

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

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1. Purpose

The North West CHD Network uses social media to:

- Share trusted information and updates about paediatric and adult congenital heart services across the Network.
- Promote events, education, and patient/public involvement opportunities.
- Facilitate peer-to-peer support and online live patient events with ACHD clinicians (via the closed NWACH Facebook Support Group).
- Provide a platform for positive engagement with patients, families, and professionals.

This policy sets out the principles, governance arrangements, responsibilities, and procedures for safe and appropriate use of social media by the Network.

2. Platforms Covered

- **X (Twitter):** Public account for official updates, education, service news, and involvement activities.
- **Instagram:** Public account for visual content (e.g. event highlights, infographics).
- **NWACH Facebook Support Group:**
 - > A closed, private Facebook group for adults with congenital heart disease across the North West, North Wales, and the Isle of Man.
 - > Owned and governed by the **North West CHD Network**.
 - > Moderated by ACHD Nurse Specialists from Liverpool Heart and Chest Hospital (LHCH), Manchester Royal Infirmary, and the Network Lead Nurse.
 - > Provides a safe space for peer support and engagement, aligned with Network standards.

3. Governance and Accountability

- The **North West CHD Network** holds ultimate responsibility for all Network social media platforms, including the NWACH Facebook Support Group.
- The **Network Lead Nurse** oversees governance and moderation standards across all platforms.
- ACHD Nurse Specialists from Level 1 and Level 2 centres support moderation of the NWACH Facebook group.

- Communications Team from LHCH provide support and advice but do not own or govern Network social media.
- Governance aligns with NHS England, RCN, and NMC guidance, and with Trust-level social media policies.

4. Roles and Responsibilities

Network Lead Nurse

- Acts as primary moderator for X (Twitter) and Instagram.
- Approves and schedules content in line with Network and Trust communication guidelines.
- Ensures timely removal of inappropriate or inaccurate content.
- Acts on safeguarding concerns raised.
- Acts as co-moderator for the NWACH Facebook Support Group.

ACHD Nurse Specialists (Liverpool & Manchester)

- Moderate the NWACH Facebook group in line with this policy.
- Vet new membership requests against eligibility criteria.
- Monitor posts, ensuring safety, respect, and compliance with rules.
- Signpost members to the ACHD helpline or treating team for clinical queries.

Communications Team at LHCH

- Provide oversight and advice of the NWACH Facebook group
- Raise concerns if any content breaches guidance.

Group Members (NWACH Facebook Group)

- Must follow group rules (see Appendix A).
- Must not share posts outside the group.
- Are responsible for reporting concerns to moderators.

5. Professional Profiles and Boundaries

- All staff using social media in a professional capacity must maintain **professional profiles** separate from personal accounts.
- Professional profiles must:
 - > Identify the staff member's role within the Network or ACHD service.

- > Follow NHS England, RCN, and NMC guidance.
- > Be used only for professional activity.
- Personal accounts must not be used to engage with patients, families, or service users.
- Moderators must not accept “friend” requests from patients or group members.

6. Content Standards

- All posts must:
 - > Be factual, respectful, and consistent with NHS and Trust values.
 - > Protect patient confidentiality and comply with GDPR.
 - > Avoid political, discriminatory, or commercially biased content.
- Health advice:
 - > General health promotion and service information may be shared.
 - > No personalised clinical advice will be given via social media.
 - > Patients will be signposted to the ACHD helpline or their treating team.

7. Moderation and Monitoring

Social Media platforms will be

- > Monitored at least weekly during working hours by the Network Lead Nurse.
- > Offensive or misleading comments removed promptly.
- > Repeat offenders may be blocked.

Specific to NWACH Facebook Support Group:

- > Membership requests are vetted (see Appendix B).
- > Moderators monitor posts and enforce rules.
- > Inappropriate or unsafe content is removed.
- > Patients are redirected to the ACHD helpline if any clinical concerns.

8. Patient and Public Engagement

Social media will be used to:

- Promote patient events, surveys, and opportunities.
- Share patient stories and images only with written consent.
- Encourage respectful discussion and peer support.
- Promote all CHD services across the Network.

9. Removal or Blocking of Individuals

In certain circumstances, it may be necessary to remove or block an individual from engaging with the Network's social media channels to maintain a safe, respectful, and supportive environment. Where possible an attempt will be made to inform the person that their behaviour is unacceptable and to let them know when a decision has been made to block or remove them.

General Principles

- Removal or blocking will only be used as a last resort, after attempts to resolve issues through warnings or reminders have been made (where appropriate).
- Decisions will be taken in line with Alder Hey NHS Foundation Trust Social Media policies, NHS England, RCN, and NMC social media guidance, ensuring transparency, fairness, and protection of staff and patients.

Harassing or Inappropriate Behaviour

- Where there is evidence of gross misconduct resulting in harassment, intimidation, or inappropriate behaviour (including but not limited to offensive posts, repeated unwanted contact, or attempts to undermine or target staff), the individual may be blocked or removed without prior warning.
- This applies regardless of whether the breach took place within the social media channel itself, or whether it occurred through other means (e.g. emails, direct messages, in-person interactions) that impact the safe running of the social media channels or wellbeing of staff.
- If an individual Trust, or the Network formally recommends that a staff member should have no further contact with an individual, this recommendation will be upheld across all Network social media platforms, including the NWACH Facebook group, X, and Instagram.
- Where gross misconduct or safeguarding concerns arise, removal may be immediate and without appeal

Removal process

- In the first instance, an attempt will be made to contact the individual and warn them about their behaviour. For members of the NWACH Face group this may be done by the most appropriate moderator.
- Decisions to remove will be made in consultation with the Network Lead Nurse and Senior Leadership Team.

- When a decision to remove an individual is made, an attempt will be made by the Network to inform them of this decision.
- Where removal has been made following a **serious issue** — such as harassment, intimidation, or inappropriate behaviour and a Trust or Network (following investigation) has recommended that no further contact be made with a staff member:
 - > The decision may be made **without prior warning**.
 - > The decision will be **final** and not open to appeal, to protect staff and ensure the safe running of the social media channels.
 - > An attempt will be made to contact the individual in writing to inform them by the Network.
- Records of removal and reasons why will be maintained.

10. Escalation and Concerns

- **Safeguarding concerns:** escalated immediately via Trust safeguarding procedures.
- **Complaints about care:**
 - > Complaints about clinical care **MUST NOT** be managed via the Facebook group or via any other social media platform.
 - > People will be directed to the appropriate CHD advice line or relevant Trust PALS service.
 - > If a person wishes to **challenge a decision to remove them**, they may do so via the Alder Hey PALS service.

11. Responding to Misinformation

- If rumours or misinformation emerge within the NWACH Facebook Support Group, or on public social media platforms such as X and Instagram, that could cause concern, confusion, or risk to patients, moderators will first discuss the matter collectively and, where necessary, escalate to the Network Lead Nurse.
- The Network Lead Nurse, in consultation with the Network SLT, will decide whether a clarification can be issued directly by moderators, Lead Nurse or whether the matter requires further discussion at Network SLT, referral to the relevant Trust Communications Team, or NHS England for an approved corporate response.
- Moderators and the Network will only clarify issues that fall within the scope of service information, patient events, or Network activity. Broader clinical, organisational, or policy matters must be escalated for appropriate approval before posting.
- Where a clarification post is issued, it will:

- > Provide accurate, factual information to correct the misinformation
 - > Avoid naming or identifying any individual member.
 - > On private platforms (e.g., the Facebook Support Group), moderators may disable comments to prevent further debate or escalation.
 - > On public platforms (X, Instagram), posts will be crafted carefully to correct misinformation without engaging in debate with individual users.
- This process ensures that all communications, whether in private or public forums, remain a safe, reliable source of information while maintaining confidentiality, professional boundaries, and alignment with NHS communication standards.

11. Media Requests

- Any approaches from **journalists, media outlets, or external organisations** made via social media (X, Instagram) must not be answered directly by individual Network staff.
- Instead:
 - Staff should acknowledge the request politely and **refer the enquiry immediately** to the relevant **Trust Communications Team** depending on the request.
 - The Communications Team will handle the enquiry in line with **NHS England media and communications policy**.
 - No member of staff should provide comment, release patient information, or make statements on behalf of the Network without prior authorisation.

This ensures a consistent, safe, and professional media response, protects patient confidentiality, and aligns with NHS England's **Standards of Business Conduct** and communication protocols.

12. Policy Framework and Compliance

This policy must be read in conjunction with:

- NHS England Social Media guidance
- RCN Social Media Guidance for Nurses and Midwives (2016, updated).
- NMC Social Media Guidance (2019).
- Relevant Trust social media policies.
- UK GDPR and Data Protection Act (2018).

Compliance will be monitored through regular review by the Network and where relevant with Trust Communications teams.

13. References

1. NMC. *Guidance on using social media responsibly* (PDF). Accessed via NMC website. [social-media-guidance.pdf](#)
2. RCN *Social Media Community Guidelines* (PDF) 2024 [RCN-social-media-community-guidelines-Nov-2024.pdf](#)
3. *Data Protection Act 2018; General Data Protection Regulation (EU) UK version.*
4. *Inclusive digital healthcare: a framework for NHS action on digital inclusion.* NHS England 2023 [NHS England » Inclusive digital healthcare: a framework for NHS action on digital inclusion](#)
5. *Social media* — NHS England Updated 4 April 2025 (first published 16 February 2023) [NHS England » Social media](#)
6. *Social Media Moderation Guidelines* Alder Hey Children's NHS Foundation Trust [Social Media Moderation Guidelines - Alder Hey Children's Hospital Trust](#)

Appendix A – NWACH Facebook Membership Procedure *(adapted from LHCH NWACH Facebook Policy V2)*

Patients will be informed about the NWACH Facebook Support Group when they first meet the ACHD team. This may occur during outpatient clinics, hospital admission, transition clinic, or within peripheral clinics across the Network.

- Membership must always be patient-led. Patients must request access themselves — staff will not initiate or invite patients.
- Moderators must not seek out patient details or add patients to the group directly.
- The group’s privacy settings are set to “Friends Only,” meaning only accepted members can see posts and activity.

Process for New Membership Requests

1. Request received

A moderator is assigned to review new membership requests.

2. Eligibility check

Applicants must answer the qualifying questions

- > Do you have congenital heart disease?
- > Do you live in the North West of England, North Wales, or the Isle of Man?
- > Are you willing to respond to an initial message from one of the moderators via Messenger. This is to verify the person is real and is a patient belonging to the NW service.

3. Identity verification

The moderator sends a private message to confirm the applicant’s identity and reason for joining. The applicant must clearly identify themselves as an adult CHD patient under the care of a provider in the North West region.

4. Decision

- If eligibility is confirmed, the applicant is admitted to the group.
- If eligibility is not confirmed, the applicant will be politely declined and signposted to other relevant resources

5. Welcome and rules

On acceptance, new members are reminded to read the group rules and always adhere to them.

Membership Restrictions

- Family members and friends are not permitted, except in cases where a family member represents an adult patient with learning disabilities. This must be clearly identified.
- Staff members other than designated moderators may not join the group.
- Moderators must not accept or send “friend” requests to patients or members.

Private Messages

If a moderator receives a private message from a patient, they must not engage in clinical discussion. Instead, they must signpost the patient to the ACHD Advice Line on **0151 254 3333**

Appendix B: NWACH Facebook Group Rules

(adapted from LHCH NWACH Facebook Policy V2)

Group Rules from the admins:

These are required when asking for permission to join

1. Be kind and courteous

We're all in this together to create a welcoming environment. Let's treat everyone with respect. Healthy debates are natural, but kindness is required.

2. No hate speech or bullying

Make sure everyone feels safe. Bullying of any kind isn't allowed, and degrading comments about things such as race, religion, culture, sexual orientation, gender or identity will not be tolerated.

3. No promotions or spam

Give more to this group than you take. Self-promotion, spam and irrelevant links aren't allowed

The following message is available within the featured section of the group and describes the rules regarding how the page will be run. New members will be directed to read them when first joining and they will be re-posted every 3 months to ensure they are visible to everyone.

"Welcome to the North West Adult Congenital Heart Support Group

This group is for anyone who has a heart condition they have been born with and is now an adult. You must be living in the North West of England, North Wales or the Isle of Man. This group is used to provide updates on services, interesting information relevant to congenital heart disease and promote events. The main purpose of this group is to provide a safe place for people with congenital heart disease to connect, share stories and support each other.

PLEASE NOTE: this group is not responsible for providing any personal medical advice. The ACHD nurse specialists do not moderate this group 24hrs a day, 7 days a week. It must not be used to contact the ACHD Nurse Specialists when you are unwell for any reason. If you are feeling low in mood this group cannot provide mental health support. You must reach out to your GP, friends and family, mental health team or crisis team. Please attend A&E in an emergency.

If you need personal help and advice, always call the ACHD helpline on 0151 254 3333. Please leave a message and one of the nurses will call you back. If you do not receive a reply within 3-4 working days, please call again and leave another message. Remember to let them know the best number to call you back on. If you privately message the nurse specialists via social media you will receive a polite reply directing you to call the helpline.

If you are worried about a post on this group - anyone can report this, and the moderators will be alerted. They will then review the post and make a collective decision as to whether the post needs to be removed or not. They will also decide if any other actions are required. They will not make this decision public to ensure people's right to privacy is protected.

Life long friendships can be made through this group. If you choose to privately message each other, you must take personal responsibility for the relationships that develop from that. Please remember that the internet is not a safe place, and we cannot guarantee that your information is secure. Please respect everyone's right for privacy. Do not share any posts outside of this group.

If you are unhappy with the care you have received personally - please do not use this face book page to resolve these issues. Please call the helpline on 0151 254 3333 so we can help you find solutions. If you remain dissatisfied, please contact the PALS department within the hospital concerned to escalate your concerns.

There are some members of this group who have mild learning disabilities. Please be kind and respectful at all times in order to be inclusive of everyone. Please be prepared to make adjustments and to show patience and accept someone else's views even if they are different to yours or don't make sense.

Please do not post anything that is inappropriate, offensive, abusive or racist. Please be kind and respectful at all times. We try to foster a positive environment on here and we may need to delete posts if they refer to individual members of this group, staff, wards or hospitals. If your posts breach any of these clear rules you may be removed from the group and we will message you explaining why.

You can use this group to chat, share information that others may find helpful, personal stories, views and opinions. You don't need to agree with each other and it's ok to have a moan, but please respect each other's views even when they are different to yours. We hope you enjoy connecting with others who have been born with a heart problem."

Appendix C – Removal Notification Template

(Adapted from LHCH policy v2.0)

Members removed for breaching rules will be notified where appropriate. For serious breaches or safeguarding issues, removal may be immediate and without right to appeal.

Date: _____

To: [Member's Name]

Email / Facebook Account Name: [Insert if known]

Dear [Member's Name],

We are writing to inform you that your recent activity within the NWACH Facebook group/social media platform has been found to be in breach of the group rules. As a result, you will be removed from the group.

Reason for Removal:

[Insert brief, factual summary of the behaviour or posts that breached the rules]

Option A – Removal with Right to Appeal

If you wish to appeal this decision, you may do so by contacting the Patient Advice and Liaison Service (PALS) team at Alder Hey Children's Hospital:

PALS Contact Details:

Patient Advice and Liaison Service
Alder Hey Children's NHS Foundation Trust,
Eaton Road,
Liverpool
L12 2AP

Online form at: [Patient Advice and Liaison Service \(PALS\) - Alder Hey Children's Hospital Trust](#)

Telephone: 0151 252 5161

Option B – Immediate Removal without Appeal

Due to the seriousness of this issue, and following recommendation, your removal from the group will take effect immediately and without prior notice. In these circumstances, there is no option to appeal this decision.

We appreciate that this may be disappointing, but as moderators we have a duty to ensure the safety, wellbeing, and respectful engagement of all members of the group and staff. These steps are taken in line with the group rules and with the best interests of the wider community in mind.

Yours sincerely,
NWACH Facebook Moderation Team
North West CHD Network