How can research help people living with COPD?

A PATIENT AND PUBLIC INVOLVEMENT EVENT

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Summary

Chronic obstructive pulmonary disease (COPD) is a chronic, progressive condition of the lungs. With the rise of "big data" and data science, there are increasing opportunities for improving the management of such chronic conditions. This potential can only be exploited if we actively involve patients in research and development processes. On 21st November 2019, researchers and people living with chronic obstructive pulmonary disease (COPD) met for a half-day Patient and Public Involvement (PPI) event at the University of Manchester.

Twenty-two participants attended the workshop (13 people with COPD, 6 researchers, 2 other related professionals). The workshop agenda involved a joint lunch for networking, two plenary exercises to understand the concerns of people with COPD and how they think research could help, and three parallel workshops. The workshops focussed on 1) visualisations of activity and air quality data and their usefulness for people with COPD, 2) frailty and lung rehabilitation, and 3) COPD exacerbations.

Based on our discussions we identified the following priorities for COPD research/interventions: (i) managing breathlessness, (ii) managing exacerbations, (iii) education & information for patients, (iv) education & information for the public, (v) improving interactions with healthcare professionals, and (vi) activity levels and maintaining independence.

The main lesson learned from workshop 1 was that generic, off-the-shelf data visualisations are unlikely to be helpful and may actually have de-motivating effects; visualisations need to be tailored to the specific needs of people with COPD. In workshop 2, the researcher developed a better understanding of what 'frailty' meant to people with COPD and learnt about participants' varied experiences of access to lung rehabilitation. Workshop 3 highlighted an unaddressed need for early diagnosis and personalized management of COPD exacerbations, including timely primary care evaluation, near-patient testing for characterization of the exacerbations, and appropriate (self-management) interventions.

We also share valuable lessons learned about PPI event organisation with patient groups with long-term conditions, including (i) the importance of building rapport, (ii) venue considerations, (iii) organising transport, (iv) time management, (v) incorporating educational components, and (vi) limitations inherent to recruitment and engagement methods. The event received excellent feedback; participants reportedly enjoyed and valued the chance to meet and talk to other people with the same condition.

Introduction

On 21st November 2019, researchers and people living with chronic obstructive pulmonary disease (COPD) met for a half-day event at the University of Manchester. The aim of the event was to bring researchers and people with COPD together to jointly generate research ideas, foster an understanding of the needs and preferences of people with COPD, and develop networks to ensure people with COPD and members of the public can become active contributors to research. This report outlines the activities we undertook during the event, the insights gained, the lessons learned, and consequent recommendations for future COPD research to support patient self-management.

COPD is a progressive condition of the lungs which is characterised by obstruction of the airways (1). Common symptoms include coughing, breathlessness, wheezing, and increased sputum production (1). Worldwide, about 65 million people suffer from COPD (2). In the UK alone, over 1 million people are currently living with COPD (2). COPD affects 10-20% of people over the age of 40 (1).

COPD does not typically occur in isolation. It is often accompanied by other health problems and chronic conditions such as asthma, heart disease, lung cancer, anxiety, depression, chronic pain and osteoporosis (3). Additionally, people with COPD frequently suffer from acute exacerbations during which symptoms and airflow limitations worsen considerably (4), and approximately one in five are also living with frailty (5). The condition is therefore associated with high disease burden and healthcare costs (3).

COPD is generally not fully reversible, but symptoms can improve with treatment and appropriate lifestyle changes such as smoking cessation and exercise (1,4). As such, successful and sustainable treatment of the condition requires people with COPD to be actively involved in self-managing their condition (6). To achieve this, people with COPD need to feel empowered and engaged.

With the rise of "big data" and novel developments in the field of data science, there are increasing opportunities for improving the management of chronic conditions (7,8). For example, Internet of Things technology such as activity trackers and blood glucose monitors can be used to collect

continuous data which can be fed back to clinicians and patients to enable decision-making. The full potential of this "big data revolution" can only be exploited if we actively involve patients in research and development processes. Only if people with COPD become active contributors to research rather than simply being passive research "subjects" can we ensure that research priorities truly meet their needs.

INVOLVE, a government-funded national advisory group for public involvement in research, defines patient and public involvement (PPI) as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (9). PPI in research is becoming increasingly prevalent as research institutions and funders recognise and prioritise its value (10). PPI has been shown to have positive impacts on all stages of the research process (11). However, much research is still carried out without input from the patients living with the health problems under study, and in many cases PPI is not carried out even when it is planned for and costed into the research budget (10).

Figure 1 shows different ways in which patients and members of the public can become involved in research.

Forming part of scientific advisory committees that advise the research team

Helping to write and review grant proposals as joint grant holders or co-applicants

Helping to develop as well as critically reviewing patient information sheets, consent forms, study advertisement materials, and other materials designated for public consumption

Carrying out interviews or surveys with research participants

Helping researchers interpret findings and what they mean in 'real world' contexts

Figure 1. Examples of how members of the public and patients can become involved in research, adapted from (9).

The aim of our COPD event was to initiate and enable such joint working. We invited both people living with COPD and researchers with an interest in this field and undertook a series of activities to allow patients to provide their input on researchers' existing ideas and to jointly develop new ideas.

Participants

Who attended?

In total, twenty-two participants attended the workshop. Of these, thirteen were people living with COPD and six were researchers (4 from the University of Manchester, 1 from King's College London, 1 from the University of Lincoln), and two were other related professionals (Innovation Agency, Salford Royal NHS Foundation Trust).

How were participants invited to take part?

Identifying and engaging relevant participants was one of the main challenges in organising this event. People with COPD often experience physical restrictions (for example due to breathlessness or co-morbid conditions) which lead to reduced community mobility and participation and, consequently, social isolation (12). As such, we needed to think carefully about how best to invite people to participate in the workshop. We reached out to people with COPD via four main strategies:

1. Contacting and attending Breathe Easy groups from the British Lung Foundation
2. Contacting patients via the "Help BEAT Respiratory Disease" database held by Research for the Future (https://www.researchforthefuture.org/), which contains a list of individuals with respiratory conditions who are interested in participating in research
3. Relevant newsletters e.g. Salford Citizen Scientist

4. Posting in COPD-related social media groups (with admin approval)

Those interested in taking part were asked to record their interest either by contacting the event organiser (Dr Julia Mueller) or by filling in a brief online survey with their contact details. Dr Mueller then contacted each person individually to provide support with arranging travel to and from the event and to ensure any specific requirements could be taken into account. Travel expenses were covered for all participants with COPD.

To identify relevant researchers, we initially sent an expression of interest form out via relevant listservs (University of Manchester Announcements, JiscMail listservs for Ageing, Ageing Body and Society, Psychology Postgraduats, Public Health) as well as contacting known researchers in the field. A substantial level of interest was recorded. We then asked researchers to complete a workshop proposal form to indicate how they would like to contribute to the event, and based on contributions, we undertook a shortlisting of researchers to include in the event. We decided to limit the number of researchers/professionals to ensure the voices of people with COPD remained at the centre of the event.

Workshop format

The broad agenda for the event is shown in Figure 2. The event began with a joint lunch, giving participants a chance to mingle and get to know one another. This was followed by an introductory session with the whole group. Each participant briefly stated their name and what they hoped to gain from the event. Each researcher/professional gave a very brief (< 3 minutes) overview of their work in plain English. Subsequently, Dr Mueller held a brief (~5 minutes) presentation on PPI (what it is, why it is important and how it can be achieved). This was followed by a short presentation by Katherine Grady from Salford Royal NHS Foundation Trust/Research for the Future to introduce the 'Help BEAT Respiratory Disease' mailing list.

Agenda for the COPD event		
Time	**What**	**Where**
12-12:45	Lunch	Innovation Suite
12:45-13:30	Introduction	Innovation Suite
13:30-14:40	Workshops	Green/Yellow/Blue Room
14:15-15:15	Tea and coffee available	"The Street" (hallway)
14:45-15:30	Summary, Q&A	Innovation Suite
15:40	Taxi pickup	Grafton Street

Figure 2. Agenda for the event.

Next, we conducted an exercise where we asked participants to write down, on a sticky note, what currently worried or concerned them (related to COPD, or more widely). The sticky notes were then collated on a flip chart.

We then split into three workshop groups which convened in separate rooms (Table 1). Splitting up into smaller groups ensured that all participants were able to contribute actively, allowing more in-depth and interactive discussions than would be possible in the wider group.

Finally, we reconvened as a whole group and each workshop group briefly presented their workshop and their outputs, and other participants were given the chance to contribute. To conclude the event, we conducted a final exercise where we asked participants to note down responses to the questions "What do you think research should focus on? How can research help?" (we requested participants to think about options other than 'cure COPD').

Finally, at the end of the event, participants were asked to complete a brief feedback form. Participants were asked to rate whether the content of the event met their expectations on a scale from 1 (no, not at all) to 5 (yes, definitely). Participants were also presented with three free-text

boxes to respond to: 1) What did you enjoy? 2) What would you change for future events? and 3) Other comments or suggestions.

Outputs

First plenary exercise

The output from our first plenary exercise is shown in Figure 3. Three recurring themes became apparent in participants' responses. Several participants expressed concerns regarding **breathlessness and activity levels**. Participants also reported concerns regarding the **underlying aetiology** of their conditions (COPD and co-morbidities) and symptoms. Participants wished to better understand their condition and what was causing it, and deficiencies in education and information available to COPD patients were discussed repeatedly throughout the day. Participants also appeared to be concerned about the **progression of their disease** and wished for information on how they might expect their situation to change in the future.

Table 1. Parallel workshops			
	Title	**Aims**	**Activities**
 Workshop 1	Visualising activity and air quality data for COPD	• To discuss whether research into activity trackers in COPD patients could be fruitful • To understand what types of data visualisations of activity tracking and air quality data could be incorporated into future interventions for COPD self-management	• What helps you be active? What stops you? (Collate on flipchart, then discuss) • Discussion: Have you used any activity trackers in the past? If yes, which ones? What did you like/not like? (Collate on flipchart) • View and discuss screenshots of existing activity trackers (printouts) • View existing visualisations of air quality (e.g. www.mappinggm.org.uk) and discuss
 Workshop 2	COPD, frailty and lung rehabilitation - how can we improve practice?	• To create a shared understanding of 'frailty' in people living with COPD • To discuss how we can better support people with COPD and frailty to engage with lung rehabilitation	• Interactive exercise (e.g. picking a picture postcard that says something about 'frailty' to them) to start a discussion of what frailty is and how it might affect people living with COPD • Sharing findings of a recent interview study with people with COPD and frailty, followed by feedback on what does and does not resonate with their experiences

	COPD exacerbations	• To identify clinical and research needs regarding the prevention, diagnosis and management of COPD exacerbations	• Discuss people's experience of having a COPD exacerbation and how this affects their lives. • Discuss current challenges of the diagnosis and management of exacerbations • Prioritise different research areas and projects
Workshop 3			

Exacerbations were also flagged as a concern, with participants mentioning the risk of flare-ups caused by external factors that are difficult to control (air conditioning), and lack of knowledge on management of exacerbations. Finally, one participant commented on **interactions with healthcare professionals**, highlighting concerns over continuity of care.

Figure 3. Plenary exercise 1: What worries or concerns you?

Second plenary exercise

Participants' suggestions for future research priorities in the second plenary exercise are shown in Figure 4. The importance of **information, education and awareness** emerged as a clear theme. This included information for patients (e.g. on available treatments, devices and services), but also for healthcare professionals and the wider public. COPD involves impairments that are not immediately visible to others and, as such, participants described feeling like they needed to justify or explain their condition to others. **Exacerbations** emerged as another key priority, and the need for more education and understanding was highlighted again in this context. Another important theme revolved around **interactions with (healthcare) professionals**. Participants appeared to have experienced some barriers to effective communications with their providers, and there seemed to be some disjointedness in the care participants received. Participants expressed a wish for a more COPD-specialised contact point (either in form of a contact point that is separate from usual doctors, or in form of doctors that are more familiar with the disease). The importance of **exercise** re-emerged (in line with the first plenary exercise), with participants expressing a need for exercise programs that are local and accessible.
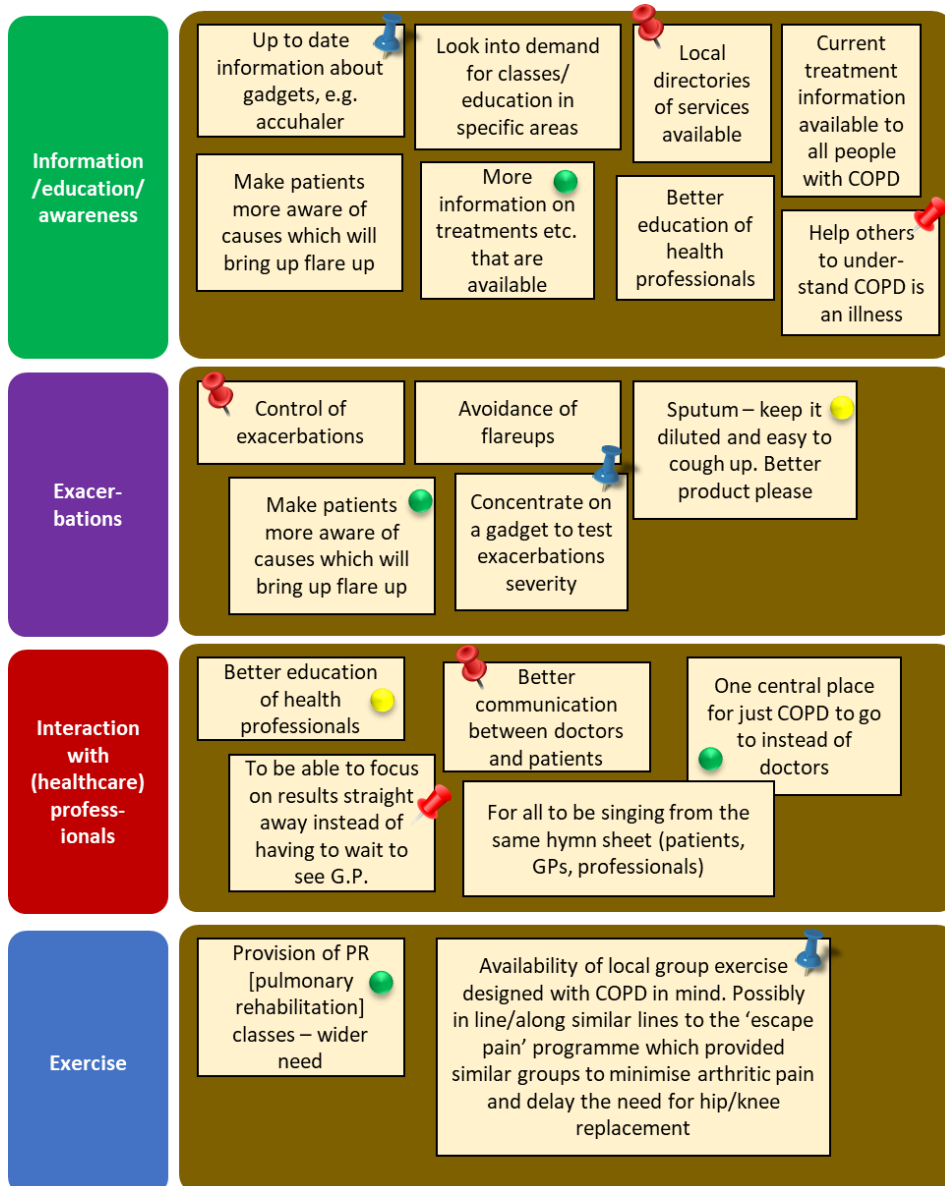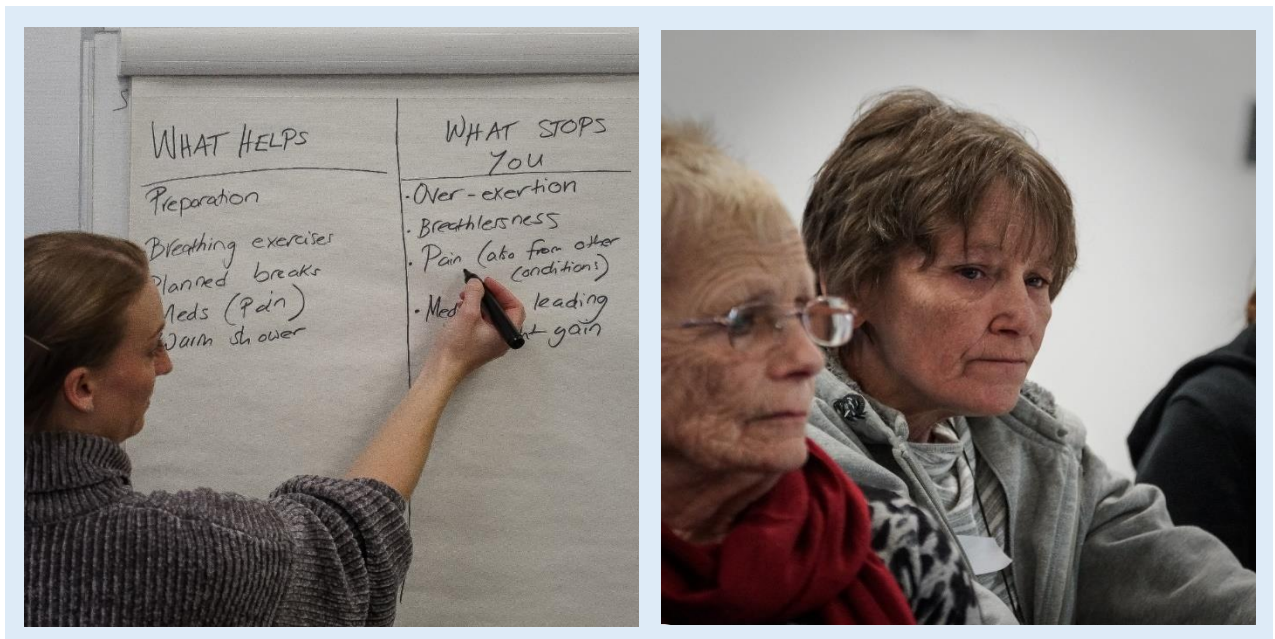
Figure 4. Plenary exercise 2: What do you think research should focus on? How can research help? (excepting 'cure COPD')

# Workshop 1 outputs: Visualising activity and air quality data for COPD

Workshop 1 focused on visualising data to enable patients to take action and self-manage their condition. We were interested in finding out whether different forms of presenting information would be perceived as more or less useful.

Barriers and facilitators of exercise

To initiate the discussion, we asked participants about things that helped them or prevented them from being active (Figure 5). In terms of facilitators, participants discussed the importance of **planning** and **preparation** (e.g. ensuring enough time can be allocated to exercise, planning breaks to prevent over-exertion), and having a **good "starting point" to enable safe exercising** (e.g. having appropriate medication, having good core stability to prevent injuries).

On the barrier side, we discussed both **external** and **internal factors**. External factors included for example the **lack of appropriate facilities**. Participants discussed **physical aspects of the environment** such as hilly landscapes that are different to navigate when feeling breathless, but also aspects relating to the **management of the environment**, such as the use of air fresheners in facilities that can cause exacerbations of symptoms. Another very interesting topic related to the **lack of awareness of COPD among the wider public**. Participants described encountering lack of understanding – and sometimes even aggression – from other people who were unable to see their disability and therefore did not understand their level of impairment. For example, one participant described judgement from other people when she used disabled parking spaces. Participants described how this led to **anxiety** and consequently prevented them from venturing outside to

exercise. Finally, we discussed the challenge of **finding the appropriate type of exercises for each individual** patient. Participants highlighted that they had unique combinations of comorbidities and therefore generic exercise programs were not always appropriate.
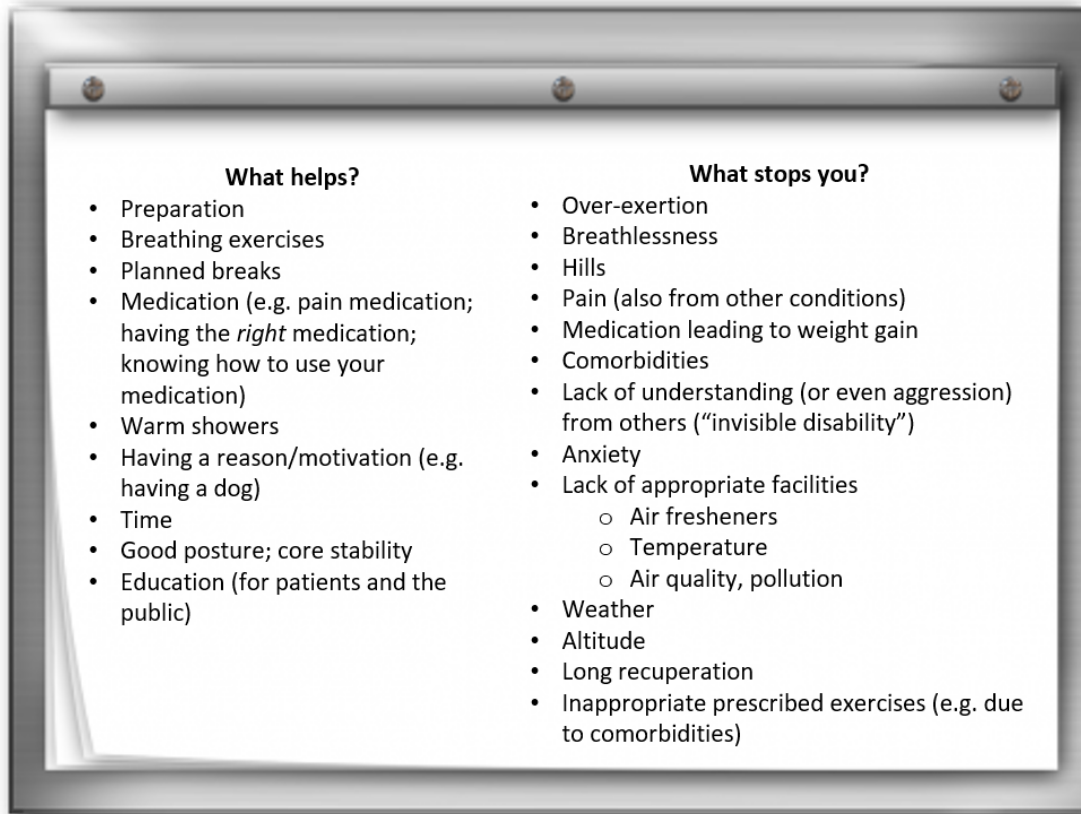
Figure 5. Outputs of brainstorming exercise to identify facilitators and barriers of physical activity in people with COPD.

Activity trackers

We then examined screenshots of different activity tracker apps, such as the one shown in Figure 6. Opinions about the usefulness of wearable devices and activity tracker apps for people with COPD were mixed. Some participants had used such devices previously and found them helpful. For example, one participant described having previously used a Fitbit that would notify her when she had been sitting for an extended period of time, to remind her to move about and take a few steps.

However, participants also identified some key issues that the research team had not considered previously. Participants pointed out that COPD is a progressive disease. As such, they were concerned that apps that show trends over time might have a discouraging effect by highlighting this development. As a group, we discussed the importance of tailoring activity tracker apps to the unique needs of the COPD population – and allowing additional tailoring to individual users based on

their unique requirements (e.g. if they have co-morbid conditions) – so that they can be helpful and useful. Our consensus was that existing, off-the-shelf activity trackers and corresponding apps are unlikely to be helpful (or at least, that tailored, personalised apps are likely to be more helpful).
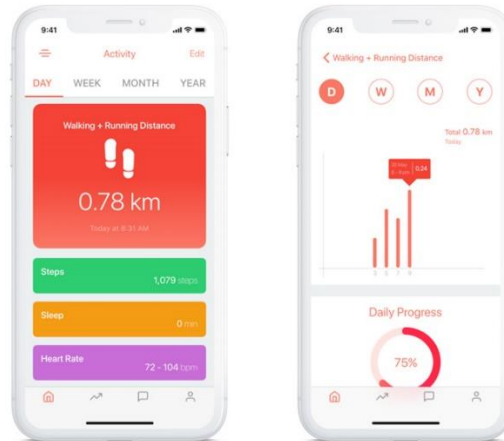

Figure 6. Screenshot of an activity tracker app. Source: https://www.sketchappsources.com/free-source/3342-fitness-tracker-app-concept-sketch-freebie-resource.html (accessed 21/04/2020)

Air quality

We briefly reviewed some existing visualisations of air quality/pollution with participants such as the one shown in Figure 7 to assess their usefulness. Participants expressed scepticism regarding the usefulness of maps visualising air pollution, as they would not be able to alter where they live so such maps may be more likely to cause worry than be of practical use (unless they were choosing an area to move to).
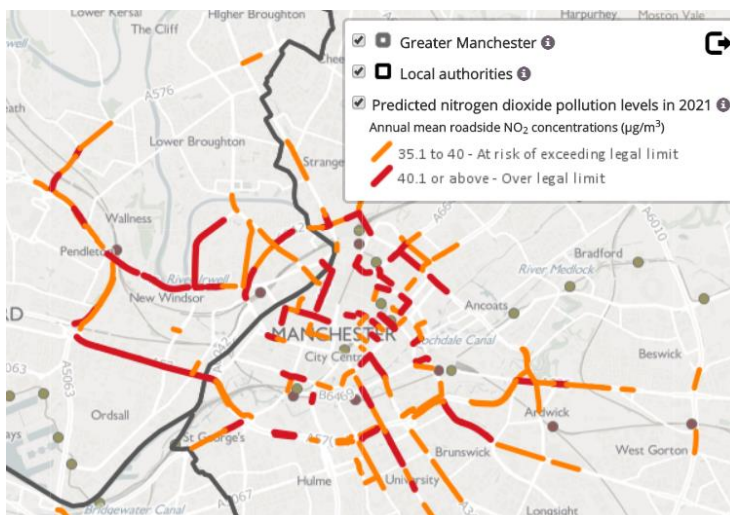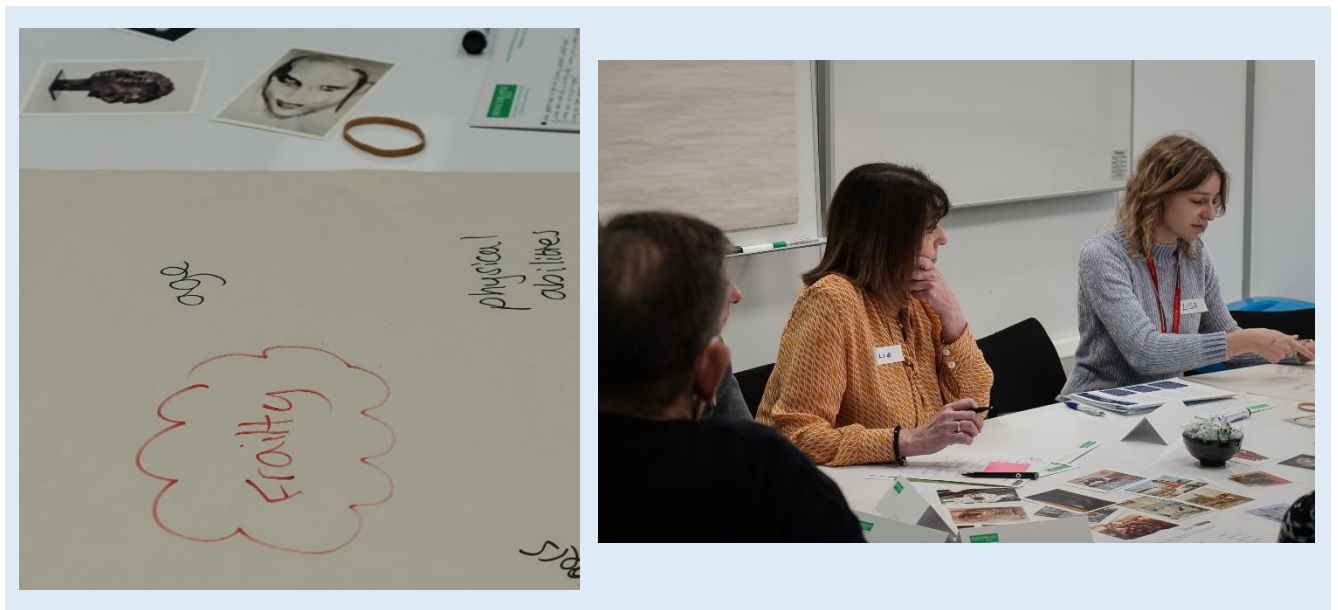

Figure 7. Map which shows levels of nitrogen dioxide in roads in Manchester: Source: mappinggm.org.uk/

Workshop 2 outputs: COPD, frailty and lung rehabilitation - how can we improve practice?

We began our workshop by each selecting a postcard from the table that to us said something about the word 'frailty'. Each person in turn then described why they had picked their postcard:

> *"We talked about 'Frailty' and what it meant to each of us. We were given cards which depicted pieces of art and it was suggested we marry one card each to Frailty. To me, Frailty is old age and a certain amount of dependency which COPD is the master of. On the card I selected, it showed an elderly man sitting outside his cottage with what looked like his shopping being delivered by donkey. It could easily have been a modern day food delivery to someone too frail to shop, which I am sure must happen with older people who suffer with COPD and who become too breathless to walk and shop etc."* **Denise Hillman (workshop participant)**

As we went through the postcard, we talked about what some existing research has told us about living with COPD and frailty, including how this might affect people's experience of exacerbations and dips in their health. For some participants, this idea of having dips in their health, and not quite recovering back to where they were before, resonated with personal experiences. We also discussed how frailty can include more than just physical aspects of a person's health, and that despite what many people think, frailty can be reversible with the right support.

In the second part of our workshop, we looked at a summary of findings and quotes from a recent interview study with people with COPD and frailty who had been referred for lung rehabilitation. In

many cases participants could resonate with the experiences of those in the research study. They also highlighted similar challenges they had faced around fatigue, feeling isolated, and not knowing who was the best professional to ask about their health – including having difficult questions around how long they might live and what might happen if they become more unwell. Some highlighted issues with access to lung rehabilitation and long waiting lists, while others had been able to attend and had enjoyed it. Participants particularly appreciated the opportunity to meet with and socialise with others with COPD. By sharing their experiences, the participants helped the researchers reach a richer understanding of the information they had collected.

> *"It was useful to understand what peoples' impressions were of the word 'frailty' as that is an important part of the project I'm working on. Hearing the participants' reflections on some of the findings of the interview study I have conducted, and their own experiences of anxiety, feelings of isolation and difficulties accessing rehabilitation, helped to enrich my interpretation of the information I had collected so far." (**Lisa Brighton, Researcher**)*

The findings of the interview study have now been accepted as a publication (13), and the authors have mentioned this group in their acknowledgements as they helped them to better interpret the findings. This workshop also meant the researcher was thinking differently about how they might run their own patient and public involvement workshops with people with COPD in the future:

> *"I also found it helpful to understand that people living with COPD are often seeking more information about their illness. As a result I have suggested to my colleagues that next time we do a public involvement event with people with COPD in our department, we should try combine it with some sort of education session as well – so we can ask our own questions but also hopefully provide some answers as well." (**Lisa Brighton, Researcher**)*

Workshop 3 outputs: COPD exacerbations

Workshop 3 focused on COPD exacerbations and aimed to identify important unaddressed clinical and research needs regarding the prevention, diagnosis and management of exacerbations.

The main issue identified by the participants was the challenges in accessing a primary care physician at the time of the exacerbation. This results in treatment delays and prolongation of the symptoms. In addition, patients are then required to blindly receive rescue packs with antibiotics and/or systemic corticosteroids that may not be indicated and may have unfavourable effects. A need for personalized therapeutic approaches was also discussed. Participants prioritized the need for near patient tests (operated by the GPs or even by the patients) that will help guide their treatments. Such interventions should be linked to self-management interventions.

Many participants highlighted the impact of exercise on improving patients' health, quality of life, decreasing their symptoms and preventing exacerbations. The need for more frequent referrals for pulmonary rehabilitation was highlighted.

Patient contribution (Alan Preston)

This was one of the best focus groups I have attended. The knowledge, histories and interactions between people were excellent. The main conclusion our group came to was that we need some sort of handheld device to be able to check when we have an exacerbation, similar to how diabetics check their blood sugar levels. It would have a twofold benefit: First, we would have the information to use together with our emergency packs (steroids or antibiotics). Secondly, it would also be possible to present readings to our doctors. This could be done via an app or in a similar manner to my Continuous Positive Airway Pressure (CPAP) machine, which sends information to the clinic via

the internet automatically. This would then alert the clinic when an exacerbation occurred and could indicate if the person requires further assistance. Presently it takes an average of 9 days to get a GP appointment by which time the exacerbation has often passed or been treated with the emergency pack. Many of us attend COPD-focused exercise classes, and find it beneficial to our breathing. It would be interesting to find out if this decreases or increases the rate of exacerbations.

Feedback

Sixteen participants completed feedback forms. Feedback was largely very positive (Table 2). Participants rated the extent to which the event's content met their expectations as **4.88 out of 5**. When asked what they enjoyed most, the majority of participants mentioned **interactivity, discussions and the chance to meet others with the same condition**. A suggested improvement was to allow **more time** for interactions in the parallel workshops and in the plenary to discuss the outcomes of the exercises and the workshops. Participants would have also liked the opportunity to participate in several workshops. Another recurring suggestion was to include some form of **educational component** with information about COPD.

Lessons learned about PPI event organisation

We learned several important lessons from organising and hosting this event that we think will be useful for others organising PPI events with people with COPD (or other long-term conditions); these lessons are summarised in Figure 8. First and foremost, we strongly encourage involving individuals living with the relevant health condition in the organisation of the event itself. This can help early identification and pre-emption of barriers.

The first crucial lesson related to **allowing sufficient time for engagement and rapport**. Organising such workshops and engaging with people who have debilitating long-term conditions requires time and effort. Despite our pre-existing contacts with researchers, clinicians and people with COPD, organisation of the workshop took approximately 5 months in total. It took time to identify the appropriate people to contact and to build trust and rapport. Patient groups are often inundated with requests for research participation or other forms of marketing and advertisement and therefore there are usually mechanisms of gatekeeping in place to safeguard members. Thus, we invested significant time and effort into contacting people, introducing ourselves (in person if possible), and explaining the aim of our event. Once we had a list of potentially interested people, we invested substantial efforts into communicating with these individuals to answer any questions and organise transport. Although this took up a considerable amount of time, attendance at our

event was very high (only two participants who had signed up did not attend), which may be attributable to the level of communication leading up to the event.

Table 2. Participant feedback.

What did you enjoy?	What would you change for future events?	Other comments/suggestions
• open discussion; patient focused topics • team effort • interactivity and focus on participant experience • group discussions and ideas • All of it meeting other people with the same complaint; the teachers who were all very helpful • Group discussions on all aspects of COPD = frailty and how each person is different and has different expectations of treatment or self medication • Introductions + chance for in depth discussion during the workshops • Meeting other people each with their own experiences, opportunity to discuss personal experiences + views on where improvements/developments are needed • All the different points of view + suggestions made • Interesting to be able to talk to other people with COPD • The group discussions • General discussions • Meeting groups and learning from each other • The whole experience as I, as a COPD sufferer am now feeling more optimistic • Great attendance from people with variety of ages, opportunity to run workshop was great	• Extra time for group discussions. More discussion as a whole group after points made by groups. • Nothing. Fully comprehensive study. • Perhaps have the chance to engage in various workshops e.g. half hour in each session • Consider adding in an educational session e.g. treatment, prevention. - Discuss latest treatments - breathing exercises. • To learn more about COPD especially from GPs • More time perhaps starting earlier or perhaps regular follow ups • Invite family member • Shorter/half day • It sounds like people wanted to learn more about COPD - so could it be combined with some education alongside PPI? Also it would be nice to do something with the list of concerns from the start within the workshop	• Thank you all for a good afternoon. • Very enjoyable • Keep doing what you do, keep up the good work • Thank you for hosting

Another important lesson learned relates to **venue considerations**. We had initially booked a venue that transpired to be unsuitable for our participants and we therefore changed the venue a few weeks before the event. Because our participants had COPD (often coupled with frailty, co-morbid

conditions, or other disabilities) we needed a venue that allowed **easy access for cars, no stair climbing, and minimal distances** to cover. Additionally, we encountered some issues with **air conditioning/heating** during the event which caused some participants breathing issues. Following discussions with the facilities manager, it was agreed that the air conditioning should ideally be switched off entirely for future events.

Finally, it should be noted that considerable time and financial resources needed to be allocated to **organising transport**. Because our participants were unwell, we wanted to ensure each individual participant would be able to travel to the event safely and comfortably. We organised for taxis to pick participants up from their homes and take them back following the event. For those who preferred to use their own vehicles, we booked parking spaces close to the venue. Additionally, we requested taxi companies to remove any air fresheners, which was not always met with sympathy and understanding. Overall, it is important that those who organise such events budget sufficient time and money to organising travel, to make attendance as easy and smooth as possible.

Our experiences show that **time management** could be further improved. We had purposely kept the event relatively short (3.5 hours) as we did not want to over-burden participants, but based on feedback this could have perhaps been extended. This would have allowed more time for engagement in the workshops and for discussions among participants (an aspect of the event which participants seemed to enjoy greatly).

In future events, we will endeavour to include **educational components** to help participants learn about their condition and existing services, as this was clearly wished by participants. This will require careful consideration and planning, however, to ensure participants remain active contributors to generating novel ideas, rather than becoming passive recipients of information.

Finally, we need to draw attention to the fact that our advertising and recruitment methods may have **missed some patient groups**. Most of our participants were either members of support groups (online or face-to-face), or were enlisted on the Help BEAT Respiratory Diseases mailing list. As such, our patient participants were likely those who were already engaged with their community, relatively health literate, and/or able to access Internet technology. Those who are socially isolated

and not well linked up with their community (sometimes referred to as 'seldom heard') had less opportunity to be included. 'Seldom heard' people rarely or never join in existing groups or events and therefore one would need to seek them out actively in the community, for example through GP practices or through stalls in public places such as malls or pubs. Another approach that has proven useful in the past in engaging vulnerable patient groups is through volunteers recruited from the

relevant communities (14–16). Such volunteers are often knowledgeable of the relevant communities and have an established rapport with its members. It may be useful to include such volunteers in recruiting participants for future PPI events.

Building rapport
•Allow enough time (possibly several months)
•Make time to visit groups and talk to people on the phone

Venue
•Easy access for cars
•Avoid stairs
•Consider air quality issues

Transport
•Ensure comfortable and safe travel for everyone
•Cover travel costs
•Communicate regularly

Time management
•Allow sufficient time for discussions among participants
•Ensure all activities and outputs are discussed meaningfully

Educational components
•If possible, include components to provide information to patients
•However, take care to ensure participants remain active contributors

Recruitment and engagement
•If possible, seek out 'seldom heard' people in the community
•Recruit via lay community volunteers
•Consider who might be missed

Figure 8. Summary of lessons learned about PPI event organisation.

Conclusions and recommendations for future research

Our event provided a unique opportunity for researchers and people with COPD to come together, discuss ideas, identify research priorities, and build networks for future collaborations. Feedback from our event shows that the event met participants' expectations and enabled them to meet and interact with other people living with COPD. Through a series of activities and workshops, we identified several aspects that are areas of concern to people with COPD and where further research would be welcomed. Combining the themes identified in the two exercises undertaken with the whole group ('What worries you?' and 'How can research help?'), we have identified key priority areas, shown in Figure 9. Future research on COPD self-management should take these themes into account, and consider how research outputs can contribute to improvements in these areas.
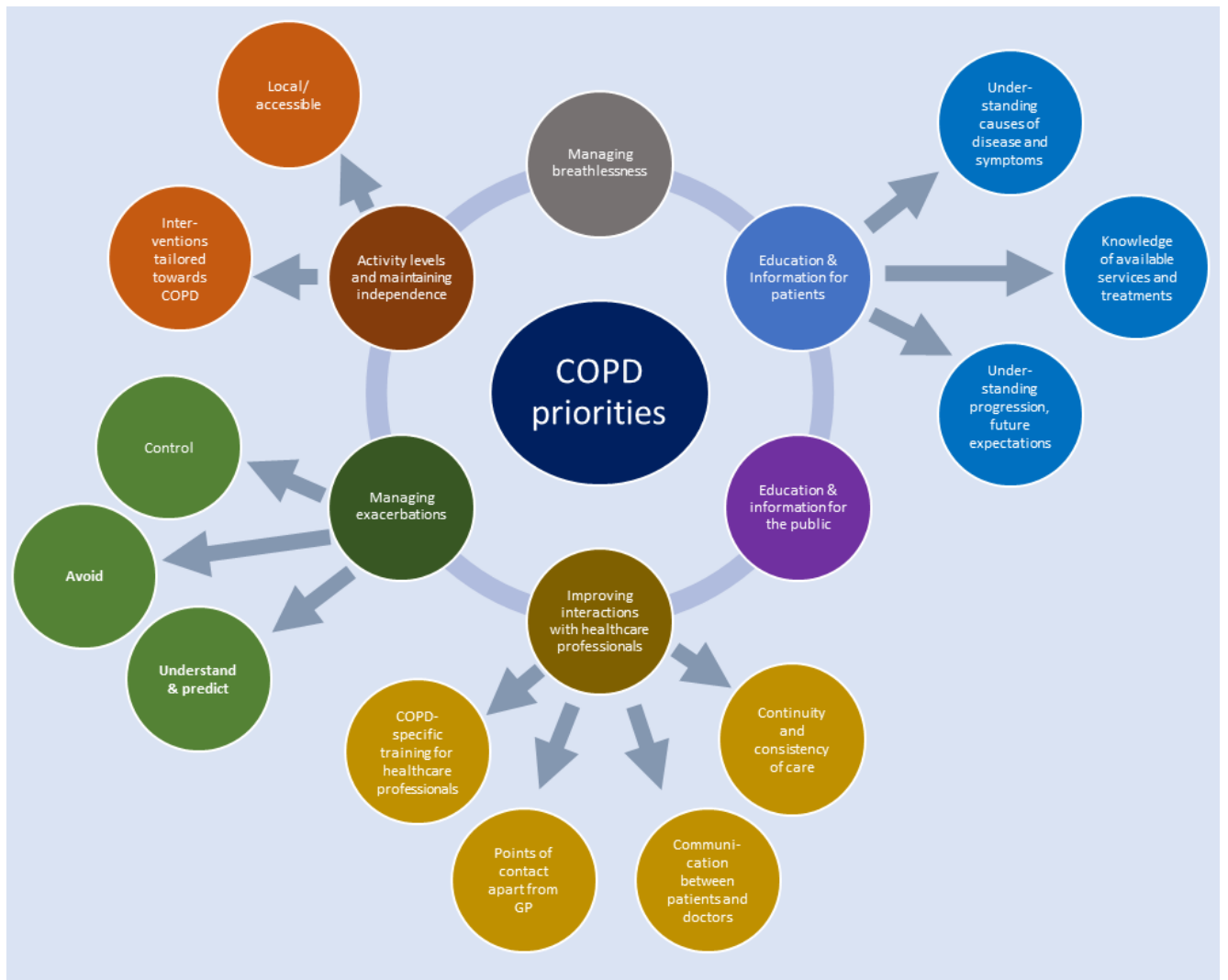
Figure 9. COPD priority areas identified through our PPI event.

Acknowledgements

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