to  
14 studies of tobacco smokers. In a large pan-European study examining COPD patients and their  
15 experience of acute exacerbations, there was wide variability in reported symptoms between  
16 patients (reported at 62.7%), high levels of self-medication, and poor understanding of their  
17 condition [14]. The impact of COPD-related symptoms on activities of daily living has been evaluated  
18 previously, with there being a high prevalence of impaired functioning amongst COPD patients  
19 across a wide range of domains. The impairment does not clearly correlate with standard clinical  
20 measures such as degree of airflow obstruction or level of dyspnoea [15, 16]. Furthermore,  
21 functional limitation was common amongst the participants in our study and was often deemed to  
22 be 'normal' by individuals. Relying on objective measures of COPD severity in this patient population  
23 may not identify individuals who would benefit from more targeted interventions, such as  
24 pulmonary rehabilitation, aiming to improve symptoms and level of functioning with regards to  
25 activities of daily living.

26 In general, our participants appeared to be taking COPD medication in an irregular and often self-  
27 directed manner. In some, inhalers were used as a vehicle for smoking drugs rather than for their  
28 intended purpose. The engagement with the primary care system in the UK was mixed, with some  
29 participants having an excellent experience of their GP, whilst others found significant barriers to  
30 attending primary care with travel and access to the GP being the principle negative factors.  
31 Participants universally found accessing hospital treatment difficult, with stigma and a feeling of  
32 having a "self-inflicted" illness limiting attendance at the hospital.

1 Poor adherence and a lack of knowledge or trust in medication has been reported in other studies of  
2 COPD patients with overuse, underuse and alteration from medication schedule commonplace [17].  
3 In a cross-sectional study of 173 patients with COPD attending outpatient clinics, 29.5% of attendees  
4 had “low adherence” to medication [18]. The theme of accessing prescription medication from peers  
5 or family members is also not unique to our population, with one study in students finding that  
6 those who access medication from peers were also more likely to use illicit drugs [19]. Stigma and  
7 significant barriers to accessing both primary and secondary are common across illicit drug users,  
8 with reports of “dissonant care” commonplace with other qualitative and narrative studies in this  
9 population describing similar findings to the analysis of our interviews [20-23].

## 10 [Strengths and limitation](#)

11 The main limitation of this study is the small number of interviews conducted and the breadth of the  
12 interviews conducted. It may have added to the depth of knowledge if healthcare providers had also  
13 been interviewed, and further study in this area would be informative. The participants who  
14 declined to take part may have led to bias, with those happier to engage or those with strong  
15 opinions about their COPD potentially more likely to take part. This study has however offered a new  
16 and unique view on the possible barriers facing heroin smokers with COPD.

## 17 [Implications for research and practice](#)

18 Our data highlight important considerations in the development of COPD services for drugs users.  
19 Clinicians should consider functional outcomes as well as clinical outcomes and objective scoring  
20 systems when discussing COPD treatment with the patient. There is potential that functional goals  
21 would be welcomed by this patient group and may help motivate the attendance to care and  
22 adherence to treatment. The use of self-medicated inhalers, nebulisers and other drugs makes  
23 clinical assessment even more challenging in this population; it is highly likely that the standard  
24 methods of assessing “medication pick up” at pharmacies does not provide an accurate picture, and  
25 that self-reported usage may be key to determining the real clinical need. Alongside this the overuse  
26 of some inhalers, potentially as drug paraphernalia, adds to an already complex clinical picture. The  
27 access to respiratory care for this patient group is limited, with barriers including transport to  
28 hospitals and a feeling of stigma. There is potential that providing respiratory care centred around  
29 venues where patients attend opioid replacement therapy would improve continuity of care and  
30 assist in obtaining accurate medication histories. This research highlights the complex needs of  
31 heroin smokers with COPD and the need to consider their functional limitations, medication  
32 management and access to care in future planning of respiratory services.

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