

## National Asthma and COPD Audit Programme (NACAP)

## Royal College of Paediatrics and Child Health (RCPCH)

### NACAP & RCPCH: Richard Driscoll Memorial Award 2022

Version 1.0: October 2022

#### Introduction

This joint submission with the RCPCH, will focus on how NACAP has engaged, worked, and produced patient resources for children and young people in collaboration with the Asthma & Me Ambassadors and RCPCH and Us.

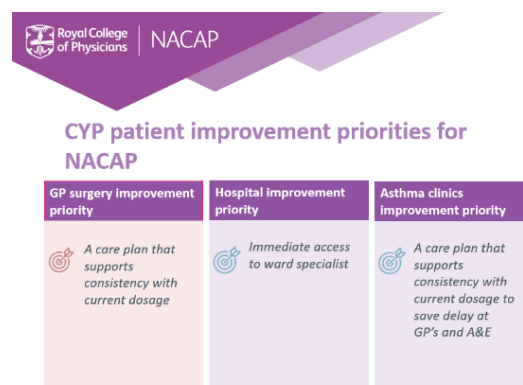
The National Asthma and COPD Audit Programme (NACAP) has a well-established and award-winning patient and public involvement and engagement (PPIE) programme. From the outset, the PPIE programme was designed to be at the heart of NACAP's audit work. Through working directly with respiratory patients and their carers, the 9+ million people in the UK living with asthma or COPD have been given a voice. NACAP and the RCPCH aim to use their powerful voice in improving patient knowledge, empowering patients, and delivering better respiratory care.

#### How are children and young people involved? How does NACAP prioritise their views? Are children and young people co-creating these outputs?

Since March 2018, the Asthma & Me Ambassadors have volunteered their time to inform and influence the NACAP programme. This group of young people aged 13-18 has been integral in creating information, resources, and materials to inform the sector and support asthma care for children and young people.

Using clinic chats between 2018 and 2019, children and young people (CYP) identified three CYP specific patient priorities. These priorities were embedded into NACAPs datasets, reports, and resources for the children and young people asthma audits to ensure what was important to them had a central focus.

The ambassadors meet with RCPCH every 6 weeks, either online or in person. This time is



spent reviewing NACAP requests and outputs, commenting on what matters to them, and developing their own quality improvement outputs based on the voices and views of children and young people with asthma. Two joint face to face meetings have also taken place to ensure that the Asthma &Me Ambassadors get a chance to discuss audit topics and initiatives with the NACAP team and the adult patient panel.

They've also been asked to be the opening speaker at the #AskAboutAsthma conference 2022 where they are sharing what matters to them to improve asthma care based on their audit project. They created the leaflets, presentation, blogs, webpage, and animation themselves, with clinical oversight from the NACAP programme – a great example of supporting patient-led engagement in a national audit programme.

**What methods are used to inform children and young people about NACAP and its results? How is it ensured that the information is inclusive and accessible?**

The Ambassadors felt there was a lack of age-appropriate audit resources available, and that children and young people would benefit from access to more engaging information. To solve this, the Ambassadors work with NACAP clinicians to influence the development of resources for their age group. This has led to the development of multiple resources with age-appropriate content and approaches with the correct clinical messaging.

Firstly, an [infographic](#) was designed to support the understanding of what should happen when children and young people are admitted to hospital because of their asthma. This idea was expanded to leaflets containing age-appropriate activities to help younger audiences engage with the information and tailored language, making them both accessible and enjoyable. These are available to three age groups [4-8 year olds](#), [9-15 year olds](#), and [16 years+](#).

**Admission to hospital for asthma attack - Infographics and leaflets for children and young people**



**Animation**

An animation has also been produced, with text on screen, to be shown in waiting rooms in clinical settings. The video is centred around a cricket with asthma and outlines the care that a child or young person should expect when in hospital because of their asthma. The animation is fun and informative; the design has been led by the members of the Asthma &Me group. There are future

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plans to add a voice over to this to make it accessible to those with sight loss and the final animation will be launched on the [Asthma &Me Ambassadors website](#) next week.

### Primary care postcard

The Asthma &Me Ambassadors felt that children and young people would benefit from access to questions they could ask their GP about their care in a simple, accessible format. Co-produced with NACAP, they designed the primary care postcard. These outline three elements of care they should expect to receive, offers prompt questions should they not receive what is expected, and includes simple ‘Colour me in’ sections to encourage children to engage with the information. It was important to the group to feel able to challenge clinicians, but this could feel daunting. Simple, accessible resources like this support the group to feel more confident and be actively involved in their care.



### Communication and dissemination

#### How does the project engage and communicate with other patients and how does the activity reach all relevant groups? What approaches to disseminate outputs are working well and how easy is it to locate the information?

NACAP robustly follows the Royal College of Physicians (RCP) value of ‘collaboration’ when engaging with patients and collecting their voice. Here is a summary of all communication mechanisms used by NACAP, RCPCH &Us, and Asthma &Me Ambassadors to engage with young people with asthma, their carers, healthcare professionals, commissioners, and all other relevant groups.

Panel meetings	Focus groups	Clinic chats*	Hardcopies of materials
Social media	Websites	Conferences and events	Plenary sessions
Open sessions**	Interviews with specialist nurses	Posters	Blogs
RCPCH magazine***	Emails (6000K + mailing list)	Newsletters and ebulletins (including external stakeholders where they have them)	Asthma friendly school initiative

\*where interviews and discussions took place between youth workers and patients in different meetings and clinics

\*\*where young people with an interest in asthma (but don't want to be part of a regular group) can join and share their views

\*\*\*which goes to over 20K

NACAPs communication is very much enhanced by what the Asthma &Me Ambassadors do. They are particularly good at actively engaging with the respiratory community and talking to them at high profile events.

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The new age specific leaflets and animation have been specifically launched at the Ask About Asthma conference to promote and encourage use in the respiratory community. The leaflets are currently being piloted in a select number of GP surgeries with the hope and intentions that they will be provided to each young person at their primary care annual asthma review. We are also reaching out to all asthma friendly schools initiatives across England to ask them to host the leaflets on their websites, accessible as a signposted set of resources for improving knowledge and education of asthma for children and young people with asthma.

We continue to try new forms of communication and find that varying the ways in which information and resources are disseminated ensure good and comprehensive coverage. Information can be easily located on a number of public spaces; however, we continue to identify new ways of doing this including getting the animation into waiting rooms at hospitals and GP surgeries.

**How are patients involved? Are they leading this work? How is the learning being shared and implemented? How are patients embedded in the programme?**

The Asthma &Me Ambassadors project is embedded into NACAP via regular requests for insight, design, input, and comment on a wide range of audit outputs/resources. Ambassador's and/or their RCPCH representative attend NACAP advisory groups and board meetings to share what they have been working on and to increase the knowledge and understanding of children and young people's hopes, wishes, and needs in relation to asthma care. Asthma &Me Ambassadors also attend national events to discuss their experience and work with healthcare professionals, commissioners, and policy makers.

This collaborative way of working cuts across the entire NACAP programme, ensuring a clear, consistent, and strong voice for children and young people across the spectrum. Audits are designed with the patient and their priorities at their centre and resources are produced with them at the helm to ensure they are useful and designed in a way that meets their needs.

Together we ensure that all resources contain useful information that is aimed at children and young people to support them in an accessible way to manage their asthma care in school, at home, when admitted to hospital or when visiting their GP. All resources produced are made accessible via NACAPs webpages, schools, hospitals, and GP surgeries, and also on their own specific [webpage](#).

**Is there evidence that the outputs are supporting people in their own care? Can patient groups use the outputs to influence their local services? Are the resources reaching the target audience?**

All resources are disseminated widely to ensure children and young people with asthma and their carers can access them and are supported and informed on the care they receive. In doing this and providing children and young people with specific advice and questions tailored to them and their asthma care, they are empowered to ask searching questions and have a direct influence on their care and local services.

In particular, the new suite of leaflets has created a huge amount of interest and conversation, particularly at the 2022 Ask About Asthma conference and RCPCH conferences. At these events Asthma &Me Ambassadors spoke directly to paediatricians and allied healthcare professionals who listened about their asthma and audit experience. They were a part of plenary sessions and interviewed the four UK Children's Commissioners on the main stage where the resources they have co-produced with NACAP were promoted.

At the Ask About Asthma conference, the new animation was launched and the results of a recent Menti poll confirmed that approximately 98% of participants are happy to share it in clinic waiting rooms, on websites, and through social media channels.

The Asthma &Me Ambassadors are incredibly proud of their role in the audit and the chance to advocate on patient priorities and resources at all opportunities. NACAP hopes with their patient resources now becoming more widely available this will become more common.

### **Conclusion**

NACAP, in collaboration with the RCPCH, prioritise the views and voice of patients and their carers, embedding this centrally through every aspect of its programme. It has been a privilege to work with such a passionate and driven group of young people to produce a range of resources that we believe will educate and empower children and young people to be actively involved in the delivery and improvement of their asthma care.

The work we have undertaken with them, and the high quality of the final products are testament to how important it is to work with patients of all ages and all background. Each person offers a unique insight into what their care means to them. We are certain that in working so closely with the Asthma &Me Ambassadors we have produced resources that will not only support children and young people with their asthma but make them feel a part of something bigger.