

CONVERSATIONS WITH PEOPLE WITH LIVED EXPERIENCES OF COPD IN UNDERSERVED COMMUNITIES IN THE LoTHIANS

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BACKGROUND

Chronic Obstructive Pulmonary Disease (COPD) is the second most common lung disease in the United Kingdom [1]. Its incidence and risk of adverse outcomes are linked with **socioeconomic deprivation, lower educational attainment and childhood disadvantage** [2,3]. We aimed to seek the views and priorities of those most impacted by COPD.

WHAT WE DID

We ran workshops in areas with high levels of deprivation. Those who came ranged from newly diagnosed to those with severe COPD. We greeted attendees (most of whom had no research experience) with refreshments and intentionally kept meetings simple, with technology use limited. We explored questions such as:

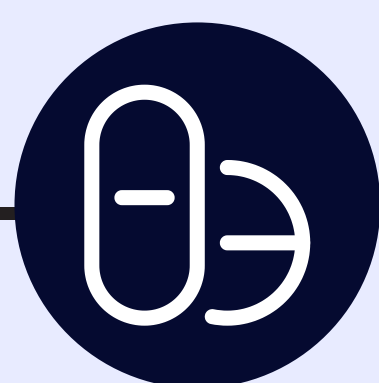
1. **What does and does not work well in your care?**
2. **How do you self-manage your COPD?**

WHAT WE LEARNED

DELAYS IN DIAGNOSIS



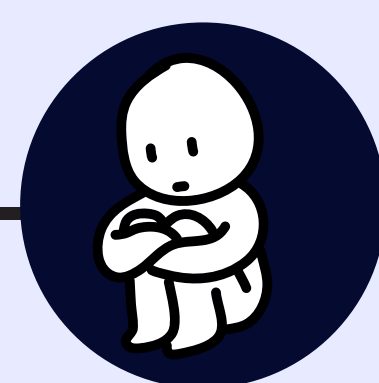
ACUTE EPISODES



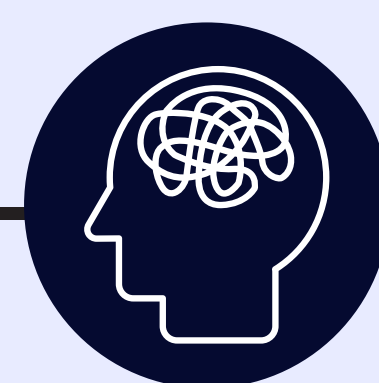
ACCESS TO INFORMATION



LACK OF SUPPORT



MENTAL HEALTH



Those from underserved communities report:

- **Longer waiting lists** and **delays in diagnosis**
- Being **under-supported** and "abandoned" during mild stages when management is vital to slow progression
- Issues accessing consultations with COPD specialists which are often only available to those whose COPD has progressed or who have been hospitalised following an acute exacerbation.
- Difficulties **understanding** terminology and the progressive nature of COPD, and were unsure how to self-manage their condition.
- **Conflicting information** received from different practitioners and resources, and expressed a need for a source of consistent and accurate information.

HOW ARE WE USING THIS INFORMATION?

The contents of this poster represent the **first of many discussions** with this group. Conversations revealed opportunities for improvement in COPD healthcare using a person-centred approach throughout the patient journey. Lessons learned will inform the design of digital and data innovations undertaken in NHS Lothian and Health Innovation South East Scotland. We will continue to work with this group, centralising the lived experience of those with COPD.

REFERENCES

1. British Lung Foundation. Chronic obstructive pulmonary disease (COPD) statistics. <https://statistics.blf.org.uk/copd>.
2. Collins et al. Influence of deprivation on health care use, health care costs, and mortality in COPD. *Int J Chron Obstruct Pulmon Dis*. 2018;13:1289–1296. doi: 10.2147/COPD.S157594
3. Gershon et al. Trends in socioeconomic status-related differences in mortality among people with chronic obstructive pulmonary disease. *Ann. Am. Thorac. Soc*. 2014;11:1195–1202.