

The Development of a Multidisciplinary Cardiac and ECMO Neurodevelopmental Outpatient Service

Introduction

- Mortality rates for children with congenital heart disease (CHD) have significantly reduced.
- Children with CHD are at increased risk of developmental delay, and this is heightened if they require open heart surgery or a prolonged hospital admission (1,2).

Confirmed
Abnormal
Neurology

NICE guidelines state: Patient assessment and outcome measure completed prior to discharge with onward referral

ECMO

ELSO guidelines advises 3 month, 6 month and 1 year neurodevelopmental assessment in an MDT clinic at a tertiary centre

Complex
CHD with
Inconclusive
Ax

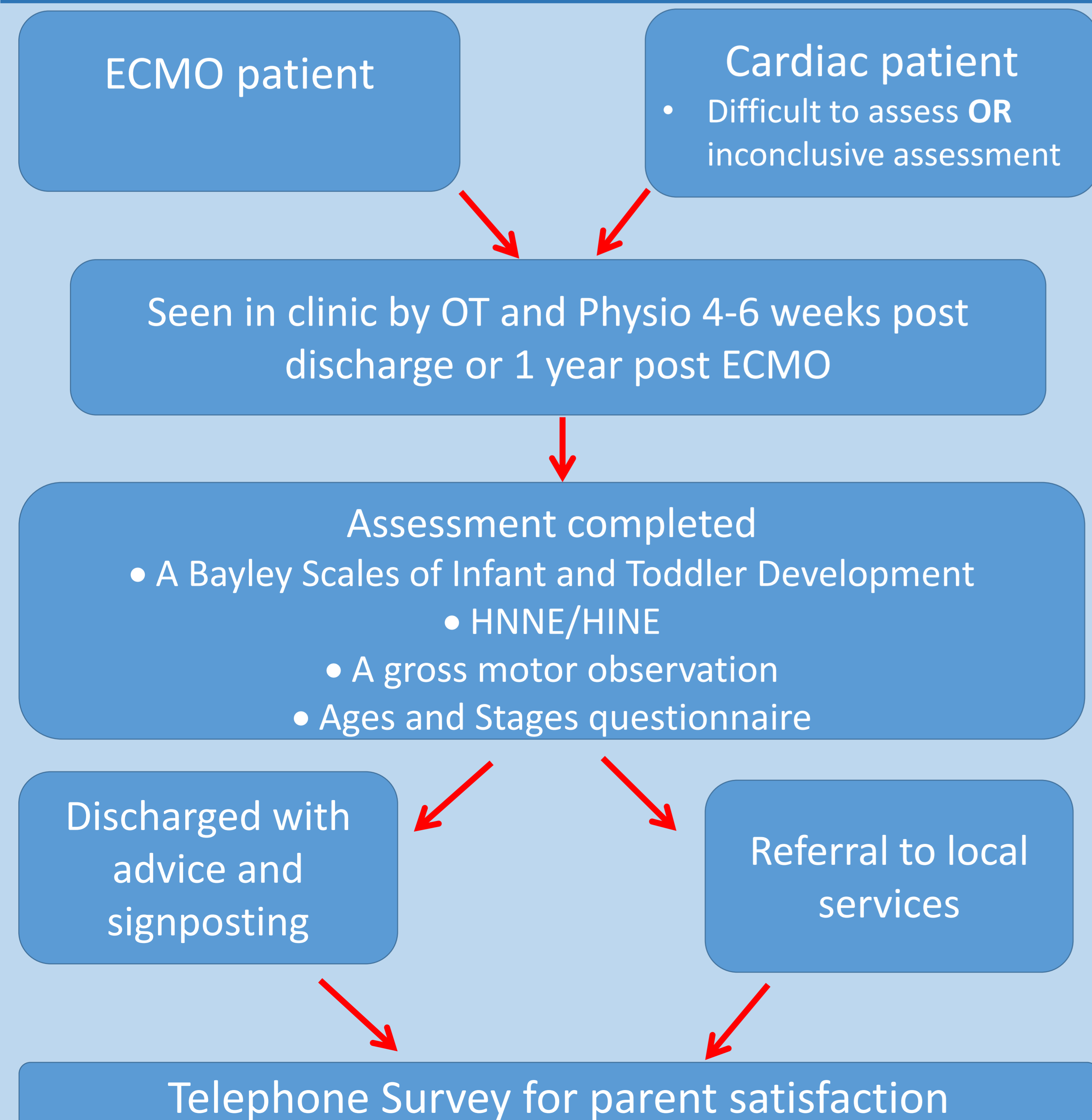
American Heart Association recommends periodic surveillance, screening and evaluation to identify deficits early and facilitate appropriate input

Aim

At Great Ormond Street Hospital we piloted the set up of a neurodevelopmental MDT follow up outpatient clinic.

- To improve continuity of care with a high quality and cost effective service
- To improve accuracy of onward referrals
- To provide advice and sign posting to parents post discharge in a receptive environment

Method



Outcomes

10 patients were seen over 5 months.

Appointments were on the same day as their cardiac follow-up appointment and lasted between 30mins - 1 hour. Following the assessment two patients required an onward referral to local services. All other patients were discharged following the clinic with advice.

Figure 1. VILD chart displaying parental satisfaction

	Participants									
	1	2	3	4	5	6	7	8	9	10
I felt more confident on discharge knowing that my child's development would be followed up at the same centre	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
It was useful to have the appointment at the same time as my other appointment	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
It was beneficial being seen by the same therapy team	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
My child was seen in a timely manner following discharge	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
I felt happy with the on going plan for my child after the clinic appt	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
I felt my child was more ready to be assessed in clinic than during their inpatient stay.	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				
I would have preferred to be referred to a local team on discharge rather than seen in clinic	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A				

Strongly Agree Agree Neither agree or disagree Disagree Strongly disagree N/A

Conclusion

This pilot study has demonstrated that an outpatient clinic effectively identifies that some onward referral to local services can be prevented for patients who had inconclusive assessments which may result in cost and time savings.

Patients requiring an onward referral had clear abnormal assessments making referrals to local services indicated and accurate.

Overall parents were highly satisfied by the service. We aim to scale up the service and re-audit patient outcomes in one year.

Next steps

Ongoing outpatient reviews

Benchmarking

Re-audit

Business Case

References

1. Marino BS, Lipkin PH, Newburger JW, Peacock G, Gerdes M, Gaynor JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation*. 2012 Aug 28;126(9):1143-72.
2. Mussatto KA, Hoffmann RG, Hoffman GM, Tweddell JS, Bear L, Cao Y, et al. Risk and prevalence of developmental delay in young children with congenital heart disease. *Pediatrics*. 2014 Mar 1;133(3):570-7.