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. 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). Having completed ROUND 1 of the Delphi Consensus Process, we invite you to ROUND 2 to delineate and 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.
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.

[Blank space for answer]
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. 

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Moderately disagree</th>
<th>Mildly disagree</th>
<th>Undecided/Don't know</th>
<th>Mildly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>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).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please add any comments you would like to make
6.  

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Moderately disagree</th>
<th>mildly disagree</th>
<th>Undecided/Don't know</th>
<th>Mildly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
</table>

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.  

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Moderately disagree</th>
<th>mildly disagree</th>
<th>Undecided/Don't know</th>
<th>Mildly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
</table>

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. 

If there are any ongoing 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**

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Moderately disagree</th>
<th>Mildly disagree</th>
<th>Undecided/Don't know</th>
<th>Mildly agree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
</table>

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