



## National Asthma and COPD Audit Programme (NACAP)

### NACAP: Richard Driscoll Memorial Award 2021

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#### **Introduction**

More than 9 million people in the UK are living with asthma or COPD, the voices of whom are essential to improving patient care, services, and outcomes. The National Asthma & COPD Audit Programme (NACAP) listens to and empowers people with respiratory disease by sharing information that meets their needs.

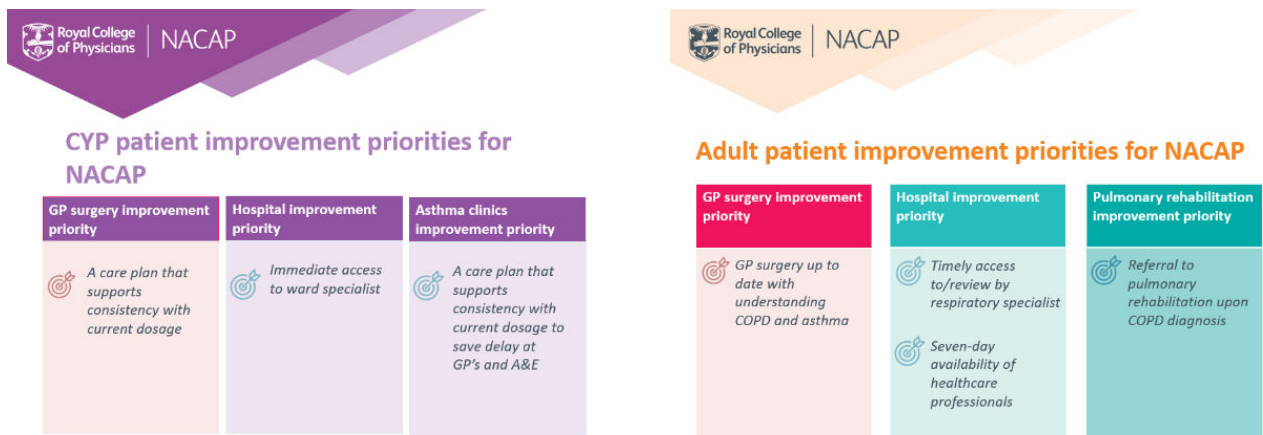
#### **Involving patients and carers in NACAP**

NACAP have established two vibrant patient panels. The first, hosted by Asthma UK & British Lung Foundation Partnership (AUK-BLF), represents adults with COPD and/or asthma who may also be carers and have other long-term conditions. The second, hosted by the Royal College of Paediatrics and Child Health (RCPCH) represents children and young people with asthma and/or other long-term health conditions, as well as parents and carers. The patient panels meet regularly online to share their priorities for respiratory care and discuss how they think NACAP can best educate and empower both patients with respiratory disease and those responsible for the care that they receive.

#### **Prioritising the views of patients and carers**

NACAP ensure that people with lived experience of respiratory disease influence our work to drive improvements. For example, in 2020 RCPCH hosted 10 clinic chats; visiting children and young people and their families in outpatient asthma clinics across the country to discuss what they thought were the key priorities for improving asthma care. In parallel to this, NACAP collected children, young people and adult patients' perspectives on key areas for bettering care via a survey.

The following patient priorities were developed as a result:



Adult patients explained why the areas of care they had prioritised were so important:

**GP surgery up to date with understanding COPD and asthma**

*“The surgery is my first port of call when my asthma is playing up, and I need to be sure that the doctors and nurses are going to be able to give me the best care possible. I want to get the most I can out of life despite having a lung condition, and I know that if the GPs are up to speed with new interventions and treatments, I have a better chance of doing so”.*

**Timely access to review by respiratory specialist**

*“Having timely access to a respiratory specialist gives me peace of mind that I am being well looked after. I can discuss things that concern me without a delay and the respiratory specialist is able to give me a good oversight into my condition and how it will affect me. Respiratory specialists are best-placed to appraise my response to medications and the quality of my daily life and can amend medications and make referrals to other teams if needed.”*

**Seven-day availability of healthcare professionals**

*“Asthma doesn’t keep to a Mon - Fri schedule so having Health care professionals available 7 days a week gives continuity of care and access to support & advice when it’s needed. If someone is struggling on a weekend, it may save their life to not leave it until Monday.”*

**Referral to pulmonary rehabilitation upon COPD diagnosis**

*“Getting help for managing COPD as quick as possible is essential. Referral to pulmonary rehabilitation upon diagnosis means you will be offered regular check-ups with a respiratory specialist. The exercise side of PR will help strengthen your lungs, and teach you exercises you can continue to do at home after the classes finish. But pulmonary rehabilitation isn’t just about the exercise. There are also education sessions attached to the classes; whether it’s about your inhalers, how to clear phlegm, your diet and the good and bad things to eat with COPD plus much more...it all helps. The sooner people are made aware of all these things, the easier it should be for them to practice self-care and manage their condition, and hopefully the less scary it will be for them.”*

## Co-creation of patient and carer-focused resources

Using patient feedback, NACAP have been able to optimise information outputs in terms of their accessibility, format, tone, layout, presentation and language.

Examples of this include:

- Creating a short, streamlined children and young people asthma clinical audit 2019-2020 patient report tailored for different age groups (older children and parents/carers). Patients felt that the shorter the report, the more likely it was that people would read it. The report contains simple summaries, patient stories and colourful infographics that are easy to understand and visually depict the data. In addition, leaflets and animations targeted at each of the 4-7, 8-12, and 13-18-year age groups are in progress and expected to be published next year
- Producing a text only version of the adult asthma national clinical audit patient report 2019-2020 for those who are visually impaired and use audio readers
- Explaining the process and flow of audit data to patients via a storyboard which will be converted into an animation with voiceovers to further enhance visualisation and understanding
- Drawing up a plan to develop an audio format of reporting outputs for those unable to read and to allow the visually impaired access to information
- Using the Hemmingway programme to create reports in simple English.
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## How we get the information to those who need it most

NACAP communicates important information to patients in the following ways:

- AUK-BLF and RCPCH communication channels
- Sharing patient experiences and feedback in reports, audit newsletters, the NACAP website, the NACAP Twitter page (@NACAPaudit)
- Incorporating patient priorities for improving respiratory care into the good practice repositories
- Exploring new approaches to increase diversity and reach out to involve people from different communities in our work.

## Beneficial Impact

Enabling patients to influence the direction of the audit programme has had a beneficial impact on:

### **1) Patient empowerment**

By listening to patients and carers we know what there is a need for (and so we have co-produced) information that can guide and promote self-management of conditions, empower patients to have conversations healthcare professionals, and question them if they are not receiving particular elements of care to the correct standards or at all.

### **2) Clinicians' understanding of patients' views**

One member of the patient panel said that they have *“enjoyed being able to attend board meetings to help put a patient's view across to the clinical leads.”*

Another said that *“empowering patients to have structured conversations with healthcare professionals will help.”*

Working with patients and carers as ‘partners’ is central to NACAP’s character. We share learning between patients and clinicians within the Programme team and we promote the importance of patients and clinicians understanding each other in local settings. For example, our new quality improvement Education Programme has a module on working with patients as partners.

### **3) Accessibility of information for patients and carers**

Working with patients and carers enables NACAP to produce information that is relevant and easy to understand for wider patient and carer groups. We are also able to work with patients to understand who needs this information most and how we can get it to them.

#### **Being part of the NACAP Team**

We asked patients what it meant to them to be a part of the NACAP team. This is what they said:

*“To be part of the NACAP audit has been interesting & has heightened my awareness of the work done ‘behind the scenes’ to help advise and support asthma & copd patients.”*

*“The audit is a great way to find out what best practice should be, and whether a GP surgery or hospital is trying to achieve it. It’s also a good way to encourage health professionals to work toward best practice, which will then improve the lives of all of us with lung conditions.”*

*“Being part of NACAP means an awful lot, to be honest. I’ve suffered from asthma since childhood and nearly died from asthma attacks more than once. I’ve had Obstructive Sleep Apnoea since around 2007, COPD since 2013, and whilst I’ve probably had it longer, I was diagnosed with bronchiectasis in 2014. I’ve spent what feels like half my life in and out of hospitals. I feel honoured to be a part of the audit so I can share my experiences and insight from a lifetime of lung problems and hopefully put across some helpful thoughts to the audit to help shape the future of lung care.*

*By being a part of NACAP, I’ve learnt that some aspects of respiratory care are not universal. Different NHS Trusts do things differently, some worse than others and everybody really should be working from the same book”*

#### **Conclusion**

As demonstrated above, NACAP have embedded meaningful patient and carer involvement in our work to drive improvements in patient care across the respiratory pathway. We will continue to listen to and learn from those with lived experience of respiratory disease so that we can make a difference in the areas that matter most to them.