Document Control

Title: Writing Clinic Letters for Patients with Congenital Heart Disease – Good Practice Guideline
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Stakeholders Consulted (list all)

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Approved By: Paediatric & ACHD Ratification Task and Finish Groups on behalf of the NW CHD Network Board
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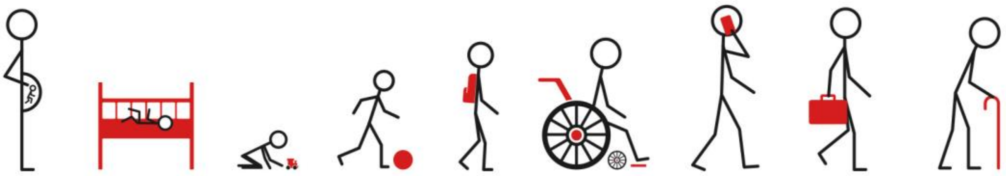
Good Practice Guideline:

Documentation and Writing Patient Letters for Patients with Congenital Heart Disease

2nd February 2026



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Purpose

This guideline ensures that all written communication to patients with congenital heart disease (CHD) is clear, supportive, clinically accurate, and aligned across the Network. This will help to support patients and families to understand and manage their condition. This should apply to all letters from congenital heart disease clinics across Level 1, 2 and 3 centres.

General Principles

- **Patient-Centred:** Letters should be written primarily for the patient (or family where appropriate), using accessible language while maintaining clinical accuracy.
- **Clear and Concise:** Avoid jargon or explain terms clearly; keep sentences short and avoid using unnecessary words.
- **Compassionate Tone:** Acknowledge the emotional impact of CHD; ensure a supportive and respectful tone throughout.
- **Consistency:** Ensure terminology, format, and structure align with network-wide standards.
- **Transparency:** Summarise discussions honestly, including diagnosis, management plans, risks, and options discussed.
- **Shared Communication:** Where possible and where the patient or parents are going to receive a copy of the letter, address it directly to them with a copy sent to relevant healthcare providers (e.g., GP, referring cardiologist).

Structure and Content Guidelines

1. Header

- Patient Name
- Date of Birth
- Hospital Number
- NHS Number
- Clinic Date
- Consultant Name (and contact for pathway co-ordinator / secretary)
- Location (e.g., Alder Hey Hospital, Liverpool Heart and Chest Hospital, etc.)
- If the letter is to act as a referral to another clinician or service, *this should be clearly indicated at the top of the letter*
- CHD Helpline numbers

2. Summary of Medical Information

This should act as a key summary of the past and current medical diagnosis and treatments and should align with recognised CHD clinical coding. This should remain contemporaneous and be regularly updated, though may be carried over from previous letters

- **Diagnosis: Clear statement of the congenital heart condition**.
  - It is useful to highlight all aspects of the CHD diagnosis here e.g., LSVC, right aortic arch
  - For certain conditions it is useful to state important negatives or tests that remain on the patient record *e.g. Normal microarray*

- **Surgery and Interventions: Relevant past interventions with dates**. It is useful to be clear on specific aspects of surgery here e.g.
  - Repair of Tetralogy of Fallot *with transannular patch*
  - Rastelli procedure *with insertion of 18 mm Hancock RV-PA conduit*
  - LPA stent *with Cook integrity stent 8 x 20 mm*

- **Medications: All current medications** should be listed with dose and frequency
  - Please note that it may be important to document brand name (eg transplant medications)
  - Warfarin doses should not be stated as they will vary, target range should be noted e.g. *Warfarin adjusted according to INR (target range 2- 3)*
  - Where a patient is under shared care, it may be more appropriate for the specialist to direct this aspect of care

- **Current Status: Current clinical status** and primary source for ongoing surveillance, it is helpful to state key investigations findings e.g.
  - Moderate left AV valve regurgitation (post AVSD repair)
  - Free pulmonary regurgitation with moderate RV dilatation and good systolic function (MRI June 24 RV EDV 115ml/m2, RF 27%)

- **Plan:**
  - Planned investigations (e.g., follow-up MRI, Holter monitoring).
  - Referrals if necessary (e.g., to adult congenital heart disease services) *eg: 24 hr tape to be arranged in Bangor*
  - **Please note any actions for clinicians on the copy list should be clearly stated here rather than in the body of the letter**
  - Plan for next review

3. Introduction

- Briefly introduce the purpose of the letter (e.g., summary of the recent consultation).
- Acknowledge any family/carers present if applicable.

Example: "Thank you for attending your consultation at Alder Hey Hospital on 10 April 2025. It was a pleasure to meet you and your parents."

4. Management Plan

- Current treatment or no change
- Planned investigations (e.g., follow-up MRI, Holter monitoring)
- Referrals if necessary (e.g., to adult congenital heart disease services)
- Any lifestyle advice given (e.g., exercise, endocarditis prophylaxis)

5. Follow-Up

- Next appointment timeframe and location.
- Any interim instructions (e.g., signs to watch for, contact numbers if concerned).

Example: "We have arranged to see you again in 12 months' time. If you notice any new symptoms such as increasing breathlessness or palpitations, please contact us earlier."

6. Closing

- Encourage contact if there are any questions or concerns.
- Sign off warmly and professionally.

Example: "Please do not hesitate to get in touch if you have any queries before your next appointment."

Style and Language Tips

- Use plain English wherever possible.
- Define medical terms briefly if used (e.g., "cyanosis (bluish skin caused by low oxygen levels)").
- Be mindful of the age and developmental stage (child, adolescent, adult).
- Avoid alarming language, phrase risks and uncertainties sensitively.
- Ensure correct spelling and full name of congenital conditions (e.g., "atrioventricular septal defect" not "AVSD" unless explained).
- Letters for transition-age patients should promote autonomy and involvement in their own care.

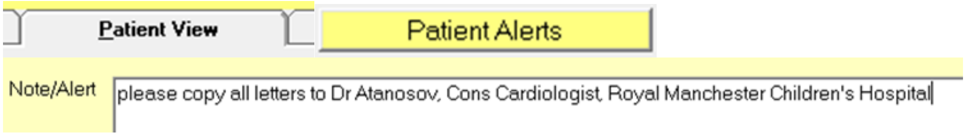
Documentation and Information Sharing

- Save a copy in the patient's EPR or paper copy to the notes at the hospital where the clinic took place
- For one-off dictations it is useful to state the type of report at the start of the letter so they can be appropriately labelled and quickly found on the EPR.
- Send copies to:
  - GP
  - Referring or primary / local cardiologist
  - Generally all patients with unrepaired or palliated CHD should have a local paediatrician copied in, so records are held locally in case of emergency
  - Relevant specialists if multidisciplinary care is involved.
  - If the patient has learning difficulties – consider if it would be appropriate to also copy this team in to your letter, especially if they will need support around the time of surgery or intervention.
  - Note for children in care be mindful not to copy in birth family if this will inadvertently disclose the address of the child, copies to the birth family should be provided by the social worker.

PRACTICAL TIPS – ALDER HEY

Checking the right people get the right information

- ✓ If the previous letter has headings dictated, please retain these unchanged *'headings as last clinic and quote the date of the letter'* with updates to procedures and medications as necessary.
- ✓ Following the first visit in the Alder Hey clinic following surgery or intervention patients should be repatriated to their Manchester cardiologist. If they are remaining under Alder Hey follow-up (e.g. post Norwood, complex pacing, parental choice) clinicians should be copied into correspondence stating the ongoing management plan.
- ✓ For complex patients living in the Manchester catchment area (remaining under AH care) the RMCH paediatric cardiology secretaries should be copied in, this will mean up-to-date records are available should the patient attend A+E or require urgent care.
- ✓ The best way to ensure letters are copied to the correct clinicians or teams is to add an alert in medisec.



Note/Alert: please copy all letters to Dr Atanosov, Cons Cardiologist, Royal Manchester Children's Hospital

Equality, Diversity, and Inclusion

- Ensure that communication is sensitive to cultural, linguistic, and accessibility needs (e.g., offering translations, large print).
- Respect and use the patient's preferred name and pronouns.

Patients under shared care

The North West, North Wales and Isle of Man network covers a wide geography and many patients will be under shared care potentially under review with teams and clinicians at L1, L2 and L3 centres.

1. For letters generated in the joint level 3 paediatric clinics

- ✓ These should be dictated and checked locally by the relevant local clinician (Paediatrician with expertise in cardiology or adult cardiologist with a special interest in ACHD)
- ✓ All letters should be uploaded to local patient records
- ✓ Letters should be sent in digital format to the L1 or L2 centre and uploaded to the EPR labelled e.g. *'Warrington Cardiac Clinic April 2024'*

2. Patients under national specialised services

- ✓ A subset of patients will be under shared care with heart failure / transplant or pulmonary hypertension services
- ✓ These letters should be scanned and uploaded to the EPR labelled e.g. *'Freeman Transplant Clinic Jan 2024'*

3. Documentation around palliative care and advanced care plans

- ✓ These care plans are key documents that must be quickly and easily accessible again labelling is helpful e.g. *Advanced Care Plan Feb 2024'*
- ✓ They should be held by all care providers for the patient

Sharing results of investigations

All investigations (other than 12 lead ECG and ECHO) should have a dictated report on the relevant hospital system (or this may be incorporated in a clinic letter). At the start of the dictation please state how the report/letter should be labelled.

- 24hr tape report
- ET report
- CPET report
- MEMO report

Feedback and Sign Posting

Invite patients and parents to share feedback about their experience of care, including all interactions and points of contact with the service. Feedback is collected via the Network's online feedback portal, which can be accessed by scanning the QR code provided in this guidance. It enables patients and families to comment on all aspects of their care. Patients and parents should also be signposted to the North West Congenital Heart Network website (www.northwestchdnetwork.nhs.uk), where further information, resources, and support are available.

Example of what to include at the end of the clinic letter:

"We welcome your feedback about your care, including your experience of clinic and all interactions with our team. Please scan the QR code to share your thoughts via the North West Congenital Heart Network feedback portal. More information is available at www.northwestchdnetwork.nhs.uk."

Conclusion

Clear, compassionate, and consistent communication is essential for the lifelong journey of patients with congenital heart disease. By following these guidelines, we can empower patients, enhance trust, and ensure excellent care throughout the Network.