Extra Corporeal Membrane Oxygenation (ECMO) for Neonates, Infants and Children: Engagement Report

16 July 2026, Version 1

Topic details

Programme of Care	Highly Specialised Services
Clinical Reference Group	Women's & Children
Unique Reference Number (URN)	1666

1. Summary

This report summarises the feedback NHS England received from stakeholder testing, as part of the engagement process.

2. Background

This service specification proposition has been updated following NHS England's Full Methods Process. The review was led by the Chair of the Clinical Reference Group (CRG) and the Lead Commissioner for the service and supported by a Specification Working Group (SWG). Membership of the SWG included Clinical members, Lead Commissioner, Public Health, Patient and Public Voice (PPV), Neurological Alliance, Getting It Right First Time (GIRFT), Royal Colleges. Co-opted members i.e. finance, quality and nursing, information and intelligence were also key members of the group.

3. Feedback analysis

3.1 Stakeholder Testing

The service specification proposition was sent for stakeholder testing.

Summary of participants

- **24 responses** were received during the 2-week stakeholder testing in **July 2023**.
- All responses were from **clinicians**, including:
    - Hospital Trust clinicians
    - Allied Health Professionals (AHPs)
    - Clinicians within transport teams
    - Operational Delivery Networks (ODNs)
- Some responses represented **multiple clinicians** within a single organisation.

Remit of Organisations:

- Responses were submitted by:
    - **Hospital Trusts** providing ECMO services
    - **Operational Delivery Networks** (ODNs) for:
        - Congenital Heart Disease (CHD)
        - Neonatal care
        - Paediatric Intensive Care
    - **Transport teams** involved in critical care transfers

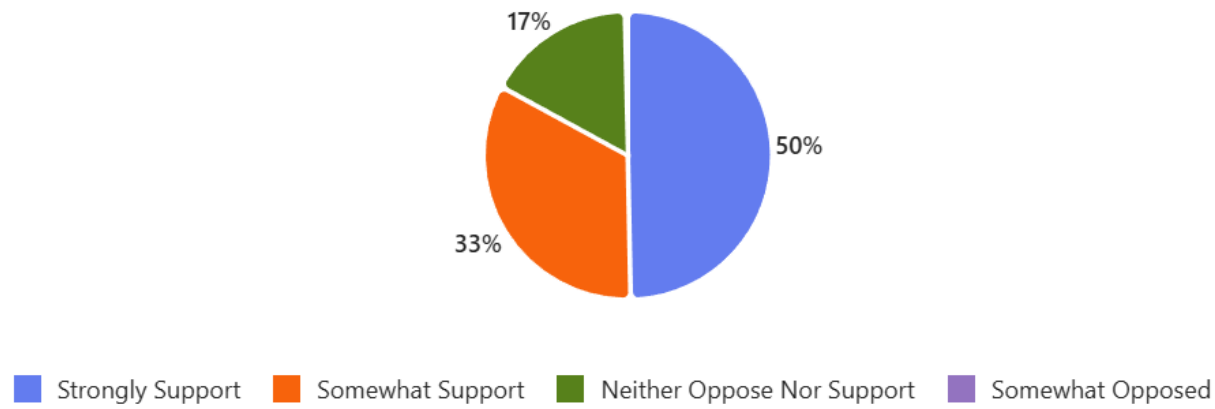
Individual respondent characteristics:

- All respondents were **clinical professionals**.
- They included a mix of:
    - ECMO providers
    - AHPs
    - Transport clinicians
    - ODN representatives

3.1.1 Responses to questions on service specification changes

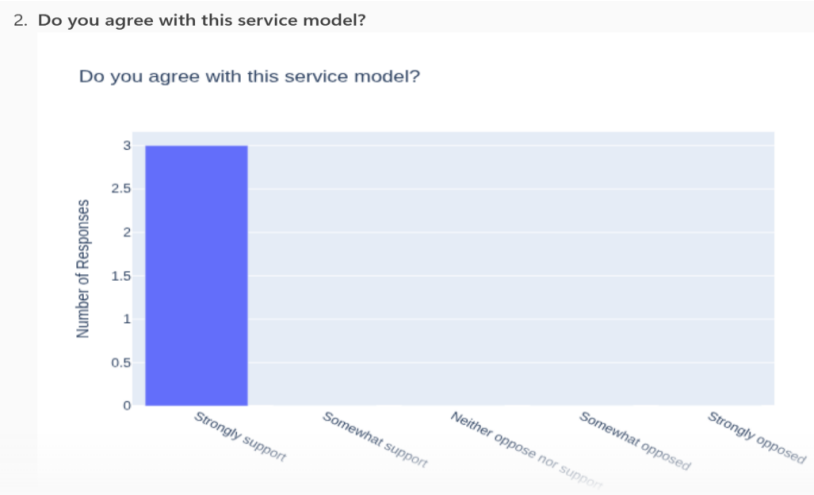
24 responses were received, 12 were on behalf of organisations. A breakdown of the responses for each question is set out below.

1. **Do you agree with these aims?**



Sample Response:
"The aim of the national paediatric ECMO service is to meet the needs of critically ill neonates, infants and children with potentially reversible severe respiratory, cardiac, cardio-respiratory and/or circulatory failure in whom ECMO support is considered clinically appropriate. A further aim of this unified cardiac and respiratory paediatric ECMO service specification is to assist with these key inter-dependencies whilst developing the capacity and training of all paediatric ECMO centres and therefore improve access to ECMO for all children within England."

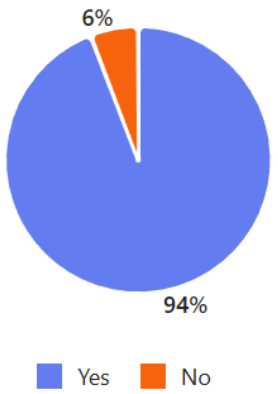
2. **Do you agree with this service model?**



Sample Response:
"All ECMO centres are expected to work collaboratively to optimise the care of children with cardiac and/or severe respiratory failure who may benefit from support with ECMO.

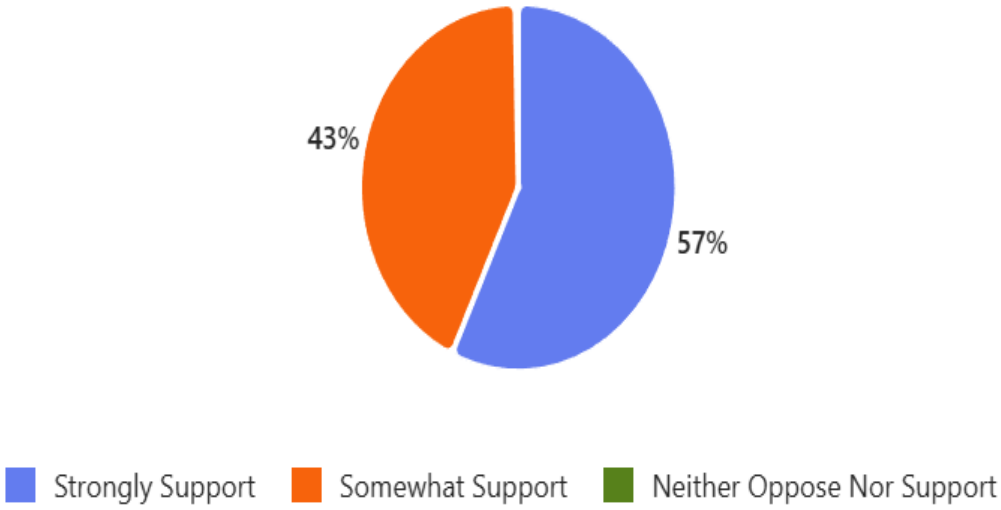
This is a significant step towards providing equitable access to all patients under 16 who require ECMO."

3. Do you agree with the criteria?



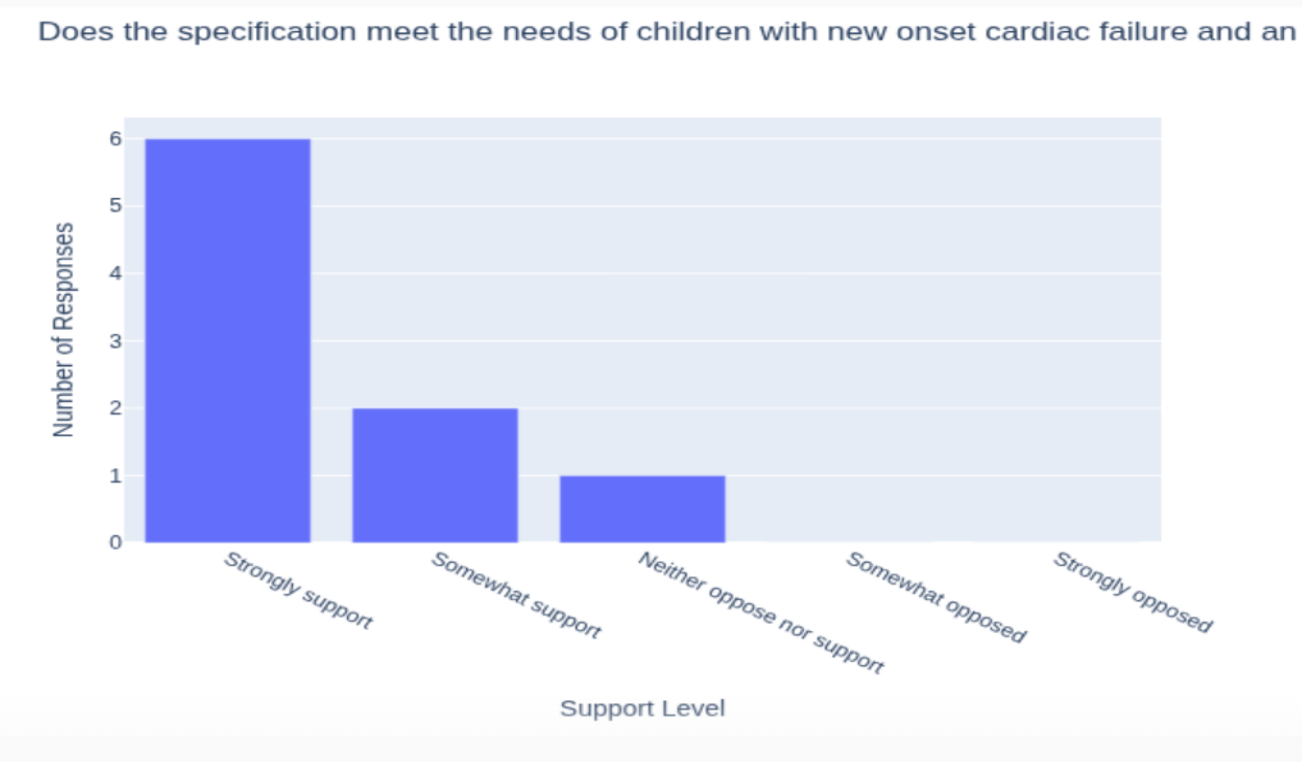
Sample Response:
"Yes, although we would require the 'clinical criteria for the care pathways' to be better defined. Comorbidities need to be factored in, and some patients may be suitable for ECMO as a bridge to transplant even if their condition is not reversible."

3. Does the specification meet the needs of the following: Conditions that lead to severe acute respiratory failure and respond to ECMO?



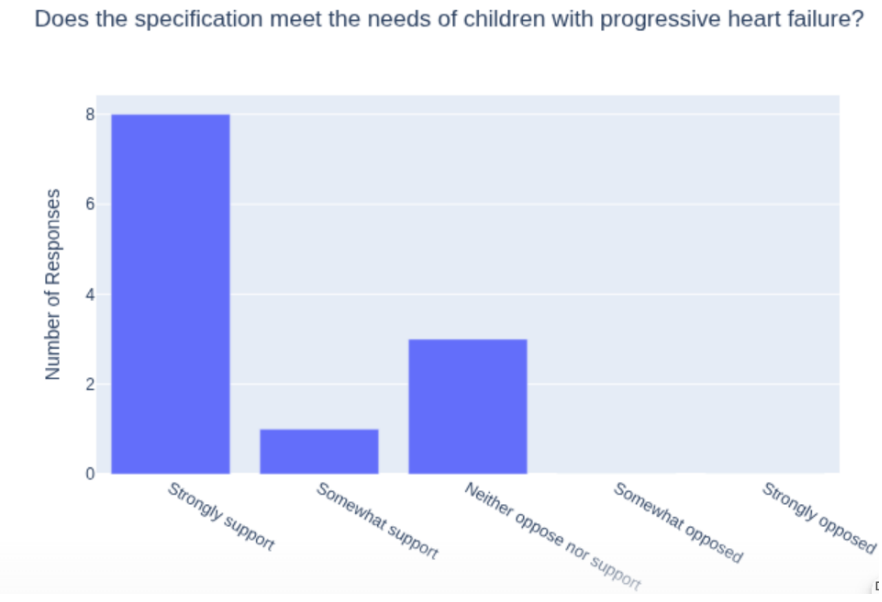
Sample Response:
" By respiratory patients being supported across all ECMO centres this will free up capacity within the cardiac transplant centres. This model has been shown in adults where transplant centres beds are ring-fenced. "

4. Does the specification meet the needs of the following: Children with new onset cardiac failure and an acute cardiac collapse/decompensation?



Sample Response:
"Yes. The proposal supports timely access to ECMO for children with acute cardiac collapse, which is critical for survival."

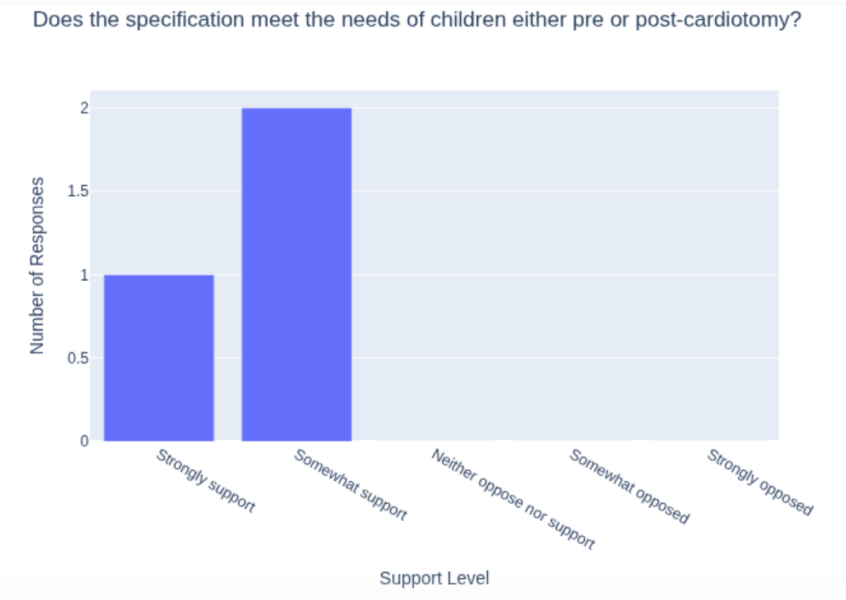
5. Does the specification meet the needs of the following: Children with progressive heart failure?



Sample Response:
"Yes, but the specification should clarify how these patients will be managed long-term,

especially in relation to transplant pathways and follow-up."

6. Does the specification meet the needs of the following: Children either pre or post-cardiotomy?



Sample Response:
"Yes, although the document lacks detail on how these patients will be supported post-operatively and how outcomes will be monitored."

A summary of the responses is set out in **Appendix 1** of the stakeholder engagement feedback document.

4. Impact of Engagement

Following a comprehensive review of the feedback from stakeholder testing, further action was taken where appropriate to update the service specification and the associated documentation. The key changes made to the document following stakeholder testing include:

- Document development to ensure a clearly articulated, comprehensive model of care, integrating respiratory and cardiac ECMO services.
- Inclusion of a Peer Review process to address concerns around quality assurance and consistency across centres.
- Clarification of referral pathways, including the role of NICUs, PICUs, and transport teams.
- Strengthened emphasis on neurodevelopmental follow-up, with recognition of the need for multidisciplinary input and standardised assessment tools.

- A commitment to strengthening the paediatric ECMO retrieval process through the development of a new service specification for transport.
- Acknowledgement of the need for psychological support for patients, families, and staff.
- Commitment to developing a national referral system and improved coordination across networks.

5. How has feedback been considered?

Responses to engagement have been reviewed by the Specification Working Group and the Programme of Care with some edits made to the service specification proposition to improve clarity.

- Feedback was fully considered.
- Concerns raised by a small number of ECMO providers regarding quality assurance, outside of and following stakeholder testing were addressed by:
    - Embedding a Peer Review process within the service specification
    - Developing plans to implement an e-Referral system across the network

6. Has anything changed in the service specification as a result of the stakeholder testing and consultation?

Yes, edits were made to the service specification proposition as a result of feedback received. A summary is appended to this report.

- The Peer Review process, a neuro developmental follow up service and e-Referral system will be introduced in direct response to stakeholder concerns about quality assurance and consistency across providers.

7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?

No. The PPVAG group was **fully assured** that all feedback had been appropriately addressed.

8. What are the next steps including how interested stakeholders will be kept informed of progress?

The service specification, change form and associated documents will be published as part of the full methods process. Confirmation will be sent to all commissioners through

the circular route and providers will receive communication relating to our intention to commission and the necessary procurement process.

In order to implement the service specification, a procurement exercise will need to be undertaken to determine which providers will be commissioned to deliver the services described.

Following contract award, a peer review process for quality assurance across all commissioned ECMO centres is proposed. This will have the role of alignment with the national Quality Teams requirement of Peer Review and will focus on monitoring outcomes. It will be led by centres with oversight from national teams and will require the demonstration of clinical skills and competency in Respiratory ECMO as well as compliance with the Paediatric Critical Care Society (PCCS) and Extracorporeal Life Support Organisation (ELSO) standards. Funding has been agreed to support the conduct of this.

Continued engagement with clinical and service leads will support preparation for both peer review and delivery of the neuro development follow up. Reporting and data upload will be a contractual requirement, reflected in the circular with national commissioners supporting access to relevant data portals.

Appendix 1: Summary of stakeholder feedback and responses.

Number of respondents: **24** all from **clinical stakeholders**

A high-level summary of stakeholder feedback and consideration/response to this is set out below. Further engagement has also taken place.

Organisation Responding	Feedback Received	Response (summary)	Resulting Action
ECMO Provider service	Questions on neurodevelopmental follow-up, MDT timelines, transplant coordination, staffing and funding	Addressed via commissioning and peer review process	Peer Review Working Group formed
ECMO Provider service	Support for regional access and standardised referral management	Noted	No change required
ECMO provider service	Need for 24/7 surgical cover and joint neonatal-surgical input for CDH cases	Incorporated into commissioning plan	Addressed in commissioning plan
Neonatal Operational Delivery Network	Clarification on referral pathways and inclusion of NICU/retrieval services	Incorporated into commissioning plan	Addressed in commissioning plan
Neonatal critical care service	Step-down pathways and neonatal governance input	Incorporated into peer review process	Peer Review Working Group formed
ECMO provider service	Support for network model, mobile ECMO, and funding needs	Incorporated into commissioning plan	Peer Review Working Group formed
Neonatal Operational Delivery Network	Physiotherapy access and MDT follow-up clarity	Incorporated into commissioning plan	Addressed in commissioning plan
Neonatal critical care service	Referral delays and need for audit of timelines	Already included in service reviews	Included in peer review process
ECMO-referring service	Concerns about decentralisation and impact on high-volume centres	Included in peer review and transport working groups	Ongoing engagement
ECMO provider service	Detailed feedback on volume-outcome relationships, referral systems, and service sustainability	Incorporated into peer review and commissioning plan	Participation in Peer Review Working Group offered

Allied health professional / psychological services	Lack of psychological support pathways and trauma-informed care	Incorporated into commissioning plan	Included in commissioning plan
Neonatal critical care service	Support for regional access and NICU involvement in referrals	Noted	No change required
Clinical stakeholder	Support for early ECMO intervention and service aims	Noted	No change required
Additional individual clinicians	Comments on affordability, training, and service clarity	Reviewed as part of EHIA and commissioning plan	Included in commissioning plan