BMJ Paediatrics Open

USING DELPHI METHODOLOGY FOR DEVELOPING CONSENSUS ON A REFERRAL PATHWAY FOR POTENTIALLY ABNORMAL NEURODEVELOPMENT IN CHILDREN WITH HEART DISEASE IN THE UNITED KINGDOM

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2019-000587
Article Type:	Original research
Date Submitted by the Author:	14-Oct-2019
Complete List of Authors:	Hoskote, Aparna; Great Ormond Street Hospital For Children NHS Foundation Trust, Cardiac Intensive Care Unit Wray, Jo; Great Ormond Street Hospital For Children NHS Foundation Trust Banks, Victoria; Great Ormond Street Hospital For Children NHS Trust, Cardiac Services Information Office Brown, Katherine; Great Ormond Street Hospital For Children NHS Foundation Trust Lakhanpaul, Monica; UCL Institute of Child Health, General and Adolescent Paediatrics Unit
Keywords:	Cardiology, Comm Child Health, General Paediatrics, Neurodevelopment, Multidisciplinary team-care

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Confidential: For Review Only

USING DELPHI METHODOLOGY FOR DEVELOPING CONSENSUS ON A REFERRAL PATHWAY FOR POTENTIALLY ABNORMAL NEURODEVELOPMENT IN CHILDREN WITH HEART DISEASE IN THE UNITED KINGDOM

AU Hoskote[1,2] MD MRCP, J Wray[1,2] PhD, V Banks[1,2] BSc, KL Brown[1,2] MD MPH, M Lakhanpaul[2,3,4] DM FRCPCH

[1]Cardiothoracic Unit, Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London, WC1N 3JH

[2]NIHR Great Ormond Street Hospital Biomedical Research Centre, Great Ormond Street Institute of Child Health, Great Ormond Street Hospital NHS Trust, University College London, London, WC1N 3JH

[3]Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, 30, Guilford Street, London WC1N 1EH

[4]Whittington NHS Trust, London, WC1N 3EH

Word count: 2500

Address for correspondence
Dr. Aparna Hoskote
Consultant in Cardiac Intensive Care
Honorary Senior Lecturer, UCL, Great Ormond Street Institute of Child Health
Great Ormond Street Hospital for Children NHS Foundation Trust
London WC1N 3JH, UK
Tel: +44 2074059200
Fax: +44 2078138262
Email: Aparna.hoskote@gosh.nhs.uk

Abstract

Introduction: Children with congenital heart disease (CHD) have complex medical and neurodevelopmental needs. We aimed to develop a multi-professional consensus-based referral pathway applicable to action the results of the Brief Developmental Assessment (BDA), a validated early recognition tool, that categorises the neurodevelopmental status as green (appropriate for age), amber (equivocal) or red (delayed) in children aged 4 months to 5 years.

Methods: A Delphi consensus survey detailing two scenarios - a child categorised as delayed (red) and another as equivocal (amber) on administration of the BDA at the time of discharge from the tertiary centre - was sent to 80 expert professionals from primary, secondary and tertiary care seeking agreement on next steps and referral pathways. An iterative process was proposed with a pre-defined rule of 75% for consensus.

Results: The survey was completed by 77 Delphi panel experts in Round 1, 73 in Round 2, and 70 in Round 3. Consensus was achieved – 1) for the child with amber or red BDA, the child should be under the care of a paediatrician with expertise in cardiology (PEC) (or general paediatrician if no PEC) based at their local hospital, 2) for the child with red BDA, the PEC should initiate referral to community services at first assessment, 3) for child with amber BDA, a re-assessment by the health visitor in 1-2 months, with referral to community services with notification to the PEC if ongoing concerns.

Conclusions: The Delphi process helped facilitate consensus on referral pathways for specialist neurodevelopmental assessment/treatment following the administration of red and amber BDA. This will help develop and establish a national pathway for children with CHD to address and intervene on the neurodevelopmental difficulties faced by these children.

Word count = 282

Introduction

Children with congenital heart disease (CHD) have complex medical requirements (cardiac surgery, multiple hospitalisations, medications, associated syndromes), which may negatively impact their neurodevelopment – a key factor in their general wellbeing and educational attainments [1-7]. Currently, there is no routine evaluation and follow-up of neurodevelopmental status for children with CHD in the UK above that offered to healthy children. Research in the USA has identified neurodevelopmental abnormalities in as many as 25% of surgical survivors [1 8-17] and the American Heart Association (AHA) in their scientific statement [18] has outlined an algorithm for a surveillance, evaluation and management for children with CHD. In the UK, a recent consultation exercise with clinicians from primary, secondary, and tertiary care and lay stakeholders as part of the NIHR-funded paediatric cardiac morbidity surgery study [19] ranked neurodevelopmental problems as the number one complication concern for those undergoing intervention for CHD [20]. Our research indicates that there are gaps in the follow-up of children with CHD with developmental difficulties [21]. Within the context of this NIHR study, an innovative, easy to administer 'early recognition tool' – Brief Developmental Assessment (BDA) – was developed and validated in 971 children aged 4 months-5 years in three paediatric tertiary cardiac centres in London, UK [22 23]. The BDA covers different age bands (17-34.9 weeks, 35-60 weeks, 15 months-2.9 years, 3.0-4.9 years) and allows categorisation of a child's current neurodevelopment as green (appropriate for age), red (delayed) or amber (equivocal) to help direct care through early recognition, enabling children with concerns to be referred for specialist assessment/treatment. The ultimate goal is for the BDA to be used in the NHS by practitioners who are not neurodevelopmental specialists, as resources do not exist for specialist assessments to be carried out on every child with CHD.

Aim and objectives of the Delphi Survey

The aim was to develop a multi-professional consensus-based protocol for actions on the application of the BDA in age groups (4 months to 5 years) in children with CHD in the UK by 1) recruiting a multidisciplinary group of health professionals from primary, secondary and tertiary healthcare caring for children with CHD and 2) seeking agreement on referral pathways for managing a child with amber or red BDA result to maximise effectiveness of the BDA tool.

Methods

Recruitment and selection of the Delphi panel

We identified a multidisciplinary group of primary, secondary and tertiary healthcare professionals within the CHD networks in the UK, comprising of paediatric cardiologists, paediatric neurologists, paediatric neurodisability professionals, paediatricians with expertise in cardiology (PEC), general paediatricians, community paediatric nurses, community paediatricians, health visitors, cardiac nurse specialists, advanced nurse practitioner/nurse consultant, general practitioners (GP) and parent representatives. To ensure an adequate knowledge base, those who had been in their role for at least 2 years were invited by email giving information on the BDA and requesting participation in the Delphi panel. Those who formally agreed were sent the Delphi survey. The regions identified were London, East of England, South East, North East, East Midlands, West Midlands, South West of England, Yorkshire and Humber, Wales, Scotland, Northern Ireland, and North West of England. The Delphi Consensus Survey was registered as a service improvement project and ethical approval was not required.

Study design for Delphi consensus survey

The survey was designed using SurveyMonkey software containing two scenarios, each presenting a BDA result for a child with CHD aged between 4 months-5 years at discharge from the tertiary centre. Alongside each scenario, respondents were sent a relevant example of the BDA along with standard information to be shared with all relevant health professionals. Scenario 1 described a child with amber BDA admitted to the tertiary centre for an intervention (surgery or catheter treatment), who is found to have *developmental concerns on the BDA* (score of amber = not fulfilling some of the milestones based on population norms, equivocal result). Scenario 2 described a child with red BDA admitted to the tertiary centre for an intervention (surgery or catheter treatment), who is found to have *developmental concerns on the BDA* (score of red = lagging behind the milestones based on population norms). The survey consisting of a mix of open questions with free text response and specific closed questions on the two scenarios was electronically sent with a unique web-link to participating professionals, who were asked to rate responses on a Likert scale: strongly disagree=1, disagree=2, moderately disagree =3, mildly disagree=4, undecided/don't know=5, mildly agree=6, moderately agree=7, agree=8, strongly agree=9. Non-responders would be sent reminder emails to complete the survey.

Data analysis

The results were coded as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3. Free-text responses were categorized and analyzed thematically. Comments and feedback were categorized and used to inform subsequent iterative rounds. Information from the feedback loops was used to inform the final analysis.

Definition of consensus

We established an a priori criterion of 75% approval to define consensus - 75% of the panellists selecting 7, 8 or 9 of the 9-point Likert Scale. Any questions or statements with a) clear disagreement or b) middle ground (no clear agreement or disagreement) would be revised and re-sent on a subsequent Delphi round until consensus was reached. The results would be sent with each iterative round.

In accordance with current national healthcare provisions, we stated a presumption that there would be a PEC in most district general hospitals, and if not, the default would be a general paediatrician. We also presumed that children <5 years of age will have a health visitor (HV) in their local community.

Results

Of the 164 invited professionals across the UK, 87 (53%) agreed to participate (Table 1). The geographical distribution was weighted towards South East of England (Table 2). All panellists were experienced with 53 (66%) who had been in the role for >5 years.

Round 1 (Supplementary material)

The results of Round 1 are outlined in Table 3. The respondents supported their choice by giving open text comments. Selected pertinent comments and themes that emerged were as follows:

Amber BDA scenario: 1) the tertiary cardiac team who has administered and identified the amber BDA will be aware of the child's GP and PEC, but will not be familiar with the community paediatric services in the child's local area, 2) the GP needs to be the one initiating new referrals, but may not be accepted consultant to consultant, 3) the PEC or general paediatrician may not be equipped to assess child development and hence undertake re-assessment and 4) there were contradictory comments about the HV skills (positive from secondary/primary care) and comments that cardiac professionals may have limited understanding of the HV service.

Red BDA scenario: there was no consensus on which health professional should be undertaking the referral to the community paediatrician which necessitated a second Delphi round. Respondents cautioned against referral delays and suggested that 'it did not matter who made the referral as long as it happened'.

Round 2 (Supplementary material)

The results of Round 2 are outlined in Table 4. For Amber BDA scenario: the required level of consensus of 75% was not reached on 1) referral by HV to PEC and 2) whether the child should be re-assessed before referral to the community paediatrician, resulting in a third Delphi round.

For Red BDA scenario: the panel agreed that referral with red BDA result should be made by the PEC to the community paediatrician (82%). The Delphi panellists commented that 1) there should be robust communication between primary, secondary and tertiary professionals, 2) delays in referral communication and multiple referral/appointments should be avoided, and 3) referral to community services should be prompt.

Round 3 (Supplementary material)

For amber BDA scenario, the panel agreed that if the HV had concerns in the 1-2-month assessment after discharge from the tertiary centre, the HV should refer to the community paediatrician (with notification to the PEC), however, only 73% of the panel agreed that the child should be re-assessed by the HV 1-2 months after discharge (Table 4). On analysing the free text comments, it appears that the response was influenced by the perception that 1) there is significant variation in HV service within the UK, 2) HV service is overburdened and 3) children who have started school (at 4 years) may no longer be under HV in some areas.

The results from 3 Delphi rounds are summarised in Table 5.

Discussion

Neurodevelopmental difficulties can potentially be the most devastating long-term sequelae for children with CHD [24-26] and as the number of survivors with complex cardiac conditions increase, there is a growing demand for these children to have adequate support within the wider healthcare system. Routine formal neurodevelopmental testing can be difficult to enforce within the constraints of the NHS. The validated BDA would theoretically function as an early recognition tool to sign-post those children with CHD who have neurodevelopmental problems. However, implementation of such a tool serves no useful purpose unless intervention and referral pathways are established. Using the Delphi consensus process with iterative rounds and feedback loops, with a panel comprising experts from primary, secondary and tertiary care within different parts of the UK, our study showed that consensus on referral patterns can be established for children with CHD who have been identified to have neurodevelopmental concerns by the BDA.

Consensus

The Delphi expert panel reached consensus that: children with either amber or red BDA should be under the care of the PEC and referred at the time of discharge from the tertiary centre by the child's primary cardiologist with results shared with the GP, HV, cardiologist and other relevant health professionals (Figure 1). Children with a red BDA should be referred to a community paediatrician and local child development team (if not already under one) at the time of the assessment to minimise any delay. Children with an amber BDA should have a re-assessment by the local HV 1-2 months after discharge and be referred to the community paediatrician if there are persisting concerns, with a notification to the PEC. The PEC or designated paediatrician at the local hospital and the HV (in the case of younger babies and toddlers) were identified as the key health professionals in an ideal position to link up a child with CHD with developmental problems and their local child development team. In addition, the PEC was identified as an important link with the tertiary cardiac centre. Of note, the Delphi responses did not support a new referral to the PEC/paediatrician coming from the specialist nursing team in the tertiary hospitals.

Health care across sectors

As a background to this consensus process, it is important to acknowledge the current care provision relevant to developmental needs for children with CHD, although this can be highly variable.

Tertiary care: Children with CHD are always under a cardiologist and a cardiac specialist nursing team, who may not necessarily have 'general paediatric' and 'child development' expertise but assess the child at critical time points particularly in early infancy. The BDA is intended for use as an early recognition tool for child neurodevelopment in this setting.

Secondary care: Within the setting of a non-specialist hospital, children with CHD are under the care of a PEC. In a small number of hospitals where a PEC is not in post, a named paediatrician will have designated responsibility for the paediatric needs of cardiac children. Not all cardiac children are formally under the care of a PEC or paediatrician (for example if they have never been to the local hospital), however a PEC or paediatrician with designated responsibility is available for a cardiac child should the need arise. The PEC (unlike the tertiary hospital team) will be aware of child development services available locally.

Primary and community care: all children, including those with CHD, are under a GP and at pre-school age, a health visitor. Both GP and HV are experienced in the referral of children with possible developmental problems to child development teams and will be cognisant of the local services. It is well known that health visitor services are under pressure, with recent reports indicating that many children miss out on these visits [27-29]. Child development teams are based within individual areas that they serve and are often linked to specific non-specialist hospitals. A child with CHD will be under the care of a child development team only if specifically referred.

Areas where agreement was more challenging

The main area where there was lack of agreement related to the child with an amber BDA. Of note, a child with suspected developmental delays may benefit from close follow-up and re-assessment given that these are crucial to identify the need for early intervention. Early identification and timely intervention contribute significantly towards a child's overall adjustment and quality of life [30]. There was only moderate support for HV re-assessment, PEC re-assessment and referral to community paediatrics if on-going concerns with the child's development, but these did not reach the required 75% level for agreement. While there was no agreement for a child with amber BDA to be under the care of the community paediatrician, there were also conflicting opinions over whether or not the PEC or paediatrician is equipped to assess child development and hence undertake the recommended re-assessment. This may reflect lack of clarity between health professionals from different sectors as to each-others roles and skills. In addition, the initial lack of consensus about who should make the referral to the community paediatrician in the case of a child with a red BDA may reflect the lack of familiarity with the way local services operated across sectors. A particular hallmark of child development in those with CHD is that this is an issue that spans sectors and hence may fall through the gaps, and the responses of the Delphi survey were consistent with this, albeit eventually reaching consensus as to responsibilities for each sector / professional group.

Strengths and Limitations

This is the first time a consensus has been developed using the Delphi process to outline referral pathways for potentially abnormal neurodevelopment from a group of primary, secondary and tertiary care professionals looking after children with CHD. The Delphi process does not involve any face-to-face contact unlike a consensus development conference or a structured discussion. While every attempt was made to enrol experts into the Delphi panel from primary healthcare, there were few GPs and HVs who accepted the invitation.

Conclusions

The Delphi process has provided the initial platform for developing consensus on a national pathway for the management of children with CHD who have either equivocal or delayed neurodevelopment. The consensus supported the vital role of the PEC as a co-ordinating link between the primary cardiologist and the community services. The health visitor as a close link to community services in liaison with the PEC was felt to be the point of contact for re-assessment of the child with borderline or equivocal results.

ACKNOWLEDGEMENTS

We would like to acknowledge Jana Gurasashvili for the administrative help with the study, and all the Delphi panellists for their participation in the iterative rounds and the support from the NIHR Great Ormond Street Hospital Biomedical Research Centre, Great Ormond Street Institute of Child Health, Great Ormond Street Hospital NHS Trust, University College London, London, WC1N 3JH.

FUNDING STATEMENT

There was no funding received for this study.

PARENT AND PUBLIC INVOLVEMENT STATEMENT

Lay stakeholders including parents were consulted along with clinicians from primary, secondary, and tertiary care as part of the NIHR-funded paediatric cardiac morbidity surgery study and they ranked neurodevelopmental problems as the number one complication concern for those undergoing intervention for CHD. Parent representatives and other stakeholders have been involved with the design, conduct and dissemination at every stage of the project.

CONTRIBUTOR STATEMENT

Conceptualisation and study design – A Hoskote, J Wray, K Brown and M Lakhanpaul

Administration of the survey and drafting of survey questions for the iterative rounds of Delphi – A Hoskote, J Wray, K Brown and M Lakhanpaul

Analyses of the study data – V Banks, A Hoskote, J Wray, K Brown and M Lakhanpaul

Write-up - A Hoskote, J Wray, K Brown and M Lakhanpaul

Editing and final approval of the final manuscript - A Hoskote, J Wray, V Banks, K Brown and M Lakhanpaul

“What is already known on this topic” – followed by a maximum of 3 brief statements (no more than 25 words per statement)

1. Children with congenital heart disease (CHD) have complex medical and neurodevelopmental needs with neurodevelopmental abnormalities leading to potentially devastating long-term sequelae.
2. Routine neurodevelopmental surveillance, screening and evaluation in children with CHD is well-established in cardiothoracic programmes in USA and parts of Europe unlike in UK.
3. An early recognition tool leading to intervention is an important first step in identifying children with delayed development in a high-volume cardiology service.

“What this study adds” – followed by a maximum of 3 brief statements (no more than 25 words per statement).

1. A multi-professional Delphi process achieved consensus on referral pathways for children (4 months-5 years) with CHD using an early recognition tool (Brief Developmental Assessment-BDA).
2. Consensus that children with delayed development (red BDA) should be referred immediately and those suspected (amber) should be re-assessed before referral to community paediatricians.
3. The paediatrician with expertise in cardiology (PEC) is central to the management of children with CHD and follow-up of suspected and/or confirmed neurodevelopmental delay.

Table 1. Professionals who participated in the Delphi Consensus Rounds

Speciality	Invited	Accepted	Completed Round 1 N=77	Completed Round 2 N=73	Completed Round 3 N=70
Tertiary care professionals n=32*					
Paediatric Cardiologist	20	12	9 (75)	9 (75)	8 (66)
Clinical Nurse Specialist	28	12	12 (100)	9 (75)	9 (75)
Advanced nurse practitioner/ Nurse Consultant	5	4	4 (100)	4 (100)	4 (100)
Paediatric Neurologist	8	4	4 (100)	4 (100)	4 (100)
Secondary care professionals n=25*					
Paediatric Neurodisability	14	8	8 (100)	8 (100)	8 (100)
Paediatrician with expertise in cardiology	15	11	11 (100)	11 (100)	11 (100)
General Paediatrician	15	6	5 (83)	4 (66)	3 (50)
Primary care professionals (n=24)*					
Community Paediatric Nurse	5	3	3 (100)	3 (100)	3 (100)
Community Paediatrician	22	12	11 (92)	11 (92)	11 (92)
Health Visitor	9	4	3 (75)	3 (75)	2 (50)
General Practitioner	12	5	3 (60)	3 (60)	3 (60)
Parent representatives n=6*					
Parent representatives	11	6	4 (67)	4 (67)	4 (67)

*Total number who accepted the invitation to join the Delphi Panel.

Table 2. Distribution of Delphi Panel Experts

Region	**Number of Delphi Panellists**
London	29
East of England	10
South East	12
North East	2
East Midlands	3
West Midlands	6
South West	5
Yorkshire and Humber	1
Wales	2
Scotland	4
Northern Ireland	1
North West	2
Total	**77**

Table 3: Delphi Consensus Survey – results from Round 1

Round 1	**% Agree**	**% Middle Ground**	**% Disagree**
Q5. All children with CHD and AMBER BDA should be under the care of a (general paediatrician if no PEC) based at their local hospital.	75	16	9
Q6. If a child with CHD and AMBER BDA is not under the care of a PEC it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC*(local general paediatrician if no PEC).	79	12	9
Q7. If a child with CHD and AMBER BDA is not under the care of a (local general paediatrician if no PEC), then a referral from the tertiary hospital under a specialist nursing team to a PEC/general paediatrician is acceptable.	60	25	16
Q8. The request for referral should have clinical details and the BDA assessment.	87	6	6
Q9. The complete results of the AMBER BDA should be shared with the child's PEC*(local general paediatrician).	91	6	3
Q10. The complete results of the AMBER BDA should be shared with the child's general practitioner (GP).	91	5	4
Q11. The complete results of the AMBER BDA should be shared with the child's health visitor (HV).	84	10	5
Q12. All children with CHD and an AMBER BDA at the point of discharge following cardiac intervention should be reassessed (in terms of development and general health) after a period of time by the PEC*(local general paediatrician).	65	21	14
Q13. All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's health visitor (HV).	71	18	10
Q14. All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's GP.	35	43	22
Q15. Referral of children with CHD and AMBER BDA (not already under local health services) to community paediatrician should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	64	22	14
Q16. Referral of children with CHD and AMBER BDA (not under local health services) to PEC*(local general paediatrician) should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	70	18	12
Q17. Children with CHD and AMBER BDA should be re-assessed after a defined period and then referred to a community paediatrician if there is on-going concern.	70	18	12
Q18. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the PEC*(local general paediatrician if no PEC).	69	21	10
Q19. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	40	35	25

Q20. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the tertiary paediatric cardiac team	48	29	23
Q21. All children with CHD and RED BDA should be under the care of a PEC* (local general paediatrician if no PEC) based at their local hospital.	77	17	6
Q22. If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician if no PEC), it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	79	17	4
Q23. If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician), then a referral from the tertiary hospital specialist nursing team to a PEC*(local general paediatrician) is acceptable.	55	29	17
Q24. The complete results of the RED BDA should be shared with the child's PEC* (local general paediatrician if no PEC).	94	5	1
Q25. The complete results of the RED BDA should be shared with the child's general practitioner (GP).	91	8	1
Q26. The complete results of the RED BDA should be shared with the child's health visitor (HV).	92	6	1
Q27. The complete results of the RED BDA should be shared with other relevant health professionals involved with the child such as neurologist, child development clinic, and geneticist	95	4	1
Q28. All children with CHD and RED BDA should be under the care of a community paediatrician and local child development team.	91	6	3
Q29. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken at the point of first assessment where an abnormal BDA is recorded at discharge following cardiac intervention (if child is not already under one).	81	16	4
Q30. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken if there is on-going concern after a period of reassessment by the child's PEC*(local general paediatrician if no PEC).	64	21	16
Q31. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's *(local general paediatrician if no PEC).	73	21	6
Q32. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	43	31	26
Q33. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's GP	39	32	29
Q34. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's paediatric cardiac team	69	19	12

The results from responses were coded as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3.

Table 4: Delphi Consensus Survey – results from Round 2 and 3

Round 2	**% Agree**	**% Middle Ground**	**% Disagree**
Q1. At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC).	77	8	14
Q2. Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no PEC at local hospital).	72	10	18
Q3. The child with Amber BDA should be re-assessed before referral to the community paediatrician.	46	30	24
Q4. If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician	86	11	3
Q5. The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC).	82	11	7
Round 3	**% Agree**	**% Middle Ground**	**% Disagree**
Q1. The child with Amber BDA should be re-assessed by the Health Visitor (HV) 1-2 months after discharge home.	73	15	12
Q2. If concerns are noted at the health visitor (HV) assessment 1-2 month after discharge from tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC (General Paediatrician if no PEC).	90	6	4

The results from responses were coded as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3.

Table 5: Delphi Consensus Survey – summary of results from Rounds 1, 2 and 3

	Amber BDA	Red BDA
Round 1		
75% consensus achieved	1) The amber BDA result should be shared with the GP, HV, PEC and other relevant health professionals (91%). 2) Child should be under PEC at local hospital (75%). 3) It is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (79%).	1) The red BDA result should be shared with the GP, HV, PEC and other relevant health professionals (90%). 2) Child should be under community paediatrician (91%). 3) Referral to a community paediatrician should be undertaken at the point of first assessment when abnormal BDA is recorded (81%).
75% consensus not achieved	1) Timing of referral and to whom: at first assessment by tertiary cardiac centre to the PEC (70%) and to the community paediatrician (64%). 2) Whether re-assessment should be undertaken before referral to the community paediatrician (70%). 3) Which professional should undertake reassessment: HV (71%), PEC (65%) and GP (35%). 4) Referral to community paediatrician by whom: PEC (69%), HV (40%) and tertiary cardiac centre (48%).	1) On who should make this referral to community paediatrician? - PEC (73%), tertiary cardiac team (69%), HV (43%) and GP (39 %).
Round 2		
75% consensus achieved	1) Child with CHD at first assessment when identified to have an Amber BDA should be referred by the tertiary cardiologist to PEC (77%).	1) The referral to the community paediatrician containing the results of the red BDA should be made by the PEC (82%). 2) If there are any on-going developmental concerns, the PEC should refer to the community paediatrician (86%).
75% consensus not achieved	1) Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by HV should be referred to PEC (72%). 2) The child with amber BDA should be re-assessed before referral to the community paediatrician (46%).	-
Round 3		
75% consensus achieved	If the HV had concerns in the 1-2-month assessment after discharge from the tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC– 90%.	-
75% consensus not achieved	The child with amber BDA should be re-assessed by the HV 1-2 months after discharge home (73%).	-

Title for Figure 1. Delphi Consensus for referral pathway for child with heart disease who has neurodevelopmental concerns - amber or red BDA - at discharge from tertiary centre

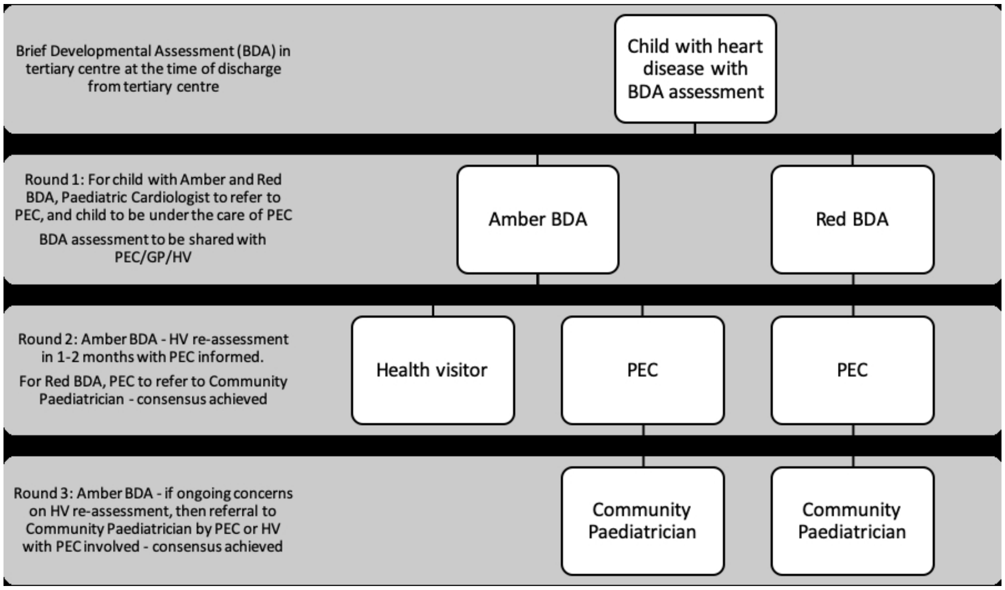
Legend for Figure 1.

The consensus for referral pathway for amber or red BDA is shown in the figure from the iterative rounds of the Delphi Consensus process.

REFERENCES

1. Mackie AS, Alton GY, Dinu IA, et al. Clinical outcome score predicts the need for neurodevelopmental intervention after infant heart surgery. *J Thorac Cardiovasc Surg* 2013;145(5):1248-54 e2. doi: 10.1016/j.jtcvs.2012.04.029 [published Online First: 2012/09/11]
2. Hovels-Gurich HH, Konrad K, Skorzenski D, et al. Long-term behavior and quality of life after corrective cardiac surgery in infancy for tetralogy of Fallot or ventricular septal defect. *Pediatr Cardiol* 2007;28(5):346-54.
3. Miatton M, De Wolf D, Francois K, et al. Neuropsychological performance in school-aged children with surgically corrected congenital heart disease. *J Pediatr* 2007;151(1):73-8, 78 e1.
4. Hovels-Gurich HH, Konrad K, Skorzenski D, et al. Long-term neurodevelopmental outcome and exercise capacity after corrective surgery for tetralogy of Fallot or ventricular septal defect in infancy. *Ann Thorac Surg* 2006;81(3):958-66. doi: 10.1016/j.athoracsur.2005.09.010 [published Online First: 2006/02/21]
5. Walker K, Holland AJA, Winlaw D, et al. Neurodevelopmental outcomes and surgery in neonates. *Journal of Paediatrics and Child Health* 2006;42(12):749-51. doi: 10.1111/j.1440-1754.2006.00969.x
6. Wernovsky G, Shillingford AJ, Gaynor JW. Central nervous system outcomes in children with complex congenital heart disease. *Curr Opin Cardiol* 2005;20(2):94-9. [published Online First: 2005/02/16]
7. Bellinger DC, Wypij D, duPlessis AJ, et al. Neurodevelopmental status at eight years in children with dextro-transposition of the great arteries: the Boston Circulatory Arrest Trial. *J Thorac Cardiovasc Surg* 2003;126(5):1385-96.
8. Andropoulos DB, Ahmad HB, Haq T, et al. The association between brain injury, perioperative anesthetic exposure, and 12-month neurodevelopmental outcomes after neonatal cardiac surgery: a retrospective cohort study. *Paediatr Anaesth* 2014;24(3):266-74. doi: 10.1111/pan.12350 [published Online First: 2014/01/29]
9. Beca J, Gunn JK, Coleman L, et al. New white matter brain injury after infant heart surgery is associated with diagnostic group and the use of circulatory arrest. *Circulation* 2013;127(9):971-9. doi: 10.1161/CIRCULATIONAHA.112.001089 [published Online First: 2013/02/02]
10. Andropoulos DB, Easley RB, Brady K, et al. Neurodevelopmental outcomes after regional cerebral perfusion with neuromonitoring for neonatal aortic arch reconstruction. *Ann Thorac Surg* 2013;95(2):648-54; discussion 54-5. doi: 10.1016/j.athoracsur.2012.04.070 [published Online First: 2012/07/07]
11. Undar A, Wang S, Guan Y, et al. Brain protection during pediatric cardiac surgery: A multidisciplinary team approach at penn state hershey children's hospital and pediatric cardiovascular research center. *Artif Organs* 2012;36 (5):A10.
12. Walker K, Holland AJA, Halliday R, et al. Which high-risk infants should we follow-up and how should we do it? *Journal of Paediatrics and Child Health* 2012;48(9):789-93. doi: 10.1111/j.1440-1754.2012.02540.x
13. Andropoulos DB, Easley RB, Brady K, et al. Changing expectations for neurological outcomes after the neonatal arterial switch operation. *Ann Thorac Surg* 2012;94(4):1250-5; discussion 55-6. doi: 10.1016/j.athoracsur.2012.04.050 [published Online First: 2012/07/04]
14. Gunn JK, Beca J, Hunt RW, et al. Perioperative amplitude-integrated EEG and neurodevelopment in infants with congenital heart disease. *Intensive Care Med* 2012;38(9):1539-47. doi: 10.1007/s00134-012-2608-y [published Online First: 2012/06/02]
15. Wernovsky G. Neurodevelopmental outcomes: Scope of the problem and current challenges. *Artif Organs* 2010;34 (4):A1.

16. Gaynor JW, Gerdes M, Nord AS, et al. Is cardiac diagnosis a predictor of neurodevelopmental outcome after cardiac surgery in infancy? *J Thorac Cardiovasc Surg* 2010;140(6):1230-7. doi: 10.1016/j.jtcvs.2010.07.069 [published Online First: 2010/10/19]
17. Hovels-Gurich HH, Bauer SB, Schnitker R, et al. Long-term outcome of speech and language in children after corrective surgery for cyanotic or acyanotic cardiac defects in infancy. *Eur J Paediatr Neurol* 2008;12(5):378-86.
18. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012;126(9):1143-72. doi: 10.1161/CIR.0b013e318265ee8a
19. Brown K PC, Ridout D, Wray J, Tsang V, Anderson D, Banks V, Barron D, Cassidy J, Chigaru L, Davis P, Franklin R, Grieco L, Hoskote A, Hudson E, Jones A, Kakat S, Lakhani R, Lakhanpaul M, McLean A, Morris S, Rajagopal V, Rodriguez W, Sheehan K, Stoica S, Tibby S, Utley M, Witter T. Selection, definition and evaluation of important early morbidities associated with paediatric cardiac surgery: a mixed methods study. *NIHR Journals Library* 2019;In Press
20. Pagel C, Brown KL, McLeod I, et al. Selection by a panel of clinicians and family representatives of important early morbidities associated with paediatric cardiac surgery suitable for routine monitoring using the nominal group technique and a robust voting process. *BMJ Open* 2017;7(5):e014743. doi: 10.1136/bmjopen-2016-014743 [published Online First: 2017/05/31]
21. AU Hoskote VB, S Kakat, DA Ridout, M Lakhanpaul, C Pagel, RC Franklin, T Witter, R Lakhani, S Tibby, D Anderson, V Tsang, J Wray, KL Brown. . Neurodevelopmental status and follow-up in pre-school children with heart disease in london uk. *Archives of Disease in Childhood in review* 2019
22. Wray J, Brown KL, Ridout D, et al. Development and preliminary testing of the Brief Developmental Assessment: an early recognition tool for children with heart disease. *Cardiol Young* 2018:1-10. doi: 10.1017/S1047951117002918 [published Online First: 2018/02/13]
23. Brown KL, Ridout DA, Pagel C, et al. Validation of the Brief Developmental Assessment in pre-school children with heart disease. *Cardiol Young* 2018;28(4):571-81. doi: 10.1017/S1047951117002773 [published Online First: 2018/03/08]
24. Robson VK, Stopp C, Wypij D, et al. Longitudinal Associations between Neurodevelopment and Psychosocial Health Status in Patients with Repaired D-Transposition of the Great Arteries. *J Pediatr* 2019;204:38-45 e1. doi: 10.1016/j.jpeds.2018.08.069 [published Online First: 2018/10/03]
25. Rometsch S, Greutmann M, Latal B, et al. Predictors of quality of life in young adults with congenital heart disease. *Eur Heart J Qual Care Clin Outcomes* 2018 doi: 10.1093/ehjqcco/qcy046 [published Online First: 2018/09/22]
26. Kasmi L, Bonnet D, Montreuil M, et al. Neuropsychological and Psychiatric Outcomes in Dextro-Transposition of the Great Arteries across the Lifespan: A State-of-the-Art Review. *Front Pediatr* 2017;5:59. doi: 10.3389/fped.2017.00059 [published Online First: 2017/04/11]
27. Anim C. Health visitors change lives - so why are numbers decreasing Royal College of Nursing2016 [Report]. Available from: https://www.rcn.org.uk/news-and-events/blogs/health-visitors-change-lives.
28. Investment needed in specialist children's nurses. Health visitors and school nurses report shift understaffing as specialist nurse numbers drop. Royal College of Nursing, 2018:Report.
29. Jozwiak G. Health Visitor numbers 'below safe level' Children & Young People Now2018 [Report]. Available from: https://www.cypnow.co.uk/cyp/news/2006032/health-visitor-numbers-below-safe-level.
30. Minkovitz CS, Hughart N, Strobino D, et al. A practice-based intervention to enhance quality of care in the first 3 years of life: the Healthy Steps for Young Children Program. *JAMA* 2003;290(23):3081-91. doi: 10.1001/jama.290.23.3081 [published Online First: 2003/12/18]


Brief Developmental Assessment (BDA) in tertiary centre at the time of discharge from tertiary centre
Child with heart disease with BDA assessment
Round 1: For child with Amber and Red BDA, Paediatric Cardiologist to refer to PEC, and child to be under the care of PEC
BDA assessment to be shared with PEC/GP/HV
Amber BDA
Red BDA
Round 2: Amber BDA - HV re-assessment in 1-2 months with PEC informed.
For Red BDA, PEC to refer to Community Paediatrician - consensus achieved
Health visitor
PEC
PEC
Round 3: Amber BDA - if ongoing concerns on HV re-assessment, then referral to Community Paediatrician by PEC or HV with PEC involved - consensus achieved
Community Paediatrician
Community Paediatrician

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

1. Introduction to Delphi Consensus Process and Brief Developmental Assessment (BDA)

The Delphi consensus development process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. Having now tested the BDA - designed as a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL, which allows categorisation of a child’s current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal), we aim to delineate and develop a consensus for a referral pathway for children following the application of BDA in an inpatient or outpatient setting.

1. Please describe your role

- ○ Health visitor
- ○ General Practitioner
- ○ Community Paediatrician
- ○ General Paediatrician
- ○ Paediatrician with expertise in cardiology (PEC)
- ○ Consultant Paediatric Neurologist
- ○ Consultant in Paediatric Neurodisability
- ○ Cardiac Liaison Nurse
- ○ Cardiac Nurse Specialist
- ○ Nurse Practitioner Neurology
- ○ Parent representative
- ○ Other

Other (please specify)

2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

☐

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England
○ East Midlands
○ London
○ North East
○ North West
○ South East
○ South West
○ West Midlands
○ Yorkshire and the Humber
○ Northern Ireland
○ Scotland
○ Wales

4. How long have you been in your current role?

○ Less than 1 year
○ 2-5 years
○ >than 5 years

Great Ormond Street Hospital for Children
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

2. Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have *developmental concerns on BDA* (score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result). The tertiary cardiac team will be in possession of the BDA results from the pre procedure assessment and information about the course of the child before, during and after surgery. Please see example of AMBER BDA attached to email.

*We expect that in most general hospitals, there is a consultant **Paediatrician with Expertise in Cardiology (PEC).** If there is no nominated PEC, then the default is general paediatrician based at the local hospital.

5. **The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and AMBER BDA should be under the care of a PEC* (general paediatrician if no PEC) based at their local hospital.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

6. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and AMBER BDA is not under the care of a PEC*, it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

7. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and AMBER BDA is not under the care of a PEC*(local general paediatrician if no PEC), then a referral from the tertiary hospital specialist nursing team to a PEC/general paediatrician is acceptable.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

8. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The request for referral should have clinical details and the BDA assessment.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

9. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child's PEC*(local general paediatrician).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

10. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child's general practitioner (GP).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

11. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

12. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed (in terms of development and general health) after a period of time by the PEC*(local general paediatrician).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

13. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

14. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's GP.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

15. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA (not already under local health services) to community paediatrician should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

16. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA (not under local health services) to PEC*(local general paediatrician) should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

17. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Children with CHD and AMBER BDA should be re-assessed after a defined period (second repeat assessment), and then referred to a community paediatrician if there is on-going concern.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

18. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

19. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

20. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the <u>tertiary paediatric cardiac team</u>.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

3. Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have <u>developmental concerns on BDA</u> (score of RED = lagging behind the milestones as based on population norms). The tertiary cardiac team will be in possession of the BDA results from the pre procedure assessment and information about the course of the child before, during and after surgery. <u>Please see RED BDA attached to email.</u>
<u>*We expect that in most general hospitals, there is a consultant paediatrician with expertise in cardiology (PEC). If there is no nominated PEC, then the default is general paediatrician based at the local hospital.</u>

21. **The score of RED referred to in the statements below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and RED BDA should be under the care of a PEC* (local general paediatrician if no PEC) based at their local hospital.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

22. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician if no PEC), it is the responsibility of the child’s paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

23. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician), then a referral from the tertiary hospital specialist nursing team to a PEC*(local general paediatrician) is acceptable.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

24. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the child's PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

25. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the child's general practitioner (GP).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

26. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

27. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with other relevant health professionals involved with the child such as neurologist, child development clinic, and geneticist.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

28. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and RED BDA should be under the care of a community paediatrician and local child development team.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

29. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken at the point of first assessment where an abnormal BDA is recorded at discharge following cardiac intervention (if the child is not already under one).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

30. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken if there is on-going concern after a period of reassessment by the child’s PEC*(local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

31. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's PEC*(local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

32. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

33. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's GP.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

34. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's paediatric cardiac team.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

4. General comments - providing neurodevelopmental assessment and interventions for children with CHD

Management of children with CHD outside of the tertiary cardiac centre. This applies to any child with CHD irrespective of whether or not the child is already known to have any developmental delay.

35. General comments about providing neurodevelopmental assessment and intervention for children with CHD.

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under general paediatrician to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

36. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under community paediatrician locally to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

37. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under Paediatrician with expertise in Cardiology (PEC) locally to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

38. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The neurodevelopmental assessment and management of every child with CHD should be under the direction of the Paediatrician with expertise in Cardiology (PEC) and/or local general paediatrician?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

39. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The neurodevelopmental assessment and management of every child with CHD should be under the direction of the <u>local community paediatrician</u>?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

40. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

1. Delphi Consensus Process and Brief Developmental Assessment (BDA) ROUND 2

Thankyou to all those who completed Round 1. As a reminder, the Delphi consensus process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. We are using this process to develop a consensus for referral pathway for children with CHD who have neurodevelopmental problems. <u>The BDA is a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL,</u> which allows categorisation of a child's current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal). Having completed ROUND 1 of the Delphi Consensus Process, we invite you to ROUND 2 to delineate and <u>develop a consensus on those questions that did not reach the agreed level of consensus (75%). For each scenario presented, we will inform which items reached consensus, and only put forward those questions that did not reach consensus.</u>

1. Please describe your role

○ Health visitor

○ General Practitioner

○ Community Paediatrician

○ General Paediatrician

○ Consultant Paediatric Cardiologist

○ Paediatrician with expertise in cardiology (PEC)

○ Consultant Paediatric Neurologist

○ Consultant in Paediatric Neurodisability

○ Cardiac Liaison Nurse

○ Cardiac Nurse Specialist

○ Nurse Practitioner Neurology

○ Parent representative

○ Other

Other (please specify)

2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England

○ East Midlands

○ London

○ North East

○ North West

○ South East

○ South West

○ West Midlands

○ Yorkshire and the Humber

○ Northern Ireland

○ Scotland

○ Wales

4. How long have you been in your current role?

○ Less than 1 year

○ 2-5 years

○ >than 5 years

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

2. Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have ***developmental concerns on BDA*** **(score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result).** **Please see example of AMBER BDA sent at the time of Round 1 and attached again with ROUND 2 email, and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years (sent as attachment with Round 2 email).**
The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals.
Delphi ROUND 1 - the required level of consensus of 75% was achieved on - 1) The results of the Amber BDA should be shared with the GP, Health Visitor, Cardiologist, PEC* (General Paediatrician if no PEC) and other relevant health professionals (91%) and **2)** All children with CHD + Amber BDA should be under PEC (General Paediatrician if no PEC) based at their local hospital (75%), and **3)** it is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (General Paediatrician if no PEC) (79%).
The required level of consensus of 75% was not reached on - 1) Timing of referral: At first assessment by tertiary cardiac centre to PEC (70%) and to community paediatrician (64%). **2)** Re-assessment before referral to community paediatrician (70%). **3)** Re-assessment by whom: by HV (71%), by PEC (65%) and by GP (35%). **4)** Referral to community paediatrician by whom: PEC (69%), HV (40%), tertiary cardiac centre (48%).
The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre. We presume that there is PEC (Paediatrician with Expertise in Cardiology) or a nominated paediatrician if no PEC at local hospital. We presume that ALL children under the age of 5 years will have a Health Visitor (HV). The tertiary cardiac team who has administered and identified the Amber BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

5. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

6. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no PEC at local hospital).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

7. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The child with Amber BDA should be re-assessed before referral to the community paediatrician.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

8. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

3. Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have **developmental concerns on BDA** **(score of RED = lagging behind the milestones as based on population norms).** **Please see RED BDA attached to email sent out with ROUND 1 and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years.** The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals, if needed.

Delphi Round 1 - the required level of consensus of 75% agreement was achieved on - **1)** the results of the Red BDA should be shared with the GP, Health Visitor, Cardiologist, PEC (General Paediatrician if no PEC) and other relevant health professionals (90%), **2)** all children with CHD + Red BDA should be under community paediatrician (91%)and **3)** Referral of children with CHD + red BDA to a community paediatrician should be undertaken at the point of first assessment where abnormal BDA is recorded (81%).

There was lack of consensus on who should make this referral - PEC (73%), HV (43%), GP (39%), tertiary cardiac team (69%). The tertiary cardiac team who has administered and identified the Red BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

9. **The score of RED referred to in the statements below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

10. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Delphi Consensus Process and Brief Developmental Assessment (BDA) ROUND 3

Thankyou to all those who completed Round 1 and Round 2. As a reminder, the Delphi consensus process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. We are using this process to develop a consensus for referral pathway for children with CHD who have neurodevelopmental problems. The BDA is a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL, which allows categorisation of a child's current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal). For each scenario presented, we will inform which items reached consensus, and only put forward those questions that did not reach consensus. Having completed ROUND 1 and ROUND 2 of the Delphi Consensus Process, we invite you to ROUND 3 to delineate and develop a consensus on those questions that did not reach the agreed level of consensus (75%) for 2 questions for AMBER BDA. We have achieved consensus for RED BDA questions. Thankyou!

* 1. Please describe your role

○ Health visitor

○ General Practitioner

○ Community Paediatrician

○ General Paediatrician

○ Consultant Paediatric Cardiologist

○ Paediatrician with expertise in cardiology (PEC)

○ Consultant Paediatric Neurologist

○ Consultant in Paediatric Neurodisability

○ Cardiac Liaison Nurse

○ Cardiac Nurse Specialist

○ Nurse Practitioner Neurology

○ Parent representative

○ Other

Other (please specify)

* 2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England

○ East Midlands

○ London

○ North East

○ North West

○ South East

○ South West

○ West Midlands

○ Yorkshire and the Humber

○ Northern Ireland

○ Scotland

○ Wales

4. How long have you been in your current role?

○ Less than 1 year

○ 2-5 years

○ >than 5 years

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have ***developmental concerns on BDA*** **(score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result).** **Please see example of AMBER BDA sent at the time of Round 1 and attached again with ROUND 2 email, and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years (sent as attachment with Round 2 email).**
The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals.
Delphi ROUND 1 - the required level of consensus of 75% was achieved on - **1)** The results of the Amber BDA should be shared with the GP, Health Visitor, Cardiologist, PEC* (General Paediatrician if no PEC) and other relevant health professionals (91%) and **2)** All children with CHD + Amber BDA should be under PEC (General Paediatrician if no PEC) based at their local hospital (75%), and **3)** it is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (General Paediatrician if no PEC) (79%).
The required level of consensus of 75% was not reached on - 1) Timing of referral: At first assessment by tertiary cardiac centre to PEC (70%) and to community paediatrician (64%). **2)** Re-assessment before referral to community paediatrician (70%). **3)** Re-assessment by whom: by HV (71%), by PEC (65%) and by GP (35%). **4)** Referral to community paediatrician by whom: PEC (69%), HV (40%), tertiary cardiac centre (48%).
Delphi ROUND 2 - **the required level of consensus of 75% was achieved on -** 1) At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC) (77%).
The required level of consensus of 75% was not reached on - 1) Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no nominated PEC) (72%), 2) The child with Amber BDA should be re-assessed before referral to the community paediatrician (46%). Hence the further 2 questions to the panel.
The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre. We presume that there is PEC (Paediatrician with Expertise in Cardiology) or a nominated paediatrician if no PEC at local hospital. We presume that ALL children under the age of 5 years will have a Health Visitor (HV). The tertiary cardiac team who has administered and identified the Amber BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local com

* 5. **Children with congenital heart disease who have had recent surgery or procedure and who score an Amber BDA may need time to recover from recent hospitalisation. A review by HV following a recovery period at home would be able to identify any ongoing concerns.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The child with Amber BDA should be re-assessed by the Health Visitor (HV) 1-2 months after discharge home.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

* 6. **<u>The score of Amber BDA relates to the assessment at the time of discharge from the tertiary centre.</u>**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If concerns are noted at the health visitor (HV) assessment 1-2 month after discharge from tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC (General Paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have **developmental concerns on BDA** **(score of RED = lagging behind the milestones as based on population norms).** **Please see RED BDA attached to email sent out with ROUND 1 and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years.** The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals, if needed.

Delphi Round 1 - the required level of consensus of 75% agreement was achieved on - **1)** the results of the Red BDA should be shared with the GP, Health Visitor, Cardiologist, PEC (General Paediatrician if no PEC) & other relevant health professionals (90%), **2)** all children with CHD + Red BDA should be under community paediatrician (91%) and **3)** Referral of children with CHD + red BDA to a community paediatrician should be undertaken at the point of first assessment where abnormal BDA is recorded (81%).

There was lack of consensus on who should make this referral - PEC (73%), HV (43%), GP (39%), tertiary cardiac team (69%). The tertiary cardiac team who has administered and identified the Red BDA will be aware of the child’s GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

Delphi Round 2 - the required level of consensus of 75% agreement was achieved on both questions addressed to the panel - 1) The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC (82%). 2) If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician (86%).

There are no further questions for Red BDA as we have achieved consensus!! Thankyou!!

7. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here

BMJ Paediatrics Open

A REFERRAL PATHWAY FOR POTENTIALLY ABNORMAL NEURODEVELOPMENT IN CHILDREN WITH HEART DISEASE IN THE UNITED KINGDOM - A DELPHI CONSENSUS

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2019-000587.R1
Article Type:	Original research
Date Submitted by the Author:	22-Jan-2020
Complete List of Authors:	Hoskote, Aparna; Great Ormond Street Hospital For Children NHS Foundation Trust, Cardiac Intensive Care Unit Wray, Jo; Great Ormond Street Hospital For Children NHS Foundation Trust Banks, Victoria; Great Ormond Street Hospital For Children NHS Trust, Cardiac Services Information Office Brown, Katherine; Great Ormond Street Hospital For Children NHS Foundation Trust Lakhanpaul, Monica; UCL Institute of Child Health, General and Adolescent Paediatrics Unit
Keywords:	Cardiology, Comm Child Health, General Paediatrics, Neurodevelopment, Multidisciplinary team-care

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Confidential: For Review Only

A REFERRAL PATHWAY FOR POTENTIALLY ABNORMAL NEURODEVELOPMENT IN CHILDREN WITH HEART DISEASE IN THE UNITED KINGDOM - A DELPHI CONSENSUS

AU Hoskote[1,2] MD MRCP, J Wray[1,2] PhD, V Banks[1,2] BSc, KL Brown[1,2] MD MPH, M Lakhanpaul[2,3,4] DM FRCPCH

[1]Cardiothoracic Unit, Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London, WC1N 3JH

[2]NIHR Great Ormond Street Hospital Biomedical Research Centre, Great Ormond Street Institute of Child Health, Great Ormond Street Hospital NHS Trust, University College London, London, WC1N 3JH

[3]Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, 30, Guilford Street, London WC1N 1EH

[4]Whittington NHS Trust, London, WC1N 3EH

Word count: 3125

Address for correspondence
Prof Monica Lakhanpaul
Professor of Integrated Community Child Health
Pro Vice Provost South Asia
Co Director CHIP (Childhood Infections and Pollution Consortium)
UCL Great Ormond Street Institute of Child Health
Faculty of Population Health Sciences
30 Guilford Street | London WC1N 1EH
Tel: 02079052259
Email: m.lakhanpaul@ucl.ac.uk

Abstract

Introduction: Children with congenital heart disease (CHD) have complex medical and neurodevelopmental needs. We aimed to develop a multi-professional consensus-based referral pathway applicable to action the results of the Brief Developmental Assessment (BDA), a validated early recognition tool, that categorises the neurodevelopmental status as green (appropriate for age), amber (equivocal) or red (delayed) in children aged 4 months to 5 years.

Methods: A Delphi consensus survey detailing two scenarios - a child categorised as delayed (red) and another as equivocal (amber) on administration of the BDA at the time of discharge from the tertiary centre - was sent to 80 expert professionals from primary, secondary and tertiary care seeking agreement on next steps and referral pathways. An iterative process was proposed with a pre-defined rule of 75% for consensus.

Results: The survey was completed by 77 Delphi panel experts in Round 1, 73 in Round 2, and 70 in Round 3. Consensus was achieved – 1) for the child with amber or red BDA, the child should be under the care of a paediatrician with expertise in cardiology (PEC) (or general paediatrician if no PEC) based at their local hospital, 2) for the child with red BDA, the PEC should initiate referral to community services at first assessment, 3) for child with amber BDA, a re-assessment by the health visitor should occur within 1-2 months, with referral to community services and notification to the PEC if ongoing concerns.

Conclusions: The Delphi process enabled a consensus to be reached between health professionals on referral pathways for specialist neurodevelopmental assessment/treatment for children with heart disease, in response to amber or red BDA results. The agreed referral pathway, if implemented, could underpin a national guideline to address and intervene on the neurodevelopmental difficulties in children with heart disease.

Word count = 294

Introduction

Children with congenital heart disease (CHD) have complex medical requirements (cardiac surgery, multiple hospitalisations, medications, associated syndromes), which may negatively impact their neurodevelopment – a key factor in their general wellbeing and educational attainments.[1-7] Currently, there is no formalised neurodevelopmental screening or surveillance pathway for children with CHD in the UK above that offered to healthy children. Research in the USA has identified neurodevelopmental abnormalities in as many as 25% of surgical survivors[1 8-17] and the American Heart Association (AHA) in their scientific statement[18] has outlined an algorithm for a surveillance, evaluation and management for children with CHD. In the UK, a recent consultation exercise with clinicians from primary, secondary, and tertiary care and lay stakeholders as part of the NIHR-funded paediatric cardiac morbidity surgery study[19] ranked neurodevelopmental problems as the number one complication concern for those undergoing intervention for CHD.[20] Our research indicates that there are gaps in the follow-up of children with CHD with developmental difficulties.[21] Whilst there are many screening tools, all require specialised personnel, are time-consuming, expensive and undeliverable on a wide-scale in a resource-constrained nationalised health service (NHS). Hence, within the context of this NIHR study, an innovative, easy to administer 'early recognition tool' – Brief Developmental Assessment (BDA) – was developed and validated in 971 children aged 4 months-5 years in three paediatric tertiary cardiac centres in London, UK.[22 23] The BDA covers different age bands (17-34.9 weeks, 35-60 weeks, 15 months-2.9 years, 3.0-4.9 years) accounting for different stages of child development and covers domains of gross motor skills, fine motor skills, daily living skills, communication, socialisation and general understanding. The BDA allows categorisation of a child's current neurodevelopment as green (appropriate for age), red (delayed) or amber (equivocal) to help direct care through early recognition, enabling children with concerns to be referred for specialist assessment/treatment. The ultimate goal is for the BDA to be used in the NHS by practitioners who are not neurodevelopmental specialists, as resources do not exist for specialist assessments to be carried out on every child with CHD.

Aim and objectives of the Delphi Survey

The aim was to develop a multi-professional consensus-based protocol for actions on the application of the BDA in age groups (4 months to 5 years) in children with CHD in the UK. The main objectives were to 1) recruit a multidisciplinary group of health professionals from primary, secondary and tertiary healthcare caring for children with CHD and 2) seek agreement on referral pathways for managing a child with amber or red BDA result to maximise effectiveness of the BDA tool.

Methods

Recruitment and selection of the Delphi panel

We identified a multidisciplinary group of primary, secondary and tertiary healthcare professionals within the CHD networks in the UK, comprising of paediatric cardiologists, paediatric neurologists, paediatric neurodisability professionals, paediatricians with expertise in cardiology (PEC), general paediatricians, community paediatric nurses, community paediatricians, health visitors, cardiac nurse specialists, advanced nurse practitioner/nurse consultant, general practitioners (GP) and parent representatives. To ensure an adequate knowledge base, those who had been in their role for at least 2 years were invited by email giving information on the BDA and requesting participation in the Delphi panel. Those who formally agreed were sent the Delphi survey. The regions identified were London, East of England, South East, North East, East Midlands, West Midlands, South West of England, Yorkshire and Humber, Wales, Scotland, Northern Ireland, and North West of England. The Delphi Consensus Survey was registered as a service improvement project and ethical approval was not required.

Study design for Delphi consensus survey

The survey was designed using SurveyMonkey software containing two scenarios, each presenting a BDA result for a child with CHD aged between 4 months-5 years at discharge from the tertiary centre. This age bracket has been chosen as the BDA was validated in this age group.[23] Alongside each scenario, respondents were sent a relevant example of the BDA along with standard information to be shared with all relevant health professionals. Scenario 1 described a child with amber BDA admitted to the tertiary centre for an intervention (surgery or catheter treatment), who is found to have *developmental concerns on the BDA* (score of amber = not fulfilling some of the milestones based on population norms, equivocal result). Scenario 2 described a child with red BDA admitted to the tertiary centre for an intervention (surgery or catheter treatment), who is found to have *developmental concerns on the BDA* (score of red = lagging behind the milestones based on population norms). The survey consisting of a mix of open questions with free text response and specific closed questions on the two scenarios was electronically sent with a unique web-link to participating professionals, who were asked to rate responses on a Likert scale: strongly disagree=1, disagree=2, moderately disagree =3, mildly disagree=4, undecided/don't know=5, mildly agree=6, moderately agree=7, agree=8, strongly agree=9. Non-responders would be sent reminder emails to complete the survey.

Development process of the Delphi Survey

A 4-step process was followed in the development of the Delphi survey. A core team – AH, KB, JW – developed the Delphi survey based on findings from two previously published studies in which the BDA was developed[22] and then validated[23] (funded by NIHR HS&DR). This draft survey was refined by the fourth author – ML. Following this, the Delphi survey and the proposed methodology were reviewed by an independent expert on Delphi methodology, which led to further refinements. The final step was pilot use of the survey with 2 paediatricians, leading to further minor modification based on their feedback.

Data analysis

The results were grouped as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3 to facilitate identification of areas of agreement or disagreement or middle ground with the main goal of reaching a consensus. This methodology has been well described in several widely used paediatric guidelines in the UK.[24-26] Free-text responses were categorized and analyzed as follows: in line with the Delphi methodology,[27] three of the authors – AH, KB, JW independently looked at all of the comments and identified the key themes. These themes were then discussed by the authors, and were then collated, summarised and synthesized to inform the next round of questions. Comments from the participants were also used to provide additional context for the findings.

Definition of consensus

We established an a priori criterion of 75% approval to define consensus - 75% of the panellists selecting 7, 8 or 9 of the 9-point Likert Scale. Any questions or statements with a) clear disagreement or b) middle ground (no clear agreement or disagreement) would be revised and re-sent on a subsequent Delphi round until consensus was reached. The results would be sent with each iterative round.

In accordance with current national healthcare provisions, we stated a presumption that there would be a PEC in most district general hospitals, and if not, the default would be a general paediatrician. We also presumed that children <5 years of age will have a health visitor (HV) in their local community.

Results

Of the 164 invited professionals across the UK, 87 (53%) agreed to participate (Table 1). The geographical distribution was weighted towards South East of England (Table 2). There were no differences in professional background or geographical location between participants and non-participants. All panellists were experienced with >5 years of experience in their speciality, at the time of completing the survey, 53 (66%) had been in the role within their current organisation for >5 years, while the rest were in the role for 2-5 years.

Round 1 (Supplementary material)

The results of Round 1 are outlined in Table 3. The respondents supported their choice by giving open text comments. Selected pertinent comments and themes that emerged were as follows:

Amber BDA scenario: 1) the tertiary cardiac team who has administered and identified the amber BDA will be aware of the child's GP and PEC, but will not be familiar with the community paediatric services in the child's local area, 2) the GP needs to be the health professional initiating new referrals, because referrals may not be accepted if made by one consultant to another (i.e. bypassing the GP), 3) the PEC or general paediatrician may not be equipped to assess child development and hence undertake re-assessment and 4) there were contradictory comments about the HV skills (positive from secondary/primary care) and comments that cardiac professionals may have limited understanding of the HV service.

Red BDA scenario: there was no consensus on which health professional should be undertaking the referral to the community paediatrician which necessitated a second Delphi round. Respondents cautioned against referral delays and suggested that 'it did not matter who made the referral as long as it happened'.

Round 2 (Supplementary material)

The results of Round 2 are outlined in Table 4. For Amber BDA scenario: the required level of consensus of 75% was not reached on 1) referral by HV to PEC and 2) whether the child should be re-assessed before referral to the community paediatrician, resulting in a third Delphi round.

For Red BDA scenario: the panel agreed that referral with red BDA result should be made by the PEC to the community paediatrician (82%). The Delphi panellists commented that 1) there should be robust communication between primary, secondary and tertiary professionals, 2) delays in referral communication and multiple referral/appointments should be avoided, and 3) referral to community services should be prompt.

Round 3 (Supplementary material)

For amber BDA scenario, the panel agreed that if the HV had concerns in the 1-2-month assessment after discharge from the tertiary centre, the HV should refer to the community paediatrician (with notification to the PEC), however, only 73% of the panel agreed that the child should be re-assessed by the HV 1-2 months after discharge (Table 4). On analysing the free text comments, it appears that the response was influenced by the perception that 1) there is significant variation in HV service within the UK, 2) HV service is overburdened and 3) children who have started school (at 4 years) may no longer be under HV in some areas. Of note, all the HVs/GPs in the panel agreed that re-assessment should be undertaken by the HV.

The results from 3 Delphi rounds are summarised in Table 5.

Discussion

Neurodevelopmental difficulties can potentially be the most devastating long-term sequelae for children with CHD [28-30] and as the number of survivors with complex cardiac conditions increase, there is a growing demand for these children to have adequate support within the wider healthcare system. Routine formal neurodevelopmental testing can be difficult to enforce within the constraints of the NHS. The validated BDA would theoretically function as an early recognition tool to sign-post those children with CHD who have neurodevelopmental problems. However, implementation of such a tool serves no useful purpose unless intervention and referral pathways are established. Using the Delphi consensus process with iterative rounds and feedback loops, with a panel comprising experts from primary, secondary and tertiary care within different parts of the UK, our study showed that consensus on referral patterns can be established for children with CHD who have been identified to have neurodevelopmental concerns by the BDA.

Consensus

The Delphi expert panel reached consensus that: children with either amber or red BDA should be under the care of the PEC and referred at the time of discharge from the tertiary centre by the child's primary cardiologist with results shared with the GP, HV, cardiologist and other relevant health professionals (Figure 1). Children with a red BDA should be referred to a community paediatrician and local child development team (if not already under one) at the time of the assessment to minimise any delay. Children with an amber BDA should have a re-assessment by the local HV 1-2 months after discharge and be referred to the community paediatrician if there are persisting concerns, with a notification to the PEC. The PEC or designated paediatrician at the local hospital and the HV (in the case of younger babies and toddlers) were identified as the key health professionals in an ideal position to link up a child with CHD with developmental problems and their local child development team. In addition, the PEC was identified as an important link with the tertiary cardiac centre. Of note, the Delphi responses did not support a new referral to the PEC/paediatrician coming from the specialist nursing team in the tertiary hospitals.

Health care across sectors

As a background to this consensus process, it is important to acknowledge the current care provision relevant to developmental needs for children with CHD, although this can be highly variable.

Tertiary care: Children with CHD are always under a cardiologist and a cardiac specialist nursing team, who may not necessarily have 'general paediatric' and 'child development' expertise but assess the child at critical time points particularly in early infancy. The BDA is intended for use as an early recognition tool for child neurodevelopment in this setting.

Secondary care: Within the setting of a non-specialist hospital, children with CHD are under the care of a PEC. In a small number of hospitals where a PEC is not in post, a named paediatrician will have designated responsibility for the paediatric needs of cardiac children. Not all cardiac children are formally under the care of a PEC or paediatrician (for example if they have never been to the local hospital), however a PEC or paediatrician with designated responsibility is available for a cardiac child should the need arise. The PEC (unlike the tertiary hospital team) will be aware of child development services available locally.

Primary and community care: all children, including those with CHD, are under a GP and at pre-school age, a health visitor. Both GP and HV are experienced in the referral of children with possible developmental problems to child development teams and will be cognisant of the local services. It is well known that health visitor services are under pressure, with recent reports indicating that many children miss out on these visits.[31-33] Child development teams are based within individual areas that they serve and are often linked to specific non-specialist hospitals. A child with CHD will be under the care of a child development team only if specifically referred.

Areas where agreement was more challenging

The main area where there was lack of agreement related to the child with an amber BDA. Of note, a child with suspected developmental delays may benefit from close follow-up and re-assessment given that these are crucial to identify the need for early intervention. Early identification and timely intervention contribute significantly towards a child's overall adjustment and quality of life.[34] There was moderate support for HV re-assessment, PEC re-assessment and referral to community paediatrics if on-going concerns with the child's development, but the consensus for re-assessment by the HV fell slightly short (73%) of the required 75% level for agreement. However, despite being in the minority in the panel, all the primary care representatives (HVs included) agreed that the child with amber BDA should have a re-assessment by the HV, and this response pattern was similar to that of the secondary and tertiary professionals. While there was no agreement for a child with amber BDA to be under the care of the community paediatrician, there were also conflicting opinions over whether or not the PEC or paediatrician is equipped to assess child development and hence undertake the recommended re-assessment. This may reflect lack of clarity between health professionals from different sectors as to each-others roles and skills. In addition, the initial lack of consensus about who should make the referral to the community paediatrician in the case of a child with a red BDA may reflect the lack of familiarity with the way local services operated across sectors. Furthermore, bearing in mind that there are significant regional and sub-regional variations in the delivery of healthcare, the process for the re-assessment of a child with amber BDA needs to be locally/regionally defined, and adapted to local resource availability. A particular hallmark of child development in those with CHD is that this is an issue that spans sectors and hence may fall through the gaps, and the responses of the Delphi survey were consistent with this, albeit eventually reaching consensus as to responsibilities for each sector / professional group.

Strengths and Limitations

This is the first time a consensus has been developed using the Delphi process to outline referral pathways for potentially abnormal neurodevelopment from a group of primary, secondary and tertiary care professionals looking after children with CHD. The Delphi process does not involve any face-to-face contact unlike a consensus development conference or a structured discussion. While every attempt was made to enrol experts into the Delphi panel from primary healthcare, there were few GPs and HVs who accepted the invitation. While every attempt was made to enrol experts into the Delphi panel from primary healthcare, there were few GPs and HVs who accepted the invitation. Despite this, the pattern of responses was similar across the groups. Furthermore, utilising only 2 virtual scenarios – one example each of amber and red BDA – may have limited the generalisability of the survey, and offering more scenarios may have generated a heterogeneous response but achieving consensus may have been difficult, and may have negatively impacted on the response rate.

Conclusions

The Delphi process has provided the initial platform for developing consensus on a national pathway for the management of children with CHD who have either equivocal or delayed neurodevelopment. The consensus supported the vital role of the PEC as a co-ordinating link between the primary cardiologist and the community services. The health visitor as a close link to community services in liaison with the PEC was felt to be the point of contact for re-assessment of the child with borderline or equivocal results. Having developed and validated the BDA as an early recognition tool, and having established consensus for the referral pathway within primary, secondary and tertiary care sectors for a child with suspected neurodevelopmental problems based on the BDA results, the next step will be a formal health care evaluation of the BDA. It is hoped that referral of children in accordance of the consensus reached in this study will ensure earlier identification of neurodevelopmental problems and timely interventions to address neurodevelopmental deficits.

ACKNOWLEDGEMENTS

We would like to acknowledge Ms Jana Gurasashvili for the administrative help with the study, Dr Roz Ullman, Senior researcher, Riches & Ullman LLP as the independent expert in Delphi methodology for her help in the initial development of the survey, and all the Delphi panellists for their participation in the iterative rounds and the support from the NIHR Great Ormond Street Hospital Biomedical Research Centre, Great Ormond Street Institute of Child Health, Great Ormond Street Hospital NHS Trust, University College London, London, WC1N 3JH.

FUNDING STATEMENT

There was no funding received for this study.

PARENT AND PUBLIC INVOLVEMENT STATEMENT

Lay stakeholders including parents were consulted along with clinicians from primary, secondary, and tertiary care as part of the NIHR-funded paediatric cardiac morbidity surgery study and they ranked neurodevelopmental problems as the number one complication concern for those undergoing intervention for CHD. Parent representatives and other stakeholders have been involved with the design, conduct and dissemination at every stage of the project.

CONTRIBUTOR STATEMENT

Conceptualisation and study design – A Hoskote, J Wray, K Brown and M Lakhanpaul

Administration of the survey and drafting of survey questions for the iterative rounds of Delphi – A Hoskote, J Wray, K Brown and M Lakhanpaul

Analyses of the study data – V Banks, A Hoskote, J Wray, K Brown and M Lakhanpaul

Write-up - A Hoskote, J Wray, K Brown and M Lakhanpaul

Editing and final approval of the final manuscript - A Hoskote, J Wray, V Banks, K Brown and M Lakhanpaul

"What is already known on this topic" – followed by a maximum of 3 brief statements (no more than 25 words per statement)

1. Children with congenital heart disease (CHD) have complex medical and neurodevelopmental needs with neurodevelopmental abnormalities leading to potentially devastating long-term sequelae.
2. Routine neurodevelopmental surveillance, screening and evaluation in children with CHD is well-established in cardiothoracic programmes in USA and parts of Europe unlike in UK.
3. An early recognition tool leading to intervention is an important first step in identifying children with delayed development in a high-volume cardiology service.

"What this study adds" – followed by a maximum of 3 brief statements (no more than 25 words per statement).

1. A multi-professional Delphi process achieved consensus on referral pathways for children (4 months-5 years) with CHD using an early recognition tool (Brief Developmental Assessment-BDA).
2. Consensus that children with delayed development (red BDA) should be referred immediately and those suspected (amber) should be re-assessed before referral to community paediatricians.
3. The paediatrician with expertise in cardiology (PEC) is central to the management of children with CHD and follow-up of suspected and/or confirmed neurodevelopmental delay.

Table 1. Professionals who participated in the Delphi Consensus Rounds

Speciality	Invited	Accepted	Completed Round 1 N=77	Completed Round 2 N=73	Completed Round 3 N=70
Tertiary care professionals n=32*					
Paediatric Cardiologist	20	12	9 (75)	9 (75)	8 (66)
Clinical Nurse Specialist	28	12	12 (100)	9 (75)	9 (75)
Advanced nurse practitioner/ Nurse Consultant	5	4	4 (100)	4 (100)	4 (100)
Paediatric Neurologist	8	4	4 (100)	4 (100)	4 (100)
Secondary care professionals n=25*					
Paediatric Neurodisability	14	8	8 (100)	8 (100)	8 (100)
Paediatrician with expertise in cardiology	15	11	11 (100)	11 (100)	11 (100)
General Paediatrician	15	6	5 (83)	4 (66)	3 (50)
Primary care professionals (n=24)*					
Community Paediatric Nurse	5	3	3 (100)	3 (100)	3 (100)
Community Paediatrician	22	12	11 (92)	11 (92)	11 (92)
Health Visitor	9	4	3 (75)	3 (75)	2 (50)
General Practitioner	12	5	3 (60)	3 (60)	3 (60)
Parent representatives n=6*					
Parent representatives	11	6	4 (67)	4 (67)	4 (67)

*Total number who accepted the invitation to join the Delphi Panel.

Table 2. Distribution of Delphi Panel Experts

Region	**Number of Delphi Panellists**
London	29
East of England	10
South East	12
North East	2
East Midlands	3
West Midlands	6
South West	5
Yorkshire and Humber	1
Wales	2
Scotland	4
Northern Ireland	1
North West	2
Total	**77**

Table 3: Delphi Consensus Survey – results from Round 1

Round 1	**% Agree**	**% Middle Ground**	**% Disagree**
Q5. All children with CHD and AMBER BDA should be under the care of a (general paediatrician if no PEC) based at their local hospital.	75	16	9
Q6. If a child with CHD and AMBER BDA is not under the care of a PEC it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC*(local general paediatrician if no PEC).	79	12	9
Q7. If a child with CHD and AMBER BDA is not under the care of a (local general paediatrician if no PEC), then a referral from the tertiary hospital under a specialist nursing team to a PEC/general paediatrician is acceptable.	60	25	16
Q8. The request for referral should have clinical details and the BDA assessment.	87	6	6
Q9. The complete results of the AMBER BDA should be shared with the child's PEC*(local general paediatrician).	91	6	3
Q10. The complete results of the AMBER BDA should be shared with the child's general practitioner (GP).	91	5	4
Q11. The complete results of the AMBER BDA should be shared with the child's health visitor (HV).	84	10	5
Q12. All children with CHD and an AMBER BDA at the point of discharge following cardiac intervention should be reassessed (in terms of development and general health) after a period of time by the PEC*(local general paediatrician).	65	21	14
Q13. All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's health visitor (HV).	71	18	10
Q14. All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's GP.	35	43	22
Q15. Referral of children with CHD and AMBER BDA (not already under local health services) to community paediatrician should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	64	22	14
Q16. Referral of children with CHD and AMBER BDA (not under local health services) to PEC*(local general paediatrician) should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	70	18	12
Q17. Children with CHD and AMBER BDA should be re-assessed after a defined period and then referred to a community paediatrician if there is on-going concern.	70	18	12
Q18. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the PEC*(local general paediatrician if no PEC).	69	21	10

Q19. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	40	35	25
Q20. Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the tertiary paediatric cardiac team	48	29	23
Q21. All children with CHD and RED BDA should be under the care of a PEC* (local general paediatrician if no PEC) based at their local hospital.	77	17	6
Q22. If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician if no PEC), it is the responsibility of the child’s paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	79	17	4
Q23. If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician), then a referral from the tertiary hospital specialist nursing team to a PEC*(local general paediatrician) is acceptable.	55	29	17
Q24. The complete results of the RED BDA should be shared with the child’s PEC* (local general paediatrician if no PEC).	94	5	1
Q25. The complete results of the RED BDA should be shared with the child’s general practitioner (GP).	91	8	1
Q26. The complete results of the RED BDA should be shared with the child’s health visitor (HV).	92	6	1
Q27. The complete results of the RED BDA should be shared with other relevant health professionals involved with the child such as neurologist, child development clinic, and geneticist	95	4	1
Q28. All children with CHD and RED BDA should be under the care of a community paediatrician and local child development team.	91	6	3
Q29. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken at the point of first assessment where an abnormal BDA is recorded at discharge following cardiac intervention (if child is not already under one).	81	16	4
Q30. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken if there is on-going concern after a period of reassessment by the child’s PEC*(local general paediatrician if no PEC).	64	21	16
Q31. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child’s *(local general paediatrician if no PEC).	73	21	6
Q32. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child’s health visitor (HV).	43	31	26
Q33. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child’s GP	39	32	29
Q34. Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child’s paediatric cardiac team	69	19	12

The results from responses were coded as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3.

Table 4: Delphi Consensus Survey – results from Round 2 and 3

Round 2	**% Agree**	**% Middle Ground**	**% Disagree**
Q1. At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC).	77	8	14
Q2. Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no PEC at local hospital).	72	10	18
Q3. The child with Amber BDA should be re-assessed before referral to the community paediatrician.	46	30	24
Q4. If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician	86	11	3
Q5. The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC).	82	11	7
Round 3	**% Agree**	**% Middle Ground**	**% Disagree**
Q1. The child with Amber BDA should be re-assessed by the Health Visitor (HV) 1-2 months after discharge home.	73	15	12
Q2. If concerns are noted at the health visitor (HV) assessment 1-2 month after discharge from tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC (General Paediatrician if no PEC).	90	6	4

The results from responses were coded as: agree - if the level of agreement was 7, 8, 9; middle ground - if the level of agreement was 4, 5, or 6; and disagree - if the level of disagreement was 1, 2 or 3.

Table 5: Delphi Consensus Survey – summary of results from Rounds 1, 2 and 3

	Amber BDA	**Red BDA**
Round 1		
75% consensus achieved	1) The amber BDA result should be shared with the GP, HV, PEC and other relevant health professionals (91%). 2) Child should be under PEC at local hospital (75%).	1) The red BDA result should be shared with the GP, HV, PEC and other relevant health professionals (90%). 2) Child should be under community paediatrician (91%).

	3) It is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (79%).	3) Referral to a community paediatrician should be undertaken at the point of first assessment when abnormal BDA is recorded (81%).
75% consensus not achieved	1) Timing of referral and to whom: at first assessment by tertiary cardiac centre to the PEC (70%) and to the community paediatrician (64%). 2) Whether re-assessment should be undertaken before referral to the community paediatrician (70%). 3) Which professional should undertake reassessment: HV (71%), PEC (65%) and GP (35%). 4) Referral to community paediatrician by whom: PEC (69%), HV (40%) and tertiary cardiac centre (48%).	1) On who should make this referral to community paediatrician? - PEC (73%), tertiary cardiac team (69%), HV (43%) and GP (39 %).
Round 2		
75% consensus achieved	1) Child with CHD at first assessment when identified to have an Amber BDA should be referred by the tertiary cardiologist to PEC (77%).	1) The referral to the community paediatrician containing the results of the red BDA should be made by the PEC (82%). 2) If there are any on-going developmental concerns, the PEC should refer to the community paediatrician (86%).
75% consensus not achieved	1) Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by HV should be referred to PEC (72%). 2) The child with amber BDA should be re-assessed before referral to the community paediatrician (46%).	-
Round 3		
75% consensus achieved	If the HV had concerns in the 1-2-month assessment after discharge from the tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC– 90%.	-
75% consensus not achieved	The child with amber BDA should be re-assessed by the HV 1-2 months after discharge home (73%).	-

Title for Figure 1. Delphi Consensus for referral pathway for child with heart disease who has neurodevelopmental concerns - amber or red BDA - at discharge from tertiary centre

Legend for Figure 1.

The consensus for referral pathway for amber or red BDA agreed from the iterative rounds of the Delphi Consensus process is shown in the figure. For the child with amber BDA, this may need to be locally/regionally defined and adapted to local resource availability.

REFERENCES

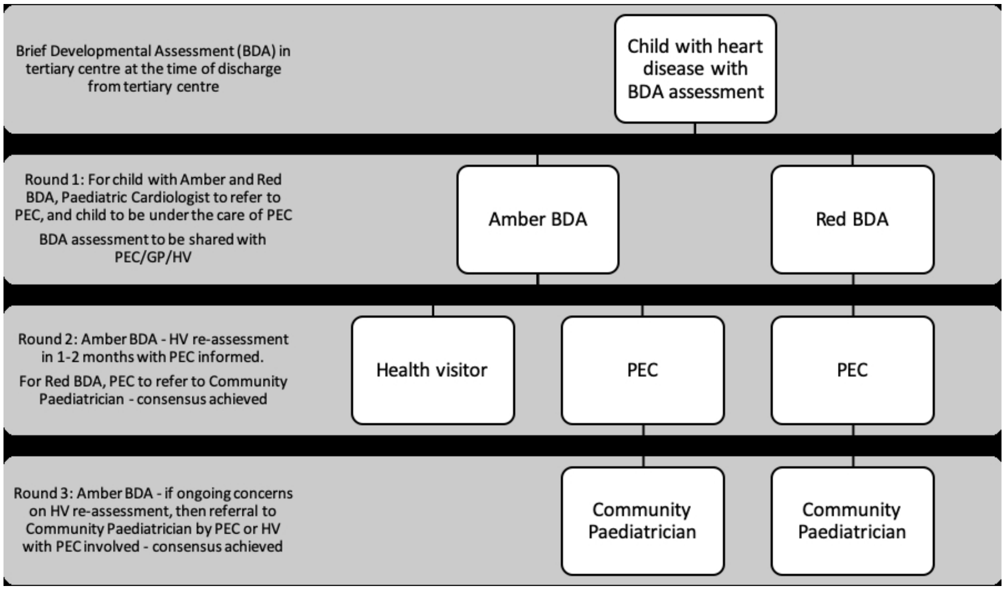
1. Mackie AS, Alton GY, Dinu IA, et al. Clinical outcome score predicts the need for neurodevelopmental intervention after infant heart surgery. *J Thorac Cardiovasc Surg* 2013;145(5):1248-54 e2. doi: 10.1016/j.jtcvs.2012.04.029 [published Online First: 2012/09/11]
2. Hovels-Gurich HH, Konrad K, Skorzenski D, et al. Long-term behavior and quality of life after corrective cardiac surgery in infancy for tetralogy of Fallot or ventricular septal defect. *Pediatr Cardiol* 2007;28(5):346-54.
3. Miatton M, De Wolf D, Francois K, et al. Neuropsychological performance in school-aged children with surgically corrected congenital heart disease. *J Pediatr* 2007;151(1):73-8, 78 e1.
4. Hovels-Gurich HH, Konrad K, Skorzenski D, et al. Long-term neurodevelopmental outcome and exercise capacity after corrective surgery for tetralogy of Fallot or ventricular septal defect in

infancy. *Ann Thorac Surg* 2006;81(3):958-66. doi: 10.1016/j.athoracsur.2005.09.010 [published Online First: 2006/02/21]

5. Walker K, Holland AJA, Winlaw D, et al. Neurodevelopmental outcomes and surgery in neonates. *Journal of Paediatrics and Child Health* 2006;42(12):749-51. doi: 10.1111/j.1440-1754.2006.00969.x
6. Wernovsky G, Shillingford AJ, Gaynor JW. Central nervous system outcomes in children with complex congenital heart disease. *Curr Opin Cardiol* 2005;20(2):94-9. [published Online First: 2005/02/16]
7. Bellinger DC, Wypij D, duPlessis AJ, et al. Neurodevelopmental status at eight years in children with dextro-transposition of the great arteries: the Boston Circulatory Arrest Trial. *J Thorac Cardiovasc Surg* 2003;126(5):1385-96.
8. Andropoulos DB, Ahmad HB, Haq T, et al. The association between brain injury, perioperative anesthetic exposure, and 12-month neurodevelopmental outcomes after neonatal cardiac surgery: a retrospective cohort study. *Paediatr Anaesth* 2014;24(3):266-74. doi: 10.1111/pan.12350 [published Online First: 2014/01/29]
9. Beca J, Gunn JK, Coleman L, et al. New white matter brain injury after infant heart surgery is associated with diagnostic group and the use of circulatory arrest. *Circulation* 2013;127(9):971-9. doi: 10.1161/CIRCULATIONAHA.112.001089 [published Online First: 2013/02/02]
10. Andropoulos DB, Easley RB, Brady K, et al. Neurodevelopmental outcomes after regional cerebral perfusion with neuromonitoring for neonatal aortic arch reconstruction. *Ann Thorac Surg* 2013;95(2):648-54; discussion 54-5. doi: 10.1016/j.athoracsur.2012.04.070 [published Online First: 2012/07/07]
11. Undar A, Wang S, Guan Y, et al. Brain protection during pediatric cardiac surgery: A multidisciplinary team approach at penn state hershey children's hospital and pediatric cardiovascular research center. *Artif Organs* 2012;36 (5):A10.
12. Walker K, Holland AJA, Halliday R, et al. Which high-risk infants should we follow-up and how should we do it? *Journal of Paediatrics and Child Health* 2012;48(9):789-93. doi: 10.1111/j.1440-1754.2012.02540.x
13. Andropoulos DB, Easley RB, Brady K, et al. Changing expectations for neurological outcomes after the neonatal arterial switch operation. *Ann Thorac Surg* 2012;94(4):1250-5; discussion 55-6. doi: 10.1016/j.athoracsur.2012.04.050 [published Online First: 2012/07/04]
14. Gunn JK, Beca J, Hunt RW, et al. Perioperative amplitude-integrated EEG and neurodevelopment in infants with congenital heart disease. *Intensive Care Med* 2012;38(9):1539-47. doi: 10.1007/s00134-012-2608-y [published Online First: 2012/06/02]
15. Wernovsky G. Neurodevelopmental outcomes: Scope of the problem and current challenges. *Artif Organs* 2010;34 (4):A1.
16. Gaynor JW, Gerdes M, Nord AS, et al. Is cardiac diagnosis a predictor of neurodevelopmental outcome after cardiac surgery in infancy? *J Thorac Cardiovasc Surg* 2010;140(6):1230-7. doi: 10.1016/j.jtcvs.2010.07.069 [published Online First: 2010/10/19]
17. Hovels-Gurich HH, Bauer SB, Schnitker R, et al. Long-term outcome of speech and language in children after corrective surgery for cyanotic or acyanotic cardiac defects in infancy. *Eur J Paediatr Neurol* 2008;12(5):378-86.
18. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation* 2012;126(9):1143-72. doi: 10.1161/CIR.0b013e318265ee8a
19. Brown K PC, Ridout D, Wray J, Tsang V, Anderson D, Banks V, Barron D, Cassidy J, Chigaru L, Davis P, Franklin R, Grieco L, Hoskote A, Hudson E, Jones A, Kakat S, Lakhani R, Lakhanpaul M, McLean A, Morris S, Rajagopal V, Rodriguez W, Sheehan K, Stoica S, Tibby S, Utley M, Witter

T. Selection, definition and evaluation of important early morbidities associated with paediatric cardiac surgery: a mixed methods study. *NIHR Journals Library* 2019;In Press

20. Pagel C, Brown KL, McLeod I, et al. Selection by a panel of clinicians and family representatives of important early morbidities associated with paediatric cardiac surgery suitable for routine monitoring using the nominal group technique and a robust voting process. *BMJ Open* 2017;7(5):e014743. doi: 10.1136/bmjopen-2016-014743 [published Online First: 2017/05/31]
21. AU Hoskote VB, S Kakat, DA Ridout, M Lakhanpaul, C Pagel, RC Franklin, T Witter, R Lakhani, S Tibby, D Anderson, V Tsang, J Wray, KL Brown. . Neurodevelopmental status and follow-up in pre-school children with heart disease in london uk. *Archives of Disease in Childhood in review* 2019
22. Wray J, Brown KL, Ridout D, et al. Development and preliminary testing of the Brief Developmental Assessment: an early recognition tool for children with heart disease. *Cardiol Young* 2018:1-10. doi: 10.1017/S1047951117002918 [published Online First: 2018/02/13]
23. Brown KL, Ridout DA, Pagel C, et al. Validation of the Brief Developmental Assessment in pre-school children with heart disease. *Cardiol Young* 2018;28(4):571-81. doi: 10.1017/S1047951117002773 [published Online First: 2018/03/08]
24. Management of children and young people with an acute decrease in conscious level – clinical guideline 2019 [Available from: https://www.rcpch.ac.uk/resources/management-children-young-people-acute-decrease-conscious-level-clinical-guideline. .
25. Management of the child with decreased conscious level – a nationally developed evidence based guideline for hospital practitioners. 2003 [Available from: https://www.nottingham.ac.uk/paediatric-guideline/Tecdoc.pdf.
26. THE BRAIN PATHWAYS GUIDELINE: A GUIDELINE TO ASSIST HEALTHCARE PROFESSIONALS IN THE ASSESSMENT OF CHILDREN WHO MAY HAVE A BRAIN TUMOUR 2017 [Available from: https://assets.headsmart.org.uk/live/media/filer_public/8e/c3/8ec36f34-1c0d-4c3c-bc5f-706570b7af34/brain_pathways_guidelines_final.pdf accessed 09 January 2020.
27. Murphy MK, Black NA, Lamping DL, et al. Consensus development methods, and their use in clinical guideline development. *Health Technol Assess* 1998;2(3):i-iv, 1-88. [published Online First: 1998/04/30]
28. Robson VK, Stopp C, Wypij D, et al. Longitudinal Associations between Neurodevelopment and Psychosocial Health Status in Patients with Repaired D-Transposition of the Great Arteries. *J Pediatr* 2019;204:38-45 e1. doi: 10.1016/j.jpeds.2018.08.069 [published Online First: 2018/10/03]
29. Rometsch S, Greutmann M, Latal B, et al. Predictors of quality of life in young adults with congenital heart disease. *Eur Heart J Qual Care Clin Outcomes* 2018 doi: 10.1093/ehjqcco/qcy046 [published Online First: 2018/09/22]
30. Kasmi L, Bonnet D, Montreuil M, et al. Neuropsychological and Psychiatric Outcomes in Dextro-Transposition of the Great Arteries across the Lifespan: A State-of-the-Art Review. *Front Pediatr* 2017;5:59. doi: 10.3389/fped.2017.00059 [published Online First: 2017/04/11]
31. Anim C. Health visitors change lives - so why are numbers decreasing Royal College of Nursing2016 [Report]. Available from: https://www.rcn.org.uk/news-and-events/blogs/health-visitors-change-lives.
32. Investment needed in specialist children's nurses. Health visitors and school nurses report shift understaffing as specialist nurse numbers drop. Royal College of Nursing, 2018:Report.
33. Jozwiak G. Health Visitor numbers 'below safe level' Children & Young People Now2018 [Report]. Available from: https://www.cypnow.co.uk/cyp/news/2006032/health-visitor-numbers-below-safe-level.
34. Minkovitz CS, Hughart N, Strobino D, et al. A practice-based intervention to enhance quality of care in the first 3 years of life: the Healthy Steps for Young Children Program. *JAMA* 2003;290(23):3081-91. doi: 10.1001/jama.290.23.3081 [published Online First: 2003/12/18]


Brief Developmental Assessment (BDA) in tertiary centre at the time of discharge from tertiary centre
Child with heart disease with BDA assessment
Round 1: For child with Amber and Red BDA, Paediatric Cardiologist to refer to PEC, and child to be under the care of PEC
BDA assessment to be shared with PEC/GP/HV
Amber BDA
Red BDA
Round 2: Amber BDA - HV re-assessment in 1-2 months with PEC informed.
For Red BDA, PEC to refer to Community Paediatrician - consensus achieved
Health visitor
PEC
PEC
Round 3: Amber BDA - if ongoing concerns on HV re-assessment, then referral to Community Paediatrician by PEC or HV with PEC involved - consensus achieved
Community Paediatrician
Community Paediatrician

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

1. Introduction to Delphi Consensus Process and Brief Developmental Assessment (BDA)

The Delphi consensus development process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. Having now tested the BDA - designed as a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL, which allows categorisation of a child's current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal), we aim to delineate and develop a consensus for a referral pathway for children following the application of BDA in an inpatient or outpatient setting.

1. Please describe your role

○ Health visitor

○ General Practitioner

○ Community Paediatrician

○ General Paediatrician

○ Paediatrician with expertise in cardiology (PEC)

○ Consultant Paediatric Neurologist

○ Consultant in Paediatric Neurodisability

○ Cardiac Liaison Nurse

○ Cardiac Nurse Specialist

○ Nurse Practitioner Neurology

○ Parent representative

○ Other

Other (please specify)

☐

2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

☐

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England

○ East Midlands

○ London

○ North East

○ North West

○ South East

○ South West

○ West Midlands

○ Yorkshire and the Humber

○ Northern Ireland

○ Scotland

○ Wales

4. How long have you been in your current role?

○ Less than 1 year

○ 2-5 years

○ >than 5 years

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

2. Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have *developmental concerns on BDA* (score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result). The tertiary cardiac team will be in possession of the BDA results from the pre procedure assessment and information about the course of the child before, during and after surgery. Please see example of AMBER BDA attached to email.

*We expect that in most general hospitals, there is a consultant **Paediatrician with Expertise in Cardiology (PEC).** If there is no nominated PEC, then the default is general paediatrician based at the local hospital.

5. **The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and AMBER BDA should be under the care of a PEC* (general paediatrician if no PEC) based at their local hospital.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

6. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and AMBER BDA is not under the care of a PEC*, it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

7. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and AMBER BDA is not under the care of a PEC*(local general paediatrician if no PEC), then a referral from the tertiary hospital specialist nursing team to a PEC/general paediatrician is acceptable.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

8. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The request for referral should have clinical details and the BDA assessment.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

9. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child’s PEC*(local general paediatrician).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

10. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child’s general practitioner (GP).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

11. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the AMBER BDA should be shared with the child’s health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

12. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed (in terms of development and general health) after a period of time by the PEC*(local general paediatrician).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

13. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

14. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with congenital heart disease and an AMBER BDA at the point of discharge following cardiac intervention should be re-assessed after a defined period of time by the child's GP.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

15. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA (not already under local health services) to community paediatrician should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

16. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA (not under local health services) to PEC*(local general paediatrician) should be undertaken at the point of first assessment when an AMBER BDA is detected at discharge following cardiac intervention.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

17. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Children with CHD and AMBER BDA should be re-assessed after a defined period (second repeat assessment), and then referred to a community paediatrician if there is on-going concern.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

18. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

19. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

20. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and AMBER BDA to a community paediatrician should be undertaken by the <u>tertiary paediatric cardiac team</u>.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

3. Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have <u>developmental concerns on BDA</u> (score of RED = lagging behind the milestones as based on population norms). The tertiary cardiac team will be in possession of the BDA results from the pre procedure assessment and information about the course of the child before, during and after surgery. <u>Please see RED BDA attached to email.</u>
<u>*We expect that in most general hospitals, there is a consultant paediatrician with expertise in cardiology (PEC). If there is no nominated PEC, then the default is general paediatrician based at the local hospital.</u>

21. **The score of RED referred to in the statements below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and RED BDA should be under the care of a PEC* (local general paediatrician if no PEC) based at their local hospital.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

22. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and RED BDA is not under the care of a PEC* (local general paediatrician if no PEC), it is the responsibility of the child's paediatric cardiologist to refer the child to a PEC* (local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

23. **.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If a child with CHD and RED BDA is <u>not under the care of a PEC* (local general paediatrician)</u>, then a referral from the tertiary hospital <u>specialist nursing team</u> to a PEC*(local general paediatrician) is acceptable.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

24. **.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the <u>child's PEC* (local general paediatrician if no PEC).</u>	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

25. **.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the <u>child's general practitioner</u> (GP).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

26. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

27. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The complete results of the RED BDA should be shared with other relevant health professionals involved with the child such as neurologist, child development clinic, and geneticist.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

28. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
All children with CHD and RED BDA should be under the care of a community paediatrician and local child development team.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

29. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken at the point of first assessment where an abnormal BDA is recorded at discharge following cardiac intervention (if the child is not already under one).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

30. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken if there is on-going concern after a period of reassessment by the child's PEC*(local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

31. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's PEC*(local general paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

32. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's health visitor (HV).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

33. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a community paediatrician should be undertaken by the child's GP.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

34. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Referral of children with CHD and RED BDA to a <u>community paediatrician</u> should be undertaken by the <u>child's paediatric cardiac team.</u>	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 1

4. General comments - providing neurodevelopmental assessment and interventions for children with CHD

Management of children with CHD outside of the tertiary cardiac centre. <u>This applies to any child with CHD irrespective of whether or not the child is already known to have any developmental delay</u>.

35. General comments about providing neurodevelopmental assessment and intervention for children with CHD.

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under <u>general paediatrician</u> to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

☐

36. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under community paediatrician locally to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

37. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Every child with CHD should be under Paediatrician with expertise in Cardiology (PEC) locally to provide on-going follow-up?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

38. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The neurodevelopmental assessment and management of every child with CHD should be under the direction of the Paediatrician with expertise in Cardiology (PEC) and/or local general paediatrician?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

39. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The neurodevelopmental assessment and management of every child with CHD should be under the direction of the <u>local community paediatrician</u>?	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

40. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

1. Delphi Consensus Process and Brief Developmental Assessment (BDA) ROUND 2

Thankyou to all those who completed Round 1. As a reminder, the Delphi consensus process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. We are using this process to develop a consensus for referral pathway for children with CHD who have neurodevelopmental problems. <u>The BDA is a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL,</u> which allows categorisation of a child's current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal). Having completed ROUND 1 of the Delphi Consensus Process, we invite you to ROUND 2 to delineate and <u>develop a consensus on those questions that did not reach the agreed level of consensus (75%). For each scenario presented, we will inform which items reached consensus, and only put forward those questions that did not reach consensus.</u>

1. Please describe your role

○ Health visitor

○ General Practitioner

○ Community Paediatrician

○ General Paediatrician

○ Consultant Paediatric Cardiologist

○ Paediatrician with expertise in cardiology (PEC)

○ Consultant Paediatric Neurologist

○ Consultant in Paediatric Neurodisability

○ Cardiac Liaison Nurse

○ Cardiac Nurse Specialist

○ Nurse Practitioner Neurology

○ Parent representative

○ Other

Other (please specify)

2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England

○ East Midlands

○ London

○ North East

○ North West

○ South East

○ South West

○ West Midlands

○ Yorkshire and the Humber

○ Northern Ireland

○ Scotland

○ Wales

4. How long have you been in your current role?

○ Less than 1 year

○ 2-5 years

○ >than 5 years

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

2. Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have ***developmental concerns on BDA*** **(score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result).** **Please see example of AMBER BDA sent at the time of Round 1 and attached again with ROUND 2 email, and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years (sent as attachment with Round 2 email).**
The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals.

Delphi ROUND 1 - the required level of consensus of 75% was achieved on - 1) The results of the Amber BDA should be shared with the GP, Health Visitor, Cardiologist, PEC* (General Paediatrician if no PEC) and other relevant health professionals (91%) and **2)** All children with CHD + Amber BDA should be under PEC (General Paediatrician if no PEC) based at their local hospital (75%), and **3)** it is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (General Paediatrician if no PEC) (79%).

The required level of consensus of 75% was not reached on - 1) Timing of referral: At first assessment by tertiary cardiac centre to PEC (70%) and to community paediatrician (64%). **2)** Re-assessment before referral to community paediatrician (70%). **3)** Re-assessment by whom: by HV (71%), by PEC (65%) and by GP (35%). **4)** Referral to community paediatrician by whom: PEC (69%), HV (40%), tertiary cardiac centre (48%).

The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre. We presume that there is PEC (Paediatrician with Expertise in Cardiology) or a nominated paediatrician if no PEC at local hospital. We presume that ALL children under the age of 5 years will have a Health Visitor (HV). The tertiary cardiac team who has administered and identified the Amber BDA will be aware of the child’s GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

5. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

6. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no PEC at local hospital).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

7. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The child with Amber BDA should be re-assessed before referral to the community paediatrician.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

8. .

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 2

3. Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have **developmental concerns on BDA** **(score of RED = lagging behind the milestones as based on population norms).** **Please see RED BDA attached to email sent out with ROUND 1 and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years.** The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals, if needed.

Delphi Round 1 - the required level of consensus of 75% agreement was achieved on - **1)** the results of the Red BDA should be shared with the GP, Health Visitor, Cardiologist, PEC (General Paediatrician if no PEC) and other relevant health professionals (90%), **2)** all children with CHD + Red BDA should be under community paediatrician (91%)and **3)** Referral of children with CHD + red BDA to a community paediatrician should be undertaken at the point of first assessment where abnormal BDA is recorded (81%).

There was lack of consensus on who should make this referral - PEC (73%), HV (43%), GP (39%), tertiary cardiac team (69%). The tertiary cardiac team who has administered and identified the Red BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

9. **<u>The score of RED referred to in the statements below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre</u>**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

10. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Delphi Consensus Process and Brief Developmental Assessment (BDA) ROUND 3

Thankyou to all those who completed Round 1 and Round 2. As a reminder, the Delphi consensus process involves emailed survey questionnaires, eliciting individual decisions, providing formal feedback of group choices, structured interaction and aggregation method of the responses. We are using this process to develop a consensus for referral pathway for children with CHD who have neurodevelopmental problems. The BDA is a tool to support a specialist referral by providing targeted additional and helpful information on the child's development - an EARLY RECOGNITION TOOL, which allows categorisation of a child's current neurodevelopmental status as GREEN (appropriate for age), RED (delayed) or AMBER (equivocal). For each scenario presented, we will inform which items reached consensus, and only put forward those questions that did not reach consensus. Having completed ROUND 1 and ROUND 2 of the Delphi Consensus Process, we invite you to ROUND 3 to delineate and develop a consensus on those questions that did not reach the agreed level of consensus (75%) for 2 questions for AMBER BDA. We have achieved consensus for RED BDA questions. Thankyou!

* 1. Please describe your role

○ Health visitor

○ General Practitioner

○ Community Paediatrician

○ General Paediatrician

○ Consultant Paediatric Cardiologist

○ Paediatrician with expertise in cardiology (PEC)

○ Consultant Paediatric Neurologist

○ Consultant in Paediatric Neurodisability

○ Cardiac Liaison Nurse

○ Cardiac Nurse Specialist

○ Nurse Practitioner Neurology

○ Parent representative

○ Other

Other (please specify)

☐

* 2. Where do you work (Name of the Hospital/Trust/Community/GP Practice). If you are a parent representative, please write so.

☐

3. In which region of the UK is your Hospital/Trust/Community/GP practice based?

○ East of England

○ East Midlands

○ London

○ North East

○ North West

○ South East

○ South West

○ West Midlands

○ Yorkshire and the Humber

○ Northern Ireland

○ Scotland

○ Wales

4. How long have you been in your current role?

○ Less than 1 year

○ 2-5 years

○ >than 5 years

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Introduction to Delphi Consensus Process+ Brief Developmental Assessment (BDA) +AMBER CATEGORISATION

SCENARIO 1

A child aged between 4 months and up to 5 years with congenital heart disease (CHD), who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment), is found to have ***developmental concerns on BDA*** **(score of AMBER = not fulfilling some of the milestones as based on population norms, equivocal result).** **Please see example of AMBER BDA sent at the time of Round 1 and attached again with ROUND 2 email, and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years (sent as attachment with Round 2 email).**
The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals.
Delphi ROUND 1 - the required level of consensus of 75% was achieved on - **1)** The results of the Amber BDA should be shared with the GP, Health Visitor, Cardiologist, PEC* (General Paediatrician if no PEC) and other relevant health professionals (91%) and **2)** All children with CHD + Amber BDA should be under PEC (General Paediatrician if no PEC) based at their local hospital (75%), and **3)** it is the responsibility of the child's paediatric cardiologist in the tertiary centre to refer the child to a PEC (General Paediatrician if no PEC) (79%).
The required level of consensus of 75% was not reached on - 1) Timing of referral: At first assessment by tertiary cardiac centre to PEC (70%) and to community paediatrician (64%). **2)** Re-assessment before referral to community paediatrician (70%). **3)** Re-assessment by whom: by HV (71%), by PEC (65%) and by GP (35%). **4)** Referral to community paediatrician by whom: PEC (69%), HV (40%), tertiary cardiac centre (48%).
Delphi ROUND 2 - the required level of consensus of 75% was achieved on - 1) At first assessment when identified to have an Amber BDA, the child with CHD (if not already under local services) should be referred by the tertiary cardiologist to PEC (General Paediatrician if no PEC) (77%).
The required level of consensus of 75% was not reached on - 1) Any on-going developmental concerns after discharge from tertiary cardiac centre if noted by Health visitor (HV) should be referred to PEC (General Paediatrician if no nominated PEC) (72%), 2) The child with Amber BDA should be re-assessed before referral to the community paediatrician (46%). Hence the further 2 questions to the panel.
The score of AMBER in the questions below relates to the overall assessment of the child at the point of discharge from the tertiary cardiac centre. We presume that there is PEC (Paediatrician with Expertise in Cardiology) or a nominated paediatrician if no PEC at local hospital. We presume that ALL children under the age of 5 years will have a Health Visitor (HV). The tertiary cardiac team who has administered and identified the Amber BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local com

* 5. **Children with congenital heart disease who have had recent surgery or procedure and who score an Amber BDA may need time to recover from recent hospitalisation. A review by HV following a recovery period at home would be able to identify any ongoing concerns.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
The child with Amber BDA should be re-assessed by the Health Visitor (HV) 1-2 months after discharge home.	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

* 6. **The score of Amber BDA relates to the assessment at the time of discharge from the tertiary centre.**

	Strongly disagree	Disagree	Moderately disagree	Mildly disagree	Undecided/Don't know	Mildly agree	Moderately agree	Agree	Strongly agree
If concerns are noted at the health visitor (HV) assessment 1-2 month after discharge from tertiary centre, the HV should refer to the community paediatrician with a notification to the PEC (General Paediatrician if no PEC).	○	○	○	○	○	○	○	○	○

Please add any comments you would like to make

Delphi Consensus for developing a referral pathway for cardiac children having neurodevelopmental concerns - ROUND 3

Introduction to Delphi Consensus Process and Brief Developmental Assessment(BDA) +RED CATEGORISATION

SCENARIO 2

A child aged between 4 months and up to 5 years with congenital heart disease (CHD) who has been admitted to the tertiary centre for an intervention (surgery or catheter treatment) is found to have **developmental concerns on BDA** **(score of RED = lagging behind the milestones as based on population norms).** **Please see RED BDA attached to email sent out with ROUND 1 and please note relevant findings from the BDA Validation Study with 960 children with CHD between the ages of 4 months to 5 years.** The tertiary cardiac team will be in possession of the BDA results from the pre or post procedure assessment. This BDA result along with a standard information sheet will be shared with all relevant health professionals to be used for appropriate referrals, if needed.

Delphi Round 1 - the required level of consensus of 75% agreement was achieved on - **1)** the results of the Red BDA should be shared with the GP, Health Visitor, Cardiologist, PEC (General Paediatrician if no PEC) & other relevant health professionals (90%), **2)** all children with CHD + Red BDA should be under community paediatrician (91%) and **3)** Referral of children with CHD + red BDA to a community paediatrician should be undertaken at the point of first assessment where abnormal BDA is recorded (81%).

There was lack of consensus on who should make this referral - PEC (73%), HV (43%), GP (39%), tertiary cardiac team (69%). The tertiary cardiac team who has administered and identified the Red BDA will be aware of the child's GP and PEC (General Paediatrician if no PEC) but will not be familiar with the community paediatric services in the child's local area. The PEC (General Paediatrician if no PEC) will have better understanding and access to local community services.

Delphi Round 2 - the required level of consensus of 75% agreement was achieved on both questions addressed to the panel - 1) The referral to community paediatrician containing the results of the RED BDA should be made by the PEC (General Paediatrician if no nominated PEC (82%). 2) If there are any on-going developmental concerns, the PEC (General Paediatrician where there is no nominated PEC) should refer to the community paediatrician (86%).

There are no further questions for Red BDA as we have achieved consensus!! Thankyou!!

7. Do you have any overall comments to make on this survey?

○ Yes

○ No

Please write your comments here