

# Patient perspectives on living well with a lung condition



## Introduction

The survey was conducted by Asthma + Lung UK for the BIOREME network, ahead of a sandpit event on asthma, COPD and other lung disease. BIOREME is a multi-disciplinary group of researchers, clinicians, healthcare industry professionals and patients working to improve the treatment and care provided for people with lung conditions. The BIOREME network is supported by the Engineering and Physical Sciences Research Council [grant number EP/W000490/1].

The survey explored themes identified as potential areas for further research or improvements to care and support that were identified in focus groups held in July 2022. This included patient perspectives on the impact of lung conditions on quality of life, their experiences of monitoring and their thoughts on medication.

The survey was conducted using an online platform and distributed through email and social media platforms in May and June 2023. This included the Asthma + Lung UK's Respiratory Voices Network, over 900 people living with lung conditions. It was also shared by BIOREME members. 265 successfully completed the survey.

## Quality of life

Improved quality of life is arguably the ultimate impact we achieve for patients when we improve clinical, performance and patient-reported outcomes. This survey sought to better understand what quality of life means to patients so that we can ensure any work we undertake to improve outcomes is done so in a way that meaningfully contributes to improved quality of life.

Survey respondents were asked to write 2 to 3 sentences on what a good quality of life means to them. Seven overarching themes were identified that represented different features of, or contributions to, quality of life when living with a lung condition.

Autonomy and freedom	Respondents expressed the need to feel in control of their life and to have the freedom to pursue goals and desires whenever they wanted. Many felt limited by the symptoms of their condition, side-effects of medication and the time or equipment required to manage their condition.  Their goals may be small, like going to a café when they wanted, or they may be more ambitious. For some, the ability to act spontaneously was essential to maintaining their quality of life.
Independence	Respondents talked about the relationship between being (or feeling) independent with a good quality of life. It is distinct to the theme of autonomy and freedom, as comments were more about self-sufficiency than self-governance and decision-making.  For some, independence was about being able to do tasks entirely on their own and not having to rely on others. For others, they felt independence and self-reliance could still be achieved with appropriate support.

	<p>Several respondents talked about the loss of independence that came from being confined to their home, and the impact of this on quality of life. This confinement might have come because of symptoms, side-effects of medication or general poor health but also triggers of their condition such as poor air quality.</p>
Physical activity	<p>Some respondents equated a good quality of life with good (or best possible) physical health. For some people a good quality of life required the absence of their condition, symptoms or medication. Others focused on the relationship between better management and control of their health and quality of life.</p> <p>The most common symptom having a negative impact on quality of life was breathlessness. Fatigue and lack of energy, pain and disrupted sleep were also mentioned.</p> <p>Exercise and good quality healthcare were cited as something that contributed to quality of life.</p>
Social connections	<p>Another significant factor to quality of life that emerged from the responses was having a fulfilling social, cultural, and family life. Respondents mentioned family, friends and leisure activities. Many named activities they particularly enjoy, including singing.</p> <p>Some wanted their symptoms or condition to be managed well enough for them to participate. For others, it was about others making adjustments to support them to be and feel included.</p>
Purpose and contribution	<p>Several respondents talked about feeling like they have value, or having the capacity to contribute, as an important aspect of quality of life. This might be through work, volunteering or caring for family (particularly children and grandchildren). Many found purpose and meaning through these activities.</p>
A (new?) normal life	<p>A proportion of respondents described a good quality of life as synonymous with being able to do what they perceived other people can do. This was often described as 'living a normal life'.</p> <p>Linked to this was a perception of poor quality of life occurring (in part) when your health or abilities did not align with societal norms or expectations. Some respondents were more pragmatic and described adjusting their expectations of what they could do in order to find a new quality of life.</p>
Absence of worry	<p>Some respondents mentioned absence of worry and good mental health as a key component of quality of life. This included alleviating anxiety and depression and addressing health-related anxiety.</p> <p>A particular source of anxiety or poor mental health were financial and housing worries. There was some variance between people who just need to cover basics and those who want enough money to enjoy life.</p>

Implications for future research could include:

- Ensuring patient outcomes measures reflecting the above themes are developed in collaboration with patients and collected alongside other clinical or performance measures
- Recognising quality of life will mean something different to people with a lung condition and that research protocols will need to be able to flex to accommodate this
- Remembering that no patient exists in isolation. Research must incorporate interactions with healthcare professionals and support networks (e.g. friends, family, colleagues) to ensure that outputs can be replicated in the real world

## Monitoring and managing lung condition

The importance of monitoring and self-management has long been recognised as crucial to maintaining good control of lung conditions. The focus groups identified several challenges people with lung conditions may experience, this included healthcare professionals not addressing patient concerns, a need for improved methods to identify exacerbations and discrepancies between how they feel and what devices are telling them. Some participants also explained how difficult it was to see their condition was deteriorating from home monitoring devices.

This survey sought to gain a deeper understanding of views on monitoring of lung conditions, and potential barriers. It included questions about care and support from healthcare professionals, use of devices and technology and self-management techniques.

- Patients wanted healthcare professionals to take into account their self-management strategies, work and hobbies, mental health and what care and support they had at home or what caring responsibilities they had
- Most respondents were satisfied with the way their lung condition was monitored and reviewed by healthcare professionals, but a notable proportion (31.7%, n=84) felt their condition was not receiving adequate attention.
- Most respondents were proactive in reviewing their lung condition outside of healthcare settings, with 82.3% (n=218) doing some sort of monitoring at home. Respondents that did monitor their condition at home used multiple devices and strategies including peak flow, pulse oximeters and wearable devices
- Barriers to self-monitoring included finding it too difficult or emotionally upsetting, lack of knowledge or confidence to use devices or interpret readings and finding a discrepancy between device readings and how they felt in themselves
- Most respondents who monitored their lung condition at home had a positive view of it (86.7%, n=189), but several felt that it only gave a 'snapshot' of their condition on any given day and that lung function measurements didn't match how they felt in their body.
- Respondents were slightly less confident in the accuracy of the readings they got from monitoring, but a majority (57.7%, n=153) agreed that a device that offered assistance with proper technique and a remote review of results by a clinical team would increase their confidence.

People living with a chronic lung condition have to implement a number of habits and behaviours on a daily basis in order to successfully manage their condition. They often only have contact with a healthcare professional one or two times a year. This is a challenge in itself, however there are a number of additional respiratory-specific challenges that make this even harder. This includes lack of a definitive biomarker, the delay between taking preventative treatment and it having an effect, and the absence of effective treatments for specific lung conditions.

This survey has confirmed that patients recognise the importance of being able to monitor and manage their condition and are keen to do so. These patients have also identified a number of challenges which if addressed could help them better monitor and self-manage:

- Receiving assistance with (monitoring) device technique
- Development of a 'new' measure that matches how they are feeling
- Being able to know when they are deteriorating and/or about to have an exacerbation
- Tracking the link between their mental health and their lung condition
- Being able to link their lung health to an outcome measure of personal relevance to them

Whilst the data from this survey shows that patients are supportive of having information collected by health apps and devices be included in medical records, it does not necessarily follow that they want to actively (or consciously) collect and share this information themselves.

Furthermore, only a very small proportion will maintain active habits in the long term, and so development of monitoring and management approaches which favour passive rather than active participation on the part of the patient are likely to be more widely adopted in the long term.

## Medication

A number of potential concerns regarding medication usage were identified during the 2022 focus groups and this survey sought to understand whether these were important to significant proportions of the overall population who live with a lung condition. In particular, the long-term impact of steroids and possible drug interactions. This survey also asked questions about side-effects.

- Almost all respondents (97.4%, n=258) were taking medication for their lung condition. Only a small percentage of this group (16%) were concerned about taking medication they may not need.
- Those taking medication had a high level of understanding about why they needed to take these medications for lung condition.
- Just over half of respondents taking medication for their lung condition had taken at least one course of oral steroids in the last year (52.7%, n = 136). There was a notable level of apprehension among respondents who had taken oral steroids in the last year about the long-term effects associated with prolonged use.
- Respondents had different levels of concern about the potential side-effects of non-steroid medication for their lung condition. There is possibly a greater variety of perspectives towards perceived risks than with steroids, or lower awareness of side effects of other medication.
- A significant number of respondents who took medication for multiple conditions did not express strong concerns about potential drug interactions.

Respondents to this survey showed high understanding of all the medications that are taking, however it is unclear whether this is truly representative of the overall population. Respondents were self-selecting and could be more engaged in, and educated about, their own health than the population overall.

Of the potential concerns identified, the only one that was supported by a majority of this population was that of the side effects of taking oral steroids for a prolonged time. This can be considered to be the highest priority concern with respect to medication.

Contact details:

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