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Authors	Marina Cronin, Head of Quality & Development Aisling Connolly, Communications and Event Lead, NOCA				
Reviewers	Bibiana Savin, Public and Patient Interest representative, NOCA Dr Susie Donnelly, Postdoctoral Researcher, University College Dublin Centre for Interdisciplinary Research Education and Innovation in Health (IRIS). Olga Brych, Data analyst, NOCA				
Approved by	Collette Tully, Executive Director, NOCA			Level 2 Approval	
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1. INTRODUCTION

1.1 Purpose

NOCA recognises the value of public and patient involvement in its activities. NOCA works to the Framework for Public Involvement in Clinical Effectiveness Processes (National Clinical Effectiveness, 2018). While clinical audit provides information on quality in the healthcare system, the patient / carer perspective provides the individual healthcare experience (Hardy and Sumner, 2012).

This consultation to capture the patient story, allows a thorough understanding of their subjective experience in healthcare, through their eyes or those of carers. It is a powerful way of increasing focus and engagement with quality and safety issues and of highlighting aspects of care covered by NOCA clinical audits. Patient stories can be used to enhance understanding of clinical data, thereby informing the quality improvement (QI) aspects of clinical audit. They can also be used to inspire, educate and enable learning, as well as for public engagement.

1.2 Scope

NOCA is committed to putting the patient's story at centre of national clinical audit. It does this through inclusion of a patient story in its reports and on its website.

1.3 Objectives

The objectives of this policy are to:

- Create opportunities for NOCA to engage and present patient stories, which present the lived experience behind audit data and may highlight important aspects arising from national clinical audit
- Develop templates to use for patient stories for staff in NOCA
- Improve the skills and capacities of NOCA staff to become involved in capturing and disseminating patient stories.

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1.4 Outcome

The outcomes of implementation are

- Development of collaborative relationship between health care professionals and patients and carers.
- Creation of opportunities to increase focus and engagement with quality and safety issues and of highlight aspects of care covered by NOCA clinical audits.

1.5 Definitions

The following terms used in this policy are defined as follows:

Table 1.1: Definitions used in this policy

Term	Definition
Collaborative relationship	<p>Health care professionals and patient partners move beyond a 'them and us' relationship (where power is held predominantly by one partner) to a more collaborative relationship where power is shared.</p> <p>A defining feature of the collaborative pair relationship is that everything is shared – for instance, establishing the shared purpose, working to a shared ambition, exercising shared leadership, with shared ownership and shared responsibility for what happens.</p>
Patient story	<p>Patient stories involve interviewing patients directly to gather their insights on the service they have received. Patients share how they felt, what they saw and heard, the emotions evoked, and in turn how this may have affected their decisions, actions and overall experience throughout their healthcare experience.</p>

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	<p>Patient stories are not something to be judged or defended, they are events that happened to the patient and they are their personal thoughts, feeling and memories about their experience. They can be positive or negative, however they often contain a mix of positive and negative experiences.</p> <p>Stories can be delivered by patients and/or carers, or staff can also tell the story from a patient's perspective, coupled with what it is like to be a member of staff involved in that persons care.</p>
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1.6 Roles and responsibilities

Table 1.2: Roles and responsibility for implementation of this policy are:

Role	Responsibility
Healthcare professionals based in healthcare provider organisation	Identify patient and or carers who may wish to share their story with NOCA
NOCA Audit Managers and executive team members	<p>Implementation and monitoring of this policy</p> <p>Audit managers – National reports</p> <ul style="list-style-type: none"> • Engage with patients and carers to collect and finalise patient stories • Review and update NOCA PIA • Write patient stories <p>Communications and Event Lead- NOCA website</p> <ul style="list-style-type: none"> • Engage with patients and carers to collect and finalise patient stories • Review and update NOCA PIA
NOCA Data Analytics Team	Support data analysis for development of stories
NOCA Head of Quality & Development	Training and evaluation of this policy

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1.7 Supporting evidence

This is a new policy. It is supported by:

- NOCA-GEN-PIL04: Invitation to participate, Healthcare experience
- NOCA-GEN-PIL 01 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for NOCA reports, June 2019
- NOCA-GEN-PIL 02 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for the NOCA website, June 2019
- NOCA-GEN-FM 01 Capturing your perspective in NOCA reports, consent form
- NOCA-GEN-FM 02 Capturing your perspective for the NOCA website, consent form
- A privacy impact assessment which is reviewed and updated as required.

2. APPROACH TO CAPTURING AND DELIVERING PATIENT STORIES FOR NOCA

2.1 Overview

Patient experiences and perspectives are primarily shared in NOCA reports and on the NOCA website. Patient / carer perspectives are digitally recorded by audio and/or video. Both interview and focus group methods are used.

2.2 Managing ethical concerns in a quality activity- Capturing the patient perspective for NOCA

NOCA works to the National Consent Policy (HSE, 2013). Autonomy (self-determination), the right to control their own life and to decide what happens to their own body, is the ethical rational underpinning consent (HSE, 2013; HQIP,

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2017). Obtaining informed consent is a key requirement before individual patient/carer interviews or focus groups begin.

Informed consent must be voluntarily given. Patient/carers must be able to participate on a strictly voluntary basis are able to withdraw at any time without need for explanation and not be acting under duress (HSE, 2013).

To ensure that privacy and confidentiality of participants is protected, a privacy impact assessment is carried out (available at: <https://www.noca.ie/publications>). Privacy and confidentiality is assessed in line with this policy and actions implemented. NOCA staff involved in capturing patient stories, review and update this as required.

In quality improvement work, formal research ethics committee (REC) approval for the capture of patient perspective is not necessary. However, it is essential to ensure an ethical approach is employed. A detailed ethical review has been conducted to support this activity and a summary is included in Appendix 1.

2.3 Collaborating with patients, carers and other healthcare professionals

NOCA recognises that front-line healthcare professionals are well placed to identify potential patients / carers who may wish to share their perspective. This process supports this approach and describes the process for collecting patients / carer perspectives for NOCA.

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2.4 Procedure for capturing patient & carer perspectives

Table 2.1: Capturing and delivering patient stories for NOCA

Process steps	Detail
Identify potential patient	<ul style="list-style-type: none"> Any patient who has had experience of the service (e.g. hip fracture care, intensive care) is eligible to share their story. Any healthcare professional can identify a patient or carer who may like to share their story. Ask patient to contact NOCA. Alternatively NOCA staff may identify and approach potential patient and carers <p>Support: NOCA-GEN-PIL04: Invitation to participate, Healthcare experience</p>
NOCA provides information	<p>NOCA Audit Manager / executive team member provides information and answers questions from the patient / carer.</p> <p>Support:</p> <ul style="list-style-type: none"> NOCA-GEN-PIL 01 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for NOCA reports, June 2019 NOCA-GEN-PIL 02 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for the NOCA website, June 2019
NOCA Audit Manager/ executive team member arranges a convenient time and place for the interview	<ul style="list-style-type: none"> Taking into consideration accessibility needs and communication needs Allowing at least an hour for the interview to take place The most convenient and appropriate location may be the patient's home. Home is often where people feel more relaxed. This tends to yield a better interview and diffuses some of the power imbalance present in clinical settings.

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Process steps	Detail
Prior to the interview	<p>The NOCA Audit Manager / executive team member</p> <ul style="list-style-type: none"> • Agree an interview schedule – questions or themes to be covered • Clinical audit has an improvement focus. Reflect this in the questions e.g. <ul style="list-style-type: none"> • Ask for comment on best or worst aspects of care • Ask for suggestions for improvement] <p>This can be shared with the participant in advance</p>
During the interview/ focus group	<ul style="list-style-type: none"> • Take equipment to record the interview e.g. dictaphone, video • Travel vouchers if appropriate • Ask patient if he/ she has any questions about the interview • Explain what will happen to the information they share • Obtain consent from the patient/carer • Help the patient/carer relax by spending time relax by spending time asking some easy general questions before recording the story. <p><u>Supports</u></p> <p>I. Patient Information</p> <p>NOCA-GEN-PIL 01 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for NOCA reports, June 2019</p> <p>NOCA-GEN-PIL 02 National Office of Clinical Audit, Patient Information Booklet, Capturing patient stories for the NOCA website, June 2019</p> <p>II. Consent form</p> <p>NOCA-GEN-FM 01 Capturing your perspective in NOCA reports, consent form</p> <p>NOCA-GEN-FM 02 Capturing your perspective for the NOCA website, consent form</p>

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Process steps	Detail
Practical suggestions when carrying out audio or video	<p>Conduct interview with patient to capture their experience. Appendix 3 contains information on</p> <ul style="list-style-type: none"> • Verbal and non-verbal communication cues • Active listening • Open questions • Elaborating and clarifying questions • Maintaining structure and direction • Closing the discussion.
A participant is dissatisfied with their care and wants to complain	<ul style="list-style-type: none"> • Firstly, reassure patients that sharing their story can focus attention and engagement with healthcare quality and safety issues. Their story can enhance understanding of clinical data, thereby informing the quality improvement (QI) aspects of clinical care. This supports improvement in healthcare, address their concerns and issues so that future patients and carers can have experiences that are more positive. • NOCA supports patients to provide this feedback to the health service, in alignment with the HSE 'Your Service, Your Say The Management of Service User Feedback for Comments, Compliments and Complaints HSE Policy 2017'. <p>https://www.hse.ie/eng/about/aavd/complaints/howto/</p>
Concluding the interview	<ul style="list-style-type: none"> • Explain that the interview will need some editing in order for NOCA to use it effectively • If the patient wishes, a copy of interview transcript may be sent to them for review and edit before it is used • A final copy of the story will be sent for review • A patient can change their mind about use of the interview at any time • Thank the patient.

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Process steps	Detail
Analysing the narrative	<p>For reports</p> <ul style="list-style-type: none"> • Transcribe the narrative • Two independent reviewers should review the transcript to identify themes / Use data analytical package to identify themes • Select two –three themes. Themes should reflect what is important to the participant and / or reflect those of the national clinical audit and / or focus on areas of improvement. • Write the story using either first or third person. <p>And / or</p> <ul style="list-style-type: none"> • Identify appropriate text which could be used as quotes in the text. <p>For the website</p> <ul style="list-style-type: none"> • Video clips should be brief • Interviews on specific topics or about particular services may be cut into separate responses, and edited so they can be picked from a digital library. • With the patients consent, clips can also be used for the NOCA Twitter account.
NOCA Report / Website	Following editing and review, the story is published in the NOCA report / website.

3. MONITORING AND EVALUATION

- Compliance with this policy is assessed on an annual basis . Evidence of audit level compliance is the NOCA website and NOCA reports should include a patient story.
- Feedback of this policy is welcomed throughout the policy lifecycle. Formal evaluation of this policy is assessed through consultations with relevant stakeholders at prior to policy revision.

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4. REVISION/UPDATE

Revision of this policy will be undertaken on a two yearly basis, or earlier in the event of changing best practices or structures as appropriate.

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APPENDIX 1 DEVELOPMENT GROUP

Name	Title	Role
Marina Cronin	Head of Quality & Development, NOCA	Author
Aisling Connolly	Communications and Event Lead, NOCA	Author
Bibiana Savin	Public and Patient Interest representative, NOCA	First line reviewer
Dr Susie Donnelly	Postdoctoral Researcher, University College Dublin Centre for Interdisciplinary Research Education and Innovation in Health (IRIS).	First line reviewer
Olga Byrch	Data analyst, NOCA	Second line reviewer

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APPENDIX 2: MANAGING ETHICAL CONCERNS IN A QUALITY ACTIVITY- CAPTURING THE PATIENT PERSPECTIVE FOR NOCA AUDIT

In 2018, the NOCA HSE QIT Co Design Working Group, a short life working group (SLWG), was convened to co-design a methodology to collate patient perspective for NOCA. The SLWG comprised of representatives from both organisations, front-line clinicians (doctors, nurses, health & social care professionals) and public and patient interest (PPI) representatives. Thirty percent of the SLWG were PPI representatives.

Acknowledgments: The NOCA HSE QIT Co Design Working Group

- Marina Cronin, NOCA Co-lead
- Dr Gemma Moore, Mila Whelan, HSE QIT - Co-leads
- Laura Binions, Connolly Hospital
- Louise Brent, NOCA
- Alan Egan, Barbara Egan, Bibiana Savin – NOCA Patient and Public Interest representatives
- Dr Susie Donnelly, University College Dublin
- Dr Rachel Doyle, Ursula Kelleher, St Vincent's University Hospital
- Joanne Larkin, Cappagh National Orthopaedic Hospital

During the course of this work, a number of resources were developed to support this work, one of which was to describe how ethical concerns are managed in this capture the patient perspective in NOCA. A summary of this work is included here. Consideration was given to the ethical principles underpinning the capture of the patient perspective. They are outlined in Table A 1.1.

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Table A1.1: Ethical principles and their application to capture of the patient perspective

Principle	Meaning	Application
Autonomy	<p>An obligation to respect the rights of people to make choices concerning their own lives, for example, by disclosing information to:</p> <ul style="list-style-type: none"> • Enable people to make decisions • Avoid assuming a controlling influence on their decisions 	<ul style="list-style-type: none"> • Provision of information about the purpose of the project and how their data will be used • Seeking patients' informed consent
Non-maleficence	<p>An obligation not to:</p> <ul style="list-style-type: none"> • Harm others • Impose risks of harm <p>Assuming a standard of due care, that is, taking sufficient and appropriate action to avoid causing harm to a person</p>	<ul style="list-style-type: none"> • Maintaining confidentiality of information about patients, and providing privacy for patients where requested • Managing all identified ethical concerns which cause a risk of harm to a patient
Beneficence	<p>An obligation to act in ways that:</p> <ul style="list-style-type: none"> • Benefit others • Prevent harm, including removing circumstances that could lead to harm 	<ul style="list-style-type: none"> • Patient perspectives can be used to enhance understanding of clinical data, thereby informing the quality improvement (QI) aspects of clinical audit. They can also be used to inspire, educate, enable learning and as well as for public engagement. • Meeting a duty of care to provide patient care that is consistent with known good practice; process for managing disclosure of experience of a serious incident that has had or could have an important effect on their health or quality of life

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Principle	Meaning	Application
Justice	The idea that the burdens and benefits must be distributed equally among all groups in society and that resources are fairly distributed.	<ul style="list-style-type: none"> The ethical principle of justice and fairness suggests that no patient / carer group should be excluded from involvement in a QI project. Inclusion criteria used to define patient groups / carers (either patient characteristics such as gender, ethnicity, age or disease site or staff characteristics) need to be clearly justified. In addition, the potential burdens or risks and the potential benefits of QI work projects should be distributed fairly across the population of patients who are served by the healthcare organisation.

Addressing ethical concerns

1. Design and management of project to capture patient perspective

Consideration should be given to design and management of such a project. This includes the following;

Table A1.2: Design and management of a project to capture patient perspective

Good practice tips	Design and management
A project group to oversee guide the project with clear accountability relationship	The NOCA HSE QID Co Design Working Group was established to oversee this project, with reporting to both NOCA and HSE QID. Clear Terms of Reference were agreed.
Conduct a Privacy Impact Assessment to identify and address privacy concerns	A data privacy impact assessment is carried out and reviewed annually.

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Good practice tips	Design and management
Develop a project plan based on project aim and objectives	This project plan formed basis of the current policy
Provision of information and consent form.	An information leaflet and consent form were developed. These have been updated and are identified in Section 1.7: Supporting evidence
Resources to guide the process	Resources such an 'Information to participate' and guidance on managing this process were developed. These have been updated and are identified in Section 1.7: Supporting evidence

2. Ensuring informed consent

Obtaining informed consent is a key requirement before interviews or focus groups begin.

This requires

- An information leaflet**
- A consent form**

Refer to Section 1.7: Supporting evidence.

3. Ensuring confidentiality and privacy

A privacy impact assessment (PIA) is carried out to provide governance in assuring that participants rights to privacy and confidentiality are appropriately protected.

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This requires:

- **conduct of a PIA, to be publically available on NOCA website.**
- **a reminder that consent for use of the full or some specific parts of the patient perspective can be withdrawn at any time will be included on the information leaflet and consent form**

Refer to <https://www.noca.ie/publications/publications-listing/P0/category/4>

4. Managing potential comments, concerns or complaints disclosed during an interview

All information collected during an interview or focus group remains confidential and is only disclosed with consent from participants. During the course of an interview or focus group, a participant may disclose comments, concerns or complaints regarding their healthcare experience.

In this case, NOCA supports participants to provide this feedback to the health service, in alignment with the HSE 'Your Service, Your Say The Management of Service User Feedback for Comments, Compliments and Complaints HSE Policy 2017.

This requires

- **supporting patients to provide the feedback to the HSE through options available at <https://www.hse.ie/eng/about/qavd/complaints/howto/>**
- **this is an appropriate approach to ensure that comments, concerns or complaints relating to the patient healthcare experience are addressed , which cannot be resolved at the point of contact i.e. post discharge interview by a NOCA or HSE QIT representative (third party).**

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APPENDIX 3 USEFUL TIPS ON CONDUCTING INTERVIEWS TO CAPTURE PATIENT STORIES

This guidance is aimed at interviewers conducting interviews to capture patient stories for NOCA

<p>Verbal and non-verbal communication cues</p>	<p>Verbal communication cues</p> <ul style="list-style-type: none"> • All verbal communication with participants should occur in a clear and audible tone of voice. • Adopt the same tone, pitch and pace to that of the participant. Interviewers need to be alert to participants who may have difficulties hearing. • Avoid using technical language or jargon. <p>Nonverbal communication cues This includes anything that can be "seen" by the other person, such as:</p> <ul style="list-style-type: none"> • Gestures • Facial expressions • Eye contact • Body language • Positioning <p>These nonverbal cues can serve as windows to people's emotions and attitudes. Changes in a person's body postures and gestures often signal changes such as;</p> <ul style="list-style-type: none"> • Moving forward or sitting up indicates interest in discussion • Relaxation of the body and smiling indicates acceptance. • Maintaining regular eye contact without staring or looking away indicates active listening • Mirroring- nods, smiles, and gestures could also indicate acceptance. <p>Cultural, gender and individual differences influence how personal space is perceived. Interviewers should monitor how their position in relation to participants. People have levels of comfort when it comes to proximity to others. Generally, where a participant appears or indicates discomfort it is important to change. This may involve moving closer or further away.</p>
<p>Active listening</p>	<p>The interviewer can demonstrate that they are actively listening to the participant by:</p> <ul style="list-style-type: none"> • Facing the participant • Maintaining eye contact • Nodding their head to acknowledge information

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	<ul style="list-style-type: none"> • Allowing the participant to provide information without interruption • Using short supportive silences to enable participants to gather their thoughts , consider what to add without feeling pressured • Remaining silent - Expect to talk for less than 10% of the time • Paraphrasing information the participant provides to clearly demonstrate understanding • Encouraging participants to elaborate on key information by 'mirroring' through elaborating or clarifying questioning – see below.
Open questions	<p>These questions are used to open or change a topic. This approach facilitates participants to share information in their own way and at their own pace. These questions cannot be answered with a 'yes' or 'no'.</p> <p>Open questions include prompts such as</p> <ul style="list-style-type: none"> • Tell me about • What do you remember about • What was it like • How did this make you feel.
Elaborating and clarifying questions	<p>Elaborating questions encourage participants to tell you more about their experience.</p> <ul style="list-style-type: none"> • What happened next? <p>Clarifying questions get the participant to be more specific about certain aspects of their story.</p> <ul style="list-style-type: none"> • You said you were worried about that. What sort of things worried you?
Maintaining structure and direction	<p>The interview schedule indicates the direction of the interview but it is important to allow participants time to provide information in their own words and at their pace.</p> <p>Some tips to maintain the structure and direction of the interview are :</p> <ul style="list-style-type: none"> • If a participant raises an issue which is relevant, but not at that stage of the discussion, acknowledge it, note it down for discussion at a more appropriate time. • If a participant raises an issue which is not relevant to the discussion, acknowledge the issue and ask them to raise it again after the formal part of the discussion is complete; • Use questions to redirect the participant back to the topic at hand, e.g. 'getting back to what happened in the ICU.....'

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Closing the discussion	<ul style="list-style-type: none"> • A discussion should always conclude with 'is there anything else you would like to say about?' and 'do you have any questions for us'? • It is also important to reiterate with the participant how their story will be used. • Remind them they will have an opportunity to review the story and transcripts. • Remind them they can withdraw their consent at any time. • Thank the participant for their time.
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APPENDIX 4 DISSEMINATION AND TRAINING PLAN

The following table sets out the dissemination and training provisions associated with this PPPG

Plan Elements	Plan Details
The Dissemination Lead is:	Marina Cronin
This document replaces existing documentation:	No
This document is to be disseminated to:	NOCA Executive Team
Training is required:	Yes
The Training Lead	Marina Cronin and Aisling Connolly
Additional Information	Training will be delivered to NOCA Executive Team – Audit Managers, Data Analytics team, Communications and Events and Administration team involved in capturing and processing patient stories for NOCA

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Name	Signature	Date	Comment