



North East &  
North Cumbria

# **Storyteller – Process to support collecting lived experiences FINAL**

**NHS Northeast and North Cumbria ICB**  
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## **Who is this Storyteller process for?**

This Storyteller process has been developed to help provide NHS North East and North Cumbria Integrated Care Board (NENC ICB) staff with guidance on how to gather stories about lived experience. This document is also for people using services, staff, and stakeholders who wish to share their lived experience.

## **What is the Storyteller process?**

The Storyteller process describes why we want to listen your lived experience, how we will do this, and what happens after listening. It allows someone who has used services, a carer, member of staff or a stakeholder to describe their lived experiences of healthcare in their own words. These stories can be either positive or negative depending on the experience of the person involved.

Listening to lived experiences enables the ICB to hear about the experiences and needs of people accessing health services across the region, as well as those members of staff who are supporting providing the care.

## **Why is NHS North East and North Cumbria ICB collecting lived experience?**

The NENC ICB wants to work with people who have used services, families, carers and staff to understand personal experiences of health and care services across the region.

Listening to storytellers share their experiences allows the ICB to understand views about local healthcare services and helps to improve decision making and buying of services. The ICB puts people who have used services at the heart of service development and decision making, in order to improve people's experiences and access to health care for the future. The experiences of staff providing this care, and stakeholders supporting people in the community can also help us to learn and improve the services we provide.

## **What to expect when sharing your lived experience?**

Any feedback relating to a health and care service commissioned by the ICB at a 'place' level will be passed on to that organisation, and they will be asked to provide a response. The ICB will attempt to collect this response for up to six months after the story has been shared, to share back with the storyteller. However, it may not always be possible to receive a response from an external organisation.

## **What about making a complaint?**

If the story you want to share relates to a complaint about a service, then you must go through the organisation's independent complaints procedure. Sharing your lived experience cannot replace this stage, nor be used if you were unhappy with the outcome of a complaint investigation.

Provider and commissioner organisations across the region will have their own established ways of listening to complaints that are raised, investigating them and providing a responses as a result.

You can still share your experiences through this process, even if you have made a complaint against a service. However, where a complaint is being raised, this process would need to be completed prior to any wider considerations regarding the opportunities to share and learn from these experiences. It would not be the responsibility of the ICB Involvement Team to directly resolve matters that are raised as complaints through this process. Rather they will seek to ensure that the instances that are highlighted and the learning that is able to be taken from them are appropriately shared with senior leaders and relevant staff teams to inform future service provision.

## **Who can collect Storytellers experiences?**

Any member of staff from the ICB can collect a lived experience from storytellers. People working across our region in a voluntary sector or community organisations may also be extremely well-placed to hear about lived experiences that need to be brought to the ICB's attention. Other staff within our partner organisations, such as Healthwatch, hospital staff, nursing home managers and the community nursing service staff are also able to help the ICB collect lived experience. Working collaboratively, efforts would be made to enable vulnerable individuals / carers who may need support from a familiar person to collect their story in a way that is accessible and comfortable for them.

## **Different ways of collecting Storytellers experiences**

There are many ways to collect lived experience from storytellers. Below are a few ideas, but you may think of other ways to collect stories:

- When engaging with people who have used services, consider if there is an opportunity to listen to their lived experience;
- Through established local groups and networks via local partners i.e., Healthwatch and local authorities.
- Advertise in the ICB pulse newsletter.
- Through our partner organisations and external providers.

- Email out to GP practices.
- Post on social media asking for participants (Twitter & Facebook).
- Use existing meetings and events.

## **Which services can Storytellers share their lived experience about?**

Examples of lived experience are welcomed from all services commissioned by the ICB as well as partner organisations. This covers the majority of services that are delivered across the North East and North Cumbria, such as; GP practices, NHS teams working out in the community, hospital services – such as an 'outpatient' appointment, a planned operation or emergency care, Mental health services in hospital or the community and many more.

## **What methods can be used to record lived experience?**

Lived experience can be shared verbally or in writing. If they are shared verbally, they can be audio recorded, or a member of staff can take detailed notes. If they are shared in writing, this can be written by the storyteller, a family member, or a member of staff who works with them. Lived experience can be shared in a face-to-face meeting, by video call (for example, Teams), over the telephone, via email, or by letter in the post.

There are many ways we can record lived experience, the method used will be the storyteller's choice and what they feel comfortable with. We will take time to discuss and agree with the storyteller beforehand about **how they want to share their story**.

It is important, however, to have the consent form completed by the storyteller for all lived experience. This can be found at the end of this document.

## **Measures in place to remain anonymous**

If requested, the storyteller can remain anonymous. The person's name, address and identifiable personal details will not be shared with anyone. The exception would be if safeguarding issues are raised during the sharing of a lived experience, which needs further action to be taken.

The ICB will make all reasonable efforts to keep the identity of the patient anonymous. However, there may be certain unique personal characteristics which may make this impossible. The storyteller is asked to consider this when sharing their story.

## **Will the storyteller get to agree their story before it is shared anywhere?**

The storyteller will need to be completely happy that the ICB have recorded their story as they want it. The storyteller will need to provide consent that they are happy with the final written piece, audio recording, or video before they are shared.

## **Where will the story be presented?**

The lived experience of people will be presented at the Quality and Safety Committee and where appropriate the ICB Board meetings. This meeting has the specific purpose of providing the ICB with assurance regarding the delivery of high quality safe patient care in our commissioned services and that there is continuous improvement in the quality of services.

The Quality and Safety Committee includes senior level staff from across a range of organisations. These include NHS Foundation trusts, Public health teams, Local Authorities as well as Directors from within the ICB.

If individuals agree, excerpts from their stories could also be used on promotional materials such as posters, adverts, websites, social media, as well as external news articles (provided the storyteller has consented to this).

## **Does the storyteller have to present their story at a meeting?**

No, not if they do not want to. If they would prefer, a member of staff can present the story on behalf of the storyteller. But we do like hearing the stories direct from patients where possible, so it would be great if they were able to present their own story. If they would prefer, a family member or carer can present the story on their behalf. We can also pre-record a story on video or audio and share that at the meeting instead. Alternatively, a member of staff will read out their story.

## **Who will help the storyteller to share their story at a meeting / over a video call**

The staff member from the ICB who has been in contact with the storyteller should support them beforehand to help them plan their story and provide any support they need.

## **What information can storytellers expect after they have shared their experience?**

If the storyteller is presenting the story at a board meeting or is present with the ICB staff member presenting the story, they should be given minutes of the meeting which covers the story they have shared.

For every patient story shared, after the meeting has taken place the chair of the board will write out to the storyteller to acknowledge the patient's experience. This will include a thank you for sharing their patient story, and any formally noted actions and notes related to their story.


### **Can this process be provided in other formats?**

The patient information document and consent forms are available as Easy Read documents.


This information can also be made available in other formats, upon request.

## Lived experience flow diagram


When you think you have found a potential story, make contact with storyteller to discuss their experience and provide them with this process.



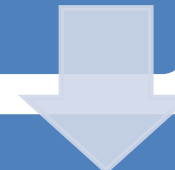
Give the storyteller time to think about their story, and make sure any questions have been answered.



Understand how the storyteller would like to share their story, and get written consent.



Make sure the storyteller is happy with the final story recorded before it is shared with Board meeting / Quality safety committee. Ask the storyteller if they would like to present their story themselves.



Present the story at board meeting / QSC. Provide the storyteller with the minutes of the meeting for their story if they attended in person. The chair will write out to them with any actions identified.



## Consent form

Thank you for agreeing to share your story with NHS North East and North Cumbria Integrated Care Board. Your story will help us look at the quality of health and care services across our region and will allow us to help shape services in the future.

Please note - If your story relates to a complaint about an external organisation, please ensure you raise this with that organisation's complaint department.

Please read the statements included in this consent form and put your initials beside the correct statements or the statements you consent to.

## About your story

Please tell us a little bit more about who this story is about and who had the experience.

	Initial
This is my story - this experience happened to me	
This is someone else's story – I am sharing the story on their behalf	

## Details of person sharing the story (storyteller)

Name:	Date:
Address:	Postcode:
Email address:	Tel
Signature:	

## Details of person who the story is about (if different from above)

Name:	Date:
Address:	Postcode:
Email address:	Tel no:
Signature:	

\*By signing this form, you are confirming that you/the patient/ patient guardian or member of staff on behalf of a consented patient agree(s) to being recognisable and/or identified on film, audio recording, photography and/or written material.

You also understand that NHS Northeast and North Cumbria ICB has no control over the future use of materials by external/media organisations.

The NENC ICB will retain the information that is provided as part of your story in adherence to its data protection and retention policies.

## Declaration

Please put your initials in the box beside each statement you agree to	Initial
I agree that this story can be shared with NHS North East and North Cumbria ICB	
I agree that my name and contact details can be shared with ICB staff.	
I agree that this story can be shared with the Quality and Safety committee.	
I agree that this story can be shared with the ICB Board meetings which is a public meeting. <i>(Please note, anonymised minutes of the meeting are published on the ICB website)</i>	
I declare I am over 16 years of age and have voluntarily signed this consent form	

## How would you like to share your story?

		Initial
Storyteller to write own story (can email or post to ICB headquarters)		
Storyteller to tell a member of staff	Over the phone	
	Over a Video meeting (Teams)	
	In person	

If you are sharing your story with a member of staff, please let us know if you are happy for us to record your story. Any recorded story will be deleted once you have signed off the final story that will be shared with ICB.

		Initial
I consent to my story being audio or video recorded.		
I do not consent to my story being recorded, and I would like the staff member to take detailed notes		

## Presenting your story

Please tell us if how you would like your patient story shared at Board meeting		Initial
I would like a member of staff to present on storytellers' behalf		
I would like to present myself	Via an audio recording and consent to being recorded	
	Via a video recording and consent to being recorded	
	In person at the meeting	
I give my permission to allow _____ to share my patient story experience on my behalf with the ICB board.		
I give my permission for my story to be included in future communications and shared with the public.		