

**Proposed congenital heart disease standards and service specifications:
a consultation - 15 September 2014 to 8 December 2014**

Guidance

Thank you for downloading our consultation response form.

You will need to submit your response to Dialogue by Design who are an independent organisation providing expert analysis of the responses to this consultation for NHS England.

Once you have completed this form please email it to:

CHDconsultation@dialoguebydesign.co.uk

Alternatively, if you are unable to provide your response electronically please print it on matt (non-shiny) paper and post it to:

**Dialogue by Design
252B Gray's Inn Road
London
WC1X 8XG**

If you would prefer to complete our online version of the consultation please go straight to our consultation hub:

www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards

About You

A: Are you responding on behalf of an organisation?

- Yes
- No

If yes, please provide the name of your organisation:

B: Which of the following relate to you?

- Person with CHD
- Family member or carer of a person with CHD
- Person who works directly with people with CHD
- Person who works within health and social care but not directly with people with CHD
- Member of charity or support group for people with CHD
- Other
- Prefer not to say

If you selected 'Other', please specify.

New Congenital Heart Disease Review

C: Where do you live?

- England
- Scotland
- Wales
- Northern Ireland
- Republic of Ireland
- Other
- Prefer not to say

If you selected 'Other', please specify.

If England, please select county:

- Bath and North East Somerset
- Bedford
- Blackburn with Darwen
- Blackpool
- Bournemouth
- Bracknell Forest
- Brighton and Hove
- Buckinghamshire
- Cambridgeshire
- Central Bedfordshire
- Cheshire East
- Cheshire West and Chester
- City of Bristol
- City of Kingston upon Hull
- Cornwall
- County Durham
- County of Herefordshire
- Cumbria
- Darlington
- Derby
- Derbyshire
- Devon
- Dorset
- East Riding of Yorkshire
- East Sussex
- Essex
- Gloucestershire
- Greater London

New Congenital Heart Disease Review

- Greater Manchester
- Halton
- Hampshire
- Hartlepool
- Hertfordshire
- Isles of Scilly
- Isle of Wight
- Kent
- Lancashire
- Leicester
- Leicestershire
- Lincolnshire
- Luton
- Medway
- Merseyside
- Middlesbrough
- Milton Keynes
- Norfolk
- North East Lincolnshire
- Northamptonshire
- North Lincolnshire
- North Somerset
- Northumberland
- North Yorkshire
- Nottingham
- Nottinghamshire
- Oxfordshire
- Peterborough
- Plymouth
- Poole
- Portsmouth
- Reading
- Redcar and Cleveland
- Rutland
- Shropshire
- Slough
- Somerset
- Southampton
- South Gloucestershire

New Congenital Heart Disease Review

- South Yorkshire
- Southend-on-Sea
- Staffordshire
- Stockton-on-Tees
- Stoke-on-Trent
- Suffolk
- Surrey
- Swindon
- Telford and Wrekin
- Thurrock
- Torbay
- Tyne and Wear
- Warrington
- Warwickshire
- West Berkshire
- West Midlands
- West Sussex
- West Yorkshire
- Wiltshire
- Windsor and Maidenhead
- Wokingham
- Worcestershire
- York

We want to be sure that the responses to the consultation represent a wide range of views from everyone affected by CHD.

If you are a **'Person with CHD'** or a **'Family member or carer of a person with CHD'** we would be grateful if you could complete the following three questions so that we can see whose views we have gathered.

If you are **answering on behalf of a 'Person with CHD'** please complete with their information.

D: Age:

- Under 12
- 12-18
- 19-25
- 26-65
- 66+
- Prefer not to say

New Congenital Heart Disease Review

E: Ethnicity:

- Welsh / English / Scottish / Northern Irish / British
- Irish
- Gypsy or Irish Traveller
- White and Black Caribbean
- White and Black African
- White and Asian
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Caribbean
- African
- Arab
- Other
- Prefer not to say

If you selected 'Other', please specify

F: Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Include any issues or problems related to old age.

- Yes, limited a lot
- Yes, limited a little
- No
- Prefer not to say

If you selected "Yes", please indicate your disability:

- Vision (e.g. due to blindness or partial sight)
- Hearing (e.g. due to deafness or partial hearing)
- Mobility, such as difficulty walking short distances, climbing stairs, lifting and carrying objects
- Learning or concentrating or remembering
- Mental Health
- Stamina or breathing difficulty
- Social or behavioural issues (e.g. due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Asperger's Syndrome)
- Prefer not to say

Consultation Questions

AIMS OF THE NEW CHD REVIEW

1a: Will the draft standards and service specifications meet these aims?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly Disagree
- Don't know

1b: Please explain your answer

MODEL OF CARE

2: What do you think of the model of care that we are proposing?

3: What do you think about our proposals for level 2 Specialist Cardiology Centres?

NETWORKS (Section A)

4: What do you think of our proposals for the development of networks?

STAFFING AND SKILLS (Section B)

5: What do you think of our proposals for staffing CHD services?

6: What do you think of our proposal that surgeons work in teams of at least four, each of whom undertakes at least 125 operations per year? Please explain your answer.

7: What do you think about our proposed approach to sub-specialisation?

INTERDEPENDENCIES (Section D)

8: What do you think of the proposed standards for service interdependencies and co-location?

INTRODUCTION TO THE PROPOSED SERVICE SPECIFICATIONS (Part 3)

9: What do you think of the proposed service specifications?

DELIVERING THE STANDARDS WITHIN EXISTING RESOURCES (Part 4)

10: To ensure that we work within the available resources, difficult decisions may need to be made. What parts of our proposals matter most to you?

MAKING IT HAPPEN (Part 5)

11: Do you have any comments on the range of approaches proposed to ensure that the standards are being met by every hospital providing CHD care?

ANY OTHER THOUGHTS

12: Is there anything else that you want to tell us or to ask us to consider? If your comments relate to a particular standard or section please specify which you are referring to.

New Congenital Heart Disease Review

If you would like more information about the NHS England's congenital heart disease review or the consultation process please visit our website:
www.england.nhs.uk/ourwork/qual-clin-lead/chd/