

National Asthma and COPD Audit Programme (NACAP)**Patient and Public Involvement and Engagement (PPIE) strategy 2021 - 2023**Version 1.2

Contents

1. Summary	2
2. Overarching strategy	3
3. PPIE within NACAP governance structure.....	4
3.1 Patient panel	4
3.2 Other governance groups	5
4. Impact evaluation	5
5. Use of social media and online platforms.....	6
5.1 Use of surveys	6
5.2 Use of social media	6
5.3 Measuring impact of social media and online services	7
6. Communication with stakeholders	8
Appendix 1: Patient Panel Terms of Reference	9
Appendix 2: Snapshot of Patient Panel feedback summary (impact log)	10
Appendix 3: Snapshot of Patient Panel output review tracker.....	11
Appendix 4: Adult patient improvement priorities for NACAP.....	12

1. Summary

Within the health service Patient and Public Involvement and Engagement (PPIE) encompasses the active inclusion of service users in project decision making and creation of public-friendly outputs.¹ Involvement can be defined as identifying priorities, membership to governance groups and providing feedback on project materials, for example. Engagement, on the other hand, involves disseminating findings, using social media and hosting events for service users.

Increasing and improving PPIE in national audit activities is a key priority area for the National Asthma and COPD Audit Programme (NACAP), commissioned by the Healthcare Quality Improvement Partnership (HQIP). Inclusion of PPIE throughout the audit programme will ensure the patient voice is central to decision making and reflected in outputs across the programme (such as datasets, national and patient reports as well as quality improvement resources).

The NACAP PPIE strategy will embed the HQIP seven principles of involvement¹:

- **Representation** – *broad representation of affected population*
- **Inclusivity** – *provide sufficient resource to overcome barriers such as access or communication*
- **Early and continuous involvement** – *in all areas of the process/activity*
- **Transparency** – *ability to see and understand how decisions are made and provision of audit data in clear and easily understood formats*
- **Clarity of purpose** – *the nature and scope of involvement is defined prior to involvement and it will be made clear how publications can be used to inform patients about the quality of services*
- **Cost effectiveness** – *involvement must add value and be cost effective*
- **Patient and public feedback**– *Outcomes of PPI activities will be fed back to participants, and feedback on products used to review and improve publications*

The audit team have subcontracted the Asthma UK-British Lung Foundation (AUK-BLF) and Royal College of Paediatric and Child Health (RCPCH) (herein collectively referenced to as ‘the subcontractors’) to coordinate the recruitment, retention and engagement of service users in audit programme activities and provide advice and support in the process. The audit team will also consult with a broader range of expert stakeholders to ensure the NACAP PPIE strategy is robust throughout the audit programme contract period.

¹ Involve. *What is public involvement in research?* [Online] Available from: <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/> [Accessed October 2018].

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2. Overarching strategy

The principal aim of the PPIE strategy is to ensure that the views of patients and carers are reflected in the delivery of NACAP and its outputs. By incorporating PPIE into the programme, we will ensure that outputs produced for service users are accessible, understandable and useful in order to empower people to ask for better care at an individual and national level.

The below table lists the key planned PPIE outputs for the audit programme. Please note the expected deadlines are subject to change throughout the programme and will be updated accordingly.

Output	Purpose	Expected completion data
1 adult AUK- BLF focus groups	To discuss adult patient priorities survey results	2022
Series of RCPCH clinic chats	To discuss children and young people priorities survey results	2021/2022
Adult patient representation and RCPCH patient representative on all NACAP governance groups	To ensure the ideas and feedback from the Patient Panel are taken into account	Ongoing
Annual primary care patient reports	To produce patient-focused primary care reports	May 2022
Annual COPD secondary care patient resources	To produce patient-focused COPD secondary care resources	2021/2022
Annual adult asthma secondary care patient resources	To produce patient-focused adult asthma secondary care resources	2021/22
Children and Young People asthma secondary care patient resources	To produce patient-focused Children and Young People asthma secondary care resources	2021/22
Pulmonary rehabilitation patient resources	To produce patient-focused pulmonary rehabilitation resources	2022
Report on impact of patient and public involvement	To review the success of patient involvement and understand where improvements in strategy are required	Regular intervals throughout contract period

**Grey rows indicate completion of output*

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3. PPIE within NACAP governance structure

NACAP Board	COPD and Asthma advisory group	Patient Panel
<ul style="list-style-type: none"> • 1 x COPD patient • 1 x adult asthma patient • 1 RCPCH rep 	<ul style="list-style-type: none"> • 1 x COPD patient • 1 x COPD patient (<i>with experience of PR</i>) • 1 x adult asthma patient • 1 x RCPCH rep 	<ul style="list-style-type: none"> • 15 x adult asthma and COPD patients • 5-10 x children with asthma and other long term health conditions

Representation on all governance groups has been and will continue to be sought via the AUK -BLF Patient Engagement Manager and RCPCH Children and Young People Engagement Manager (the subcontractors). The subcontractors have the continued responsibility to recruit to the Patient Panel and approach members of the panel to attend the NACAP Board and Advisory Group meetings.

Membership to all NACAP governance groups operates on a flexible basis; members should feel free to step-down from the group at any time for any reason. The subcontractors will ensure that spaces on all groups are optimally filled and, where possible, broadly representative to include a range of:

- Moderate and severe disease acuity
- Gender
- Ethnicities
- Be from more than one region
- Patients who have been admitted to hospital within the last year
- Patients who have not been admitted to hospital but receive or should be receiving regular primary care support/management
- Patients who have attended pulmonary rehabilitation

3.1 Patient panel

The Patient Panel will ensure the patient voice is represented by working with the NACAP audit team on outputs including, but not limited to, datasets, patient information documents, communication

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strategies, patient resources, and other nationally available outputs. The group will predominately work virtually, with less frequent face-to face meetings.

a. Face-to-face meetings

Face-to-face/virtual Patient Panel meetings will be hosted in 2022, facilitated and supported by both the RCP and subcontractors. Terms of reference will be provided to subcontractors and panel members (see appendix 1).

3.2 Other governance groups

Members of the Patient Panel that opt to attend other governance group meetings are not be required to attend each one; patients will be approached ahead of each meeting and chosen based on availability to attend. This strategy has been put in place to ensure maximum attendance to each governance group meeting and allow different members the opportunity to represent the views of the wider Patient Panel.

To ensure maximum engagement in all NACAP meetings (virtual or face-to-face) lay-friendly summaries of any information that is provided to governance group members will be produced. The summaries will clearly highlight the purpose of each document and, where required, the type of feedback that will be requested. All information will be provided to members 10 working days in advance of face-to-face meetings to ensure they are well-informed and comfortable taking part in discussions. The NACAP team will also aim to provide video and teleconferencing facilities for representatives to join virtually if needed.

4. Impact evaluation

Evaluation of the NACAP Patient Panel impact will aim to:

- Understand how feedback provided by the Patient Panel on NACAP outputs and activities has directly **impacted decision making** for the programme
- Understand how NACAP can **incorporate the Patient Panel most effectively** into audit programme activities

Evaluation of the impact of the Patient Panel will occur at a number of levels as depicted in the below table.

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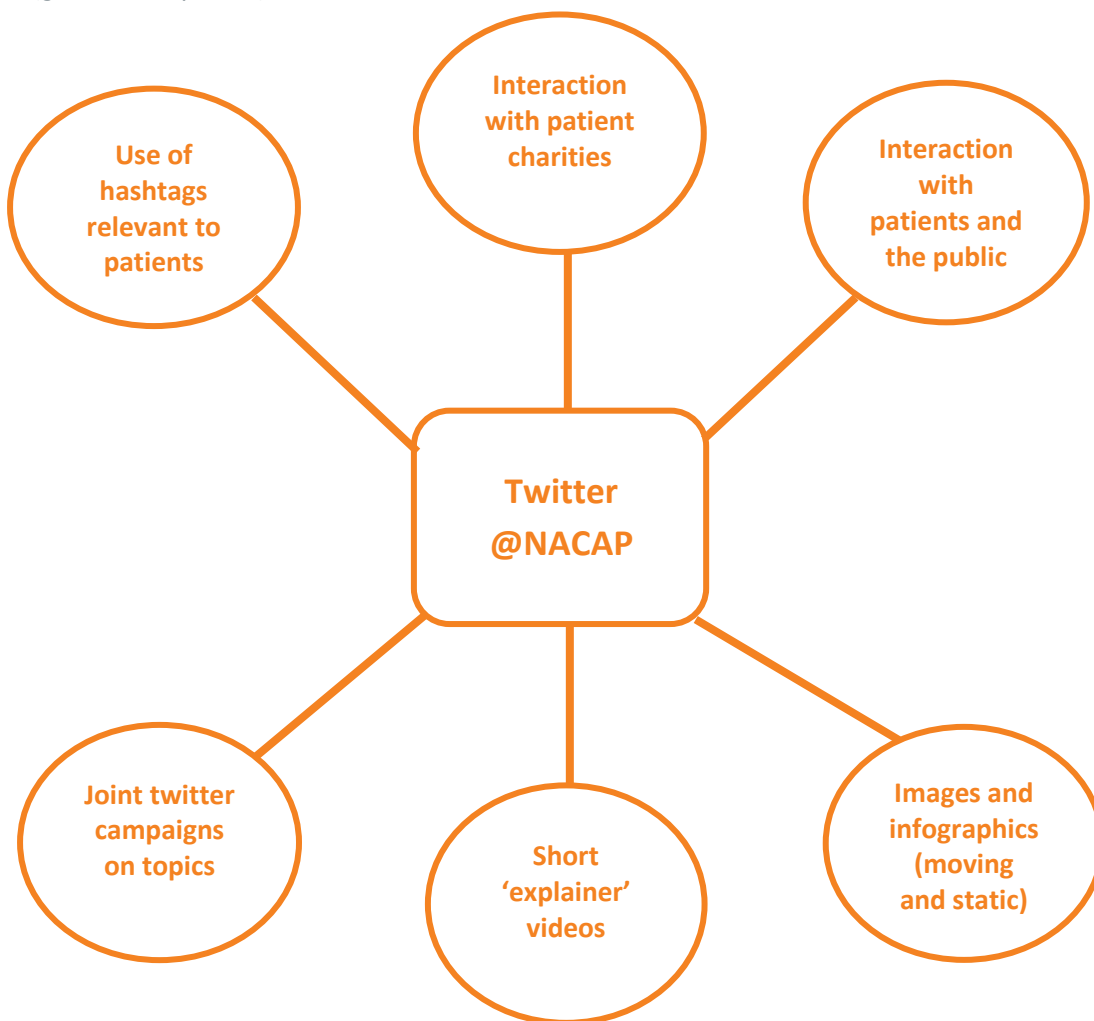
5. Use of social media and online platforms

5.1 Use of surveys

Online surveys provide a quick and easy approach to gaining wider feedback from a larger and more diverse range of people. The audit programme will look to use short online surveys to gain feedback on national reports via SurveyMonkey and will seek engagement from stakeholders to host future surveys on their social media platforms.

5.2 Use of social media

Use of social media will form a pivotal part of the patient and public involvement and engagement communication strategy for NACAP. The Patient Panel will be regularly consulted on how NACAP can disseminate lay-friendly outputs (general or specific) to service users and increase reach. The Patient Panel will also be involved in the creation of these materials for social media. They will also be consulted on how best NACAP can interact with patients and the public to collect opinions and feedback on audit outputs (general or specific).



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Whilst the NACAP twitter (@NACAP) has a following of 3,234 people (as of 21 May 2021), the audience is predominately healthcare professionals. As part of the communication strategy, it will be important to engage with key patient organisations on joint twitter campaigns to extend reach of messages to individual patients and smaller patient groups. Aligning campaigns and individual tweets with relevant annual calendar dates such as 'World COPD Day', 'World Asthma Day' and 'World Mental Health Day' will be planned.

5.3 Measuring impact of social media and online services

a. Online surveys

Reach of online surveys will be measured by recording participation in-line with the dates that specific communications were initiated e.g. posting of survey link on patient organisation Facebook page.

b. Twitter activity

Reach of twitter activity will be measured through use of readily available twitter analytics which rank tweets by number of interactions received (number of clicks, retweets, favourites, replies). We will also track the number of followers gained on a quarterly basis and liaise with the RCP communications team on how best to specifically engage patients and carers.

6. Communication with stakeholders

The below table provides an overview of the main stakeholders through which elements of the NACAP PPIE work will be communicated and/or disseminated, and how often this communication will occur. Other key NACAP stakeholders will be made aware of PPIE activities throughout the lifetime of the programme via NACAP governance group updates and/or emails pertaining to particular PPIE outputs such as the publication of patient reports.

Stakeholder	Aim of communication	Type of communication	Frequency of communication
Royal College of Paediatrics and Child Health and Asthma UK – British Lung Foundation - Joint	Ongoing communication around Patient Panel activities.	Virtual meetings with email updates in between meetings	Monthly/when required
Asthma UK – British Lung Foundation	Ensuring stakeholder up-to-date with audit programme objectives	Virtual meetings with email updates in between meetings	Monthly/When required
Royal College of Physicians Patient and Carer Network	Dissemination of PPIE outputs and provisions of ‘calls to action’ that arise from Patient Panel (e.g. requests for comment or opinions on particular topics/outputs which are planned in advance))	Email	Ad hoc
Academic Health Science Networks	Ongoing communication around patient-led quality improvement activities	Email/face-to-face	Ad hoc
NHS Patient safety network (Ellie Wells) Patient safety lead for AHSN (Ursula Clarke)	Ongoing communication around patient-led quality improvement activities	Email/face-to-face	Ad hoc
Association of Respiratory Nurse Specialists	Ongoing communication around patient-led quality improvement activities	Email/face-to-face	Ad hoc

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Appendix 1: Patient Panel Terms of Reference



NACAP patient
panel ToR adults_v1

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Appendix 2: Snapshot of Patient Panel feedback summary (impact log)

1. Feedback on the audit programme (NACAP-wide feedback)		
What was the feedback?	Who provided the feedback?	What action has been taken?
<p>The patient panel have said that the current format of the patient reports <u>are</u> difficult for those using audio readers to read due to the data being presented in picture format. It was highlighted that patients who were blind/unable to read would struggle to access audit findings and navigate through the report easily.</p>	<p>Adults, at the online advisory group meeting</p>	<p>The NACAP team have published a text only version of the latest COPD clinical audit patient report which was reviewed by the patient panel. A text only version of the latest adult asthma adult asthma clinical audit patient report is due to be published Autumn 2021.</p>
<p>The patient panel were shown an example of the NACAP audit data flow maps which are publicly available. The panel were asked to think about what they would like to know about where their data goes, and how it should be communicated to them. The general feedback was that the data flows are complex, meaning the most popular format of explaining the data flow was in person, visually, and with less acronyms. In addition, it was highlighted that the key things patients want to know about their data regard:</p> <ul style="list-style-type: none"> • Whether the data is anonymous • Who has the data and why • What the purpose of the data being held is • Whether the data is kept securely <p>Reassurance that inclusion of data in the audit and its wider data flows does not impact the care an individual receives</p>	<p>Adults, <u>children</u> and young people at the patient panel annual face-face meeting</p>	<p>The NACAP team have creates a story board (PowerPoint presentation) that explains the audit data flow process. The story board may be converted into an animation with voiceovers. This will enable the data flow process to be explained verbally and depicted visually. The story board will be sent to the patient panel before it is converted into the animation.</p>
<p>The patient panel were asked to search for NACAP reports and patient information online, imagining they did not know the term 'NACAP'. The group found it was hard to find anything about the programme unless they used specific search terms like 'COPD national audit'. The panel made the following suggestions:</p> <ul style="list-style-type: none"> • Include patient reports and leaflets on relevant charity websites (ie Asthma UK, BLF, RCPCH) as well as NHS choices/other relevant NHS pages • As well as using terms like audit, patients may use the following search terms: <ul style="list-style-type: none"> o Best practice for asthma care/COPD care o Standards of care o What can I expect if I need hospital treatment for an exacerbation? o COPD/asthma data, COPD/asthma care o Asthma/COPD care consistency/issues o Improving services for COPD/asthma sufferers o Asthma management 	<p>Adults, <u>children</u> and young people at the patient panel annual face-face meeting</p>	<p>The NACAP team will review the types of tags they add to reports and leaflets online to try and make them more visible on search engines (using the search terms provided by the panel to improve this).</p> <p>The NACAP team will also discuss with the relevant charities whether appropriate reports (and other patient material) could sit on their webpages.</p> <p>In addition to the above the NACAP team will be producing animations as part of suite of patient outputs we currently produce.</p>

Patient Panel Feedback Summary | Version 1.2 August 2021
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Page 3 of 24

PPI Strategy 2021 - 2023

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Appendix 3: Snapshot of Patient Panel output review tracker

RCPCH NACAP Output Review		2021							
		May	June	July	August	September	October	November	December
Workstream/Output									
CYP asthma									
	Combined patient report - patient panel review								
	Animation x 3 - patient panel review								
	Leaflet x 3 - patient panel review								
	CYP audit webinar - Emma Sparrow presenting								
Primary care audit									
	Patient report								

AUK/BLF NACAP Output Review		2021							
		May	June	July	August	September	October	November	December
Workstream/Output									
Adult asthma									
	Text only patient report								
COPD audit									
PR audit									
	Patient report (Full and text only)								
	PR pathway guide								
Primary care audit									
	2020 patient booklet		28th - 7th						
	2020 postcard for children		28th - 7th						
NACAP									
	Senior clinical lead interviews			5th and 8th					


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Appendix 4: Adult patient improvement priorities for NACAP



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Adult patient improvement priorities for NACAP

GP surgery improvement priority	Hospital improvement priority	Pulmonary rehabilitation improvement priority
 <i>GP surgery up to date with understanding COPD and asthma</i>	 <i>Timely access to/review by respiratory specialist</i>  <i>Seven day availability of healthcare professionals</i>	 <i>Referral to pulmonary rehabilitation upon COPD diagnosis</i>

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