

**Hearing Lived Experience:**

**Protocol and Consent Form
June 2025**

# Who this guide is for

This guide is for anyone who wants to tell the Integrated Care Board (ICB) about their care. It is also for staff who help people share their experiences. The guide explains how we collect and use stories and how we keep people’s information safe and private.

# Why we want to hear from you

We want to listen to your experience of health and care. Both the good and the bad. Your story helps us understand what’s working well and what needs to change. It helps us make better decisions and improve care for everyone.

# Who can help collect your story

Different people can help collect your story, including NHS staff, Healthwatch, community groups, and others we work with. We all follow the same rules to make sure your story is collected safely and respectfully.

# How you can share your experience

There are lots of ways to share your story. You can talk to someone, write it down, record a video or audio message, or choose another way that works for you. You can share the story yourself, ask a family member to do it for you, or ask a staff member to present it on your behalf. It’s up to you.

# What you can talk about

You can tell us about any care you’ve had. This could be at a GP, hospital, community health team, or mental health service. You can also talk about things that made it easier or harder to get the care you needed.

# Consent and keeping your story private

Before we use your story, we will ask you to fill in a consent form. This means you give us permission to use your story in certain ways. You get to choose who can see or hear your story and where it can be shared. We won’t share anything without your permission.

If you want your story to stay private, we can remove names or details that might identify you. We can also ask someone else to read or voice your story. If there’s a serious safety issue, we might have to share it with the right people to keep someone safe, but we will always explain this to you.

# Making sure your story is right

After you share your experience, we will check it with you to make sure we got everything right. You can let us know if there are mistakes or missing parts, and we will fix them. We will only share your story once you say you are happy with it.

# Where your story might be shared

Your story might be shared at an ICB meeting such as the Quality and Safety Committee or the ICB Board. These meetings are where we check if care is good and safe. If your story is shared, we will check with you first and make sure you are happy with when and where it is shown.

Some meetings are public and may be shown online or recorded. Your story might also be included in reports, newsletters, or on the NHS website or social media – but only if you give us permission in your consent form.

# Do you have to speak at a meeting?

No, you don’t have to go to a meeting or speak in person. If you want, we can help you record your story by video or audio and play it at the meeting. You can also ask a family member or NHS staff to share it for you. For big meetings like the ICB Board, we usually prefer video stories.

# What happens after you share your experience

After your story is shared, we will send you a thank you and let you know what is happening because of your story. Sometimes this may need us to contact the part of the NHS involved in your care. This could be to take an action, or to share your experience. Sometimes, this can take time. But we will aim to write out to you within six months of the story being shared.

# If your story is a complaint

If your story is a complaint, you must go through the NHS complaints process first. We can’t review it as lived experience until the complaint has been looked at properly. This guide is not a replacement for the complaints process.

If you have a complaint about a service, please contact the organisation which provided the service. If you do not want to contact the service provider, you can contact our Complaints team. Please note the Complaints team will need to contact your provider to investigate your complaint.

NENCICB.Complaints@nhs.net.
0191 374 4218

FREEPOST, NENC ICB Complaints,
North East and North Cumbria ICB, Pemberton House,
Colima Avenue, Sunderland, SR5 3XB

# Looking after your information (GDPR)

We follow a law called GDPR, which sets rules on how we collect, use, and protect your personal information. We only collect what we need and always store it safely. We never share your details with anyone else unless you have agreed or if the law says we must.

After we have shared your story and told you what happened, we will delete your contact details from our systems after 12 months.

# Looking after you

We understand that telling your story can sometimes be hard or bring up strong feelings. Before you share, we will talk to you about what support you have – for example, from friends, family, or carers. You can change your mind and stop at any time.

After your story is shared, we will check in with you again to see how you are feeling and explain what happens next. You might want to have someone with you for support.

# Formats and accessibility

If you need this guide or the consent form in a different format, just let us know. We can give it to you as Easy Read, large print, audio, video, or in another language – whatever works best for you.

# Lived experience process – step by step for staff

1. **Find a potential experience**
If you think someone has a story about their care to share, contact them. Or ask if you can share their contact details with the Involvement Team so we can reach out. Explain how the process works and give them this guide.
2. **Give them time**
Let the person take time to think about their experience. Answer any questions they have clearly.
3. **Agree how to share the story**
Ask how they want to share their experience (talk, write, video, audio, etc.). Get their written consent to collect and use their story.
4. **Record and check the story**
Collect their experience in the way they want. Then check with them to make sure the story is right, and they are happy with it.
5. **Share the story with the ICB Board or Quality and Safety Committee (QSC)**
Present the experience at the Board or QSC meeting. Please support the person sharing their story if they are attending.
6. **Follow up**
Write to the person with any actions or decisions that came from sharing their story. Keep in touch to update them on progress.



# Consent form – sharing your story

Thank you for sharing your story with the NHS North East and North Cumbria Integrated Care Board (ICB). Your experience helps us make health and care services better for everyone.

If your story is a complaint about another organisation, please contact their complaints team first.

# About your story

Who is the story about? Please tick one box:

[ ]  This is my story – it happened to me.

[ ]  This is someone else’s story – and I have their permission to share it.

# Your details (person sharing the story)

|  |  |  |
| --- | --- | --- |
| Name: |  |  |
| Address: |  |  |
|  |  | Postcode: |
| Email |  |  |
| Phone |  |  |

# If different – details of who the story is about

|  |  |  |
| --- | --- | --- |
| Name: |  |  |
| Address: |  |  |
|  |  | Postcode: |
| Email |  |  |
| Phone |  |  |
| Relationship to you: |  |  |

**Please tick the boxes you agree with:**

**What you agree to**

[ ]  I agree that NHS ICB staff can read my story.

[ ]  I agree that my name and contact details can be shared with ICB staff.

[ ]  I agree that a version of my story without my name can be shared in the ICB’s annual report.

[ ]  I agree that my story can be shared on the ICB’s website.

[ ]  I agree that my story can be shared with ICB committees.

[ ]  I agree that my story can be shared in public ICB meetings (these are recorded and available online).

[ ]  I understand that notes from public meetings are also shared on the ICB website.

[ ]  I confirm that I am over 16 years old, and I am giving my permission freely.

[ ]  I give permission for my story to be used in future ICB reports and online content that is shared with the public.

# How would you like to share your story?

[ ]  I will email or post my story to the ICB.

[ ]  A staff member can write down my story for me.

[ ]  I would like to tell my story at a meeting (face-to-face).

[ ]  I would like a staff member to help me record my story as:

[ ]  Audio (e.g. phone)

[ ]  Video (e.g. Microsoft Teams)

# How would you like your story to be shared at public meetings?

[ ]  A staff member can tell my story for me

(without using my own voice or video).

[ ]  I would like to present my story:

  [ ]  Using a recorded audio message

[ ]  Using a recorded video

  [ ]  Joining live via Microsoft Teams

[ ]  In person at the meeting

# If someone else will share your story for you:

[ ]  I give permission for the following person:

|  |
| --- |
|  |

to share my story on my behalf at ICB meeting

|  |  |  |
| --- | --- | --- |
| Your signature |  |  |
|  | Signature can be written, typed or pasted. |  |
| Date |  |  |
|  |  |  |