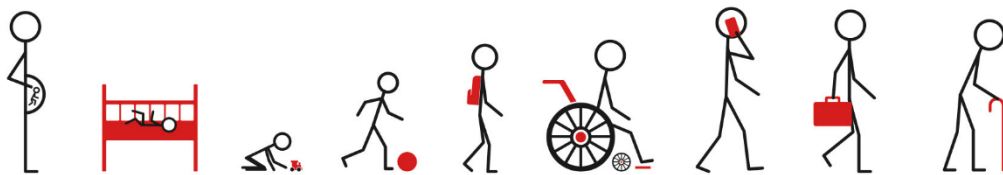


Sharing Patient Stories

How patients, families and carers can share their experiences to help shape the work of the North West CHD Network

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Purpose

This guidance explains how the North West CHD Network collects, uses and shares patient stories. Patient stories help us understand what is working well and what could be improved, so that patients and families help shape the work of the Network.

Patient stories may be:

- Shared at Network Board meetings
- Included in the Network's annual online newsletter
- Published on the Network website: www.northwestchdnetwork.nhs.uk
- Promoted through our social media channels
- Recorded (audio or video) and made available online

We will always ask for consent before sharing a story in any of these ways.

Who can share a story

Stories can be shared by:

- Patients
- Parents or carers
- Family members
- Healthcare professionals (with explicit patient consent)

Stories can describe positive experiences, challenges, or suggestions for improvement. All views are welcome.

Consent and choice

Before a story is shared:

- Written consent must be given by the patient, or by a parent or guardian if the patient is under 18
- The person sharing the story can choose:
 - > Whether their name is used, or they remain anonymous
 - > Where their story is shared (Board meeting, newsletter, website, social media, recording)
 - > Whether they want their story read out, recorded, or shared in writing only

People can withdraw their story at any time.

The Network's responsibility to promote patient stories

The Network has a responsibility to make sure patients and families know that they can share their stories, and why this is important.

To do this, the Network will:

- Regularly promote patient stories
- Clearly explain why patient stories matter and how they help shape services
- Share information on how to get involved through the Network website, newsletter and social media channels

How to submit a story

As an easy first step, people can complete an **online form** to show that they are interested in sharing a story:

<https://forms.office.com/e/YgPPLCQZ1Y>

This form is for initial contact only. After someone completes the form:

- A Network representative will get in touch
- We will talk through what they would like to share and how they would like to do this
- We will explain the different options (written, recorded, anonymous, Board meeting, newsletter, online)

Stories can also be sent by email to: **northwestchdnetwork@alderhey.nhs.uk**

Email should include:

- The patient's name (or state if they wish to be anonymous)
- A short-written story (around 300–500 words)
- Any key messages or feedback for the Network (optional)
- Contact details, in case we need to follow up

To be included at a Board meeting, stories should be submitted **at least two weeks in advance** and take no more than 5 minutes to read out.

Reviewing and selecting stories

- The Network Lead Nurse will review all stories to make sure they are respectful and appropriate
- Stories will be chosen to reflect a range of experiences
- Minor edits may be made for clarity or length, but these will be agreed with the person who submitted the story
- If a story raises concerns about care or safety, this will be followed up using the correct NHS processes and will be discussed at the Network SLT meeting for any Network wide actions

Managing concerns, complaints and positive feedback raised through patient stories

Patient stories shared with the Network may include positive feedback, concerns, or issues relating to care received at a treating Trust. To ensure appropriate governance, clarity of responsibility and timely follow-up, the Network will distinguish between:

- Stories shared to illustrate experience and inform service improvement
- Formal or informal concerns or complaints
- Positive stories or acknowledgements of good care

When submitting a story, individuals will be asked to indicate:

- Whether the story represents:
 - > A positive experience
 - > A concern or issue they wish the Network to be aware of
- If a concern is raised, whether:
 - > A formal complaint has already been made to the treating Trust
 - > An informal concern has been raised locally
 - > This is the first time the issue has been raised

Where a story raises concerns about care, safety or experience, the Network will:

- Clarify whether the issue has already been raised with the treating Trust
- Explain the difference between sharing a story and making a formal complaint
- Offer information and support on how to raise concerns through the appropriate Trust complaints or PALS processes, where needed

- Escalate themes or learning to the Network Senior Leadership Team (SLT) for discussion of any Network-wide learning or actions

The Network does not replace local Trust complaints processes. Responsibility for investigating individual patient complaints remains with the treating organisation.

To support appropriate follow-up, individuals will also be asked:

- > Would you like to speak to a member of the clinical team or Network team about the issues raised in your story?

Where consent is given, and where appropriate, this will help ensure that concerns are not only heard but are directed through the correct formal channels and that learning is captured transparently.

This approach helps ensure that:

- Positive feedback is shared and celebrated
- Concerns are not left unactioned or informally held
- Clear governance arrangements are maintained
- Network Clinical Leads and Directors are not assumed to hold responsibility for unresolved local issues by default

Sharing stories at Board meetings

- Patient or family member will be supported by the Network Lead Nurse
- A patient story is shared at the start of a Board meeting
- The story can be:
 - > Read by the patient or family member
 - > Or read by one of the PPV members attending the Board
- Once the story has been read out, they will be asked to leave the meeting
- The patient or family member will receive a briefing on what to expect at the Board. Once they have read their story, they will be asked to step out of the meeting. Any issues or concerns highlighted will be reviewed by the Network Senior Leadership Team (SLT)
- The patients or family member can use the template in Appendix A to help guide their story – but this is not compulsory

Using stories in newsletters, online and on social media

With consent, patient stories may also be:

- Included in the Network's annual online newsletter
- Published on the Network website
- Shared or promoted through social media channels
- Recorded (audio or video) and hosted on the Network website and/or YouTube Channel

We will clearly explain how and where each story will be used before it is shared.

Supporting patients and families

We recognise that sharing a personal story can be emotional.

To support people:

- The Network Lead Nurse will talk through any concerns before the story is shared
- People can choose how their story is presented
- A respectful and supportive environment will be maintained at all times
- After sharing, people will be thanked and offered information about support services if needed and what will happen with the information they have shared

Feedback and follow-up

- The Board will acknowledge and thank the person for sharing their story
- If actions are agreed as a result of the story, these will be recorded in the meeting minutes
- A short summary of discussion or actions can be shared with the patient or family, if they wish.

APPENDIX A

North West, North Wales and the Isle of Man Congenital Heart Disease Network

Patient story submission Form for NW CHD Network Board

This form is to help you share your story with the Board in a clear, concise, and effective manner. Please focus on key issues and limit your story to a maximum of 5 minutes.

| Section 1: Patient Information | |
|--|--|
| Name of patient | Age of patient |
| Name of person submitting the form (if different from above) | Are you? Patient <input type="checkbox"/> Parent <input type="checkbox"/> Other family member <input type="checkbox"/> Friend <input type="checkbox"/> |
| If you are not the patient, do you have permission to share this story Yes <input type="checkbox"/> No <input type="checkbox"/> | |
| Telephone number (optional) | |
| Email address | |
| Date of story/event | |
| Which hospital did the story/event take place in (if several locations were involved please state them all) | |
| Where did the story event take place (tick all that apply) Clinic <input type="checkbox"/> Ward <input type="checkbox"/> A+E <input type="checkbox"/> GP <input type="checkbox"/> Other (please describe) | |

Section 2: Key details of your story

Describe briefly the background

Include what the person's heart problem is and any recent history that is important to the story

Describe what happened

Who was involved (doctors, nurses, other staff)?
What specific actions were taken (or not taken) that are significant to the story

Describe the outcome or impact of this experience

How did this experience affect your/their health, well-being, or trust in the healthcare system?

Section 3: Important Issues to raise

What do you feel was done well?

Consider any positive interactions, effective treatments, or areas where you felt supported

What concerns or issues do you want to tell the Board about?

This could include communication issues, delays in care, feeling unheard, or anything else significant

What changes do you think may improve care for future patients?

Be specific about what could have made your experience better

Section 4: What would you like to happen?

Is your story mainly about:

- A positive experience / good care
- A concern or issue about care

Would you like support or contact regarding the issues raised?

- Yes, I would like to speak to someone
- No, I am sharing for learning only

If raising a concern:

Has this been raised with the treating Trust?

- Yes – formally
- Yes – informally
- No – this is the first time I have mentioned it

| | |
|--|--|
| Section 5: Summary (optional) | |
| Please summarise your story in a few sentences: | What is the main message you want the Board to remember from your story |
| | |

Who would you like to tell the story? (please indicate by ticking the box)

1. I would like to attend the Board and tell the story myself
2. I would like a member of the Patient and Public Voice Group (PPV) to read out my story

Practice Your Story: Before submitting to the Board, please practice your story to ensure it fits within the 5-minute limit. Focus on the most critical points.

Timing Tips

- Introduction and background: 1 minute
- Key details of the event: 2 minutes
- Concerns and recommendations: 2 minutes

Submitting your story:

Please send your story via email FAO Michelle McLaren (Lead Nurse) to northwestchdnetwork@alderhey.nhs.uk She will acknowledge receipt of your story and will offer to meet up with you to talk about it to ensure that we understand the key points you want to deliver.

Once accepted, your story will be read out at the next available Board Meeting. Please note these meetings occur 3 times a year. You will be informed of the date and will receive feedback as to what the outcome was, and any recommendations made.

By submitting this form, you consent to sharing your story with the Board for the purposes of improving patient care.

Signature: _____

Date: _____

Thank you for taking the time to share your story. Your experience is invaluable in helping to shape better care for all patients.

Kind Regards
CHD Network