



Services for people born with heart problems



December 2014

M	T	W	T	F	S	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Please tell us what you think.

You need to tell us by:
Monday 8 December 2014

This is an EasyRead version of:
Proposed congenital heart disease Standards and Service Specifications: A consultation

What is in this paper?



What this paper is about

1.



Working together

5.



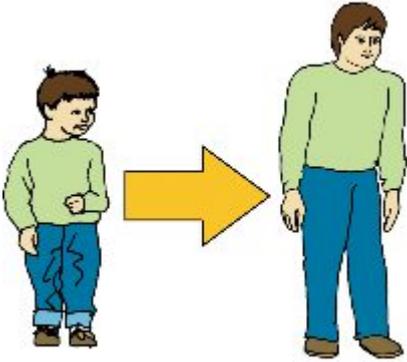
Talking to each other

7.



What we need from hospitals

11.



Growing up and moving to adult services

13.



Care at the start of life

15.



Care when someone is dying

16.



Tell us what you think

17.



What this paper is about



We are NHS England.

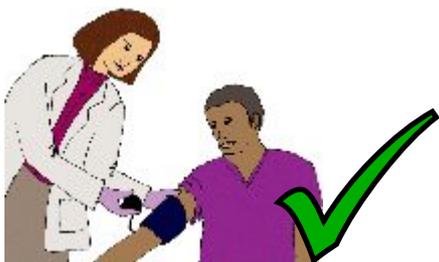


We want to include people in everything we do.



This EasyRead paper is asking you what you think about services for people born with heart problems.

This is called Congenital Heart Disease or CHD for short.



Services are good already, but we want them to get better.



So we have made a list of **Standards**, these are rules about how a good service should be.



We try not to use difficult words, when we do we put them in **bold** and say what they mean underneath.

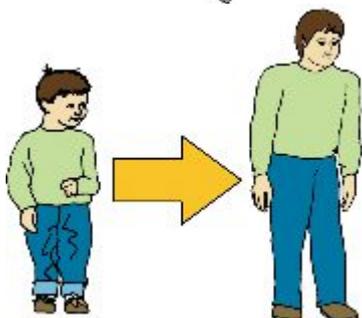


We have written the Standards to cover every part of your life:

- from when a problem is found out before you are born



- growing up as a child



- moving to adult services



- having your own family



- care at the end of your life.

We want to make sure:



- people with CHD live a longer better life



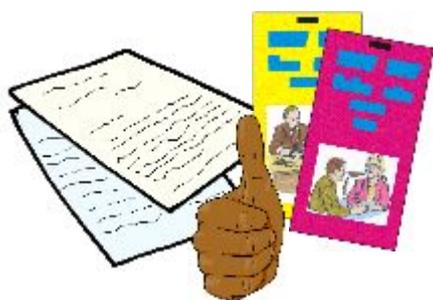
- services are the same across England



- people can get a good service at any time of day or night



- people say their service is great



- people get good information



- families get help when they have to be away from home.

To make these Standards we have worked with:



- people born with CHD



- expert CHD doctors



- special CHD hospitals



- organisations speaking up for people with CHD



- staff and others.



Working together



We want to make sure the special CHD hospitals and services work well with each other and think about what is best for patients.



Having a heart operation

We have heard lots about:



- how many doctors doing operations each team should have



- how many operations each doctor should do each year to keep up to date



- doctors only doing things they know they can do



- how patients with rare problems can get the best care.



The Standards say what this would look like.



They also say how many staff there should be to give a good service in the other areas of congenital heart care as well.



Sometimes it can take too long to get help from other places when it is needed.



We want to make sure all the experts that might be needed can be there quickly.

Talking to each other



The Standards will try to make sure:



- patients and families are helped to understand what is wrong and what will happen



- patients are asked what they think and are listened to



- staff give good support and advice



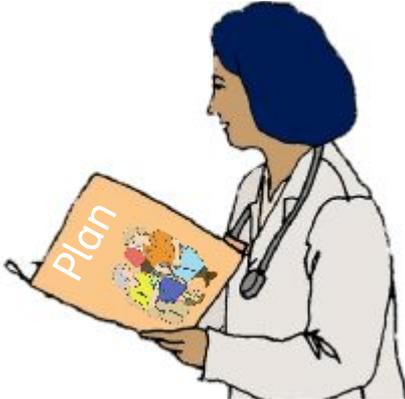
- staff explain what is happening



- patients have a written care plan of their own



- plans say what happens next



- plans are passed on to all staff and doctors who need to know about them



- people with learning disabilities have **advocates**, these are people who speak up for you or help you speak up for yourself



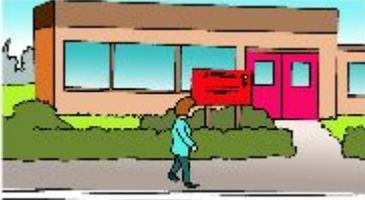
- deaf people and people who don't speak English have interpreters



- people of faith get support from people who understand.



The information that is given out should include details about all the areas that might be affected, like:



- social and community services



- benefits



- sex lives and getting pregnant



- dentists



- infections



- school



- work.



Patients need to know:

- how to complain, if they need to



- their complaint will be treated seriously and get sorted out



- they can see another doctor to look at what is wrong if they want to.



Services need to share information about a patient so they know what they need to.



What we need from hospitals



We have heard how important expert nurses and other staff are in helping people with CHD.

The Standards will try to make sure:



- there are enough expert nurses supporting patients of all ages and their families



- people can see **psychologists** as well.



Psychologists help with feelings about being ill and other difficult things that might be happening.

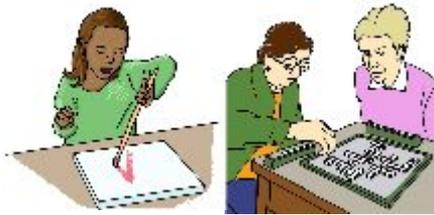


We want to help patients, families and carers to live as ordinary a life as possible when in hospital.

We have said that special hospitals should have:



- good hospital information



- places suitable for people of different ages



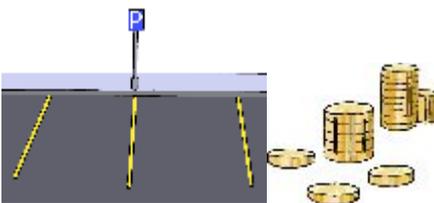
- Wi-Fi



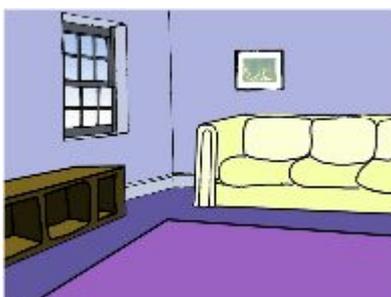
- places where families can prepare food and drink



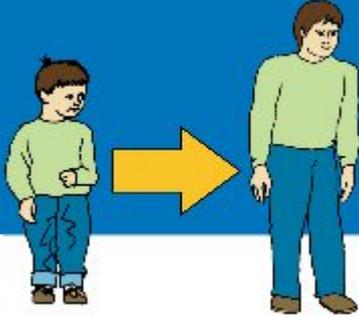
- teaching for children who are missing school



- car parks that don't cost too much



- spare rooms.



Growing up and moving to adult services



We know this can sometimes be difficult.

So we want to make sure:



- young people get more support at this time



- services work better together.



The Standards will help make the move to adult services easier.



Planning should usually start at age 12 or before and finish by 18.



It should include:

- meeting the adult services people



- listening to what you have to say



- agreeing a plan that's right for you



- moving your details over



- thinking about the needs of people with learning disabilities.



Care at the start of life



It is helpful to find any heart problems before a baby is born.



We are better at finding heart problems in some parts of the country than others.



We want more babies with heart problems to be identified before they are born.

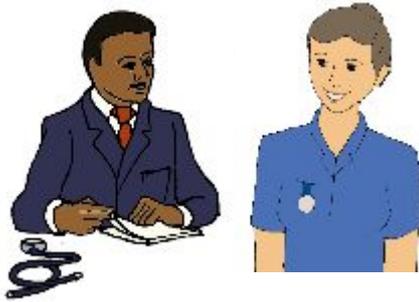


We want people to get the same service wherever they live.



If a problem shows up we want mums and dads to be able to get answers and support quickly.

Care when someone is dying



When someone is dying a named nurse and doctor will be agreed, they will:



- help make sure a plan is made and written down



- make sure the patient is supported up to their death



- make sure the family are supported up to and after death.



Tell us what you think



We want to hear what people think about our new Standards.



Not everyone agrees with everything we are saying, like:

- how many doctors should be working in one service



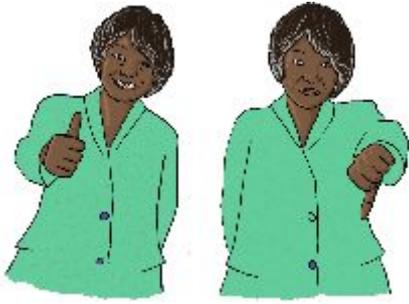
- how much work they should do



- which services should be near each other



- should some treatments only be done in a few special hospitals?



It's very important that we know what you do and don't agree with in the standards.



Do you think we have talked about the right changes?



Is there anything we haven't included?



Is there something that you think should be changed?



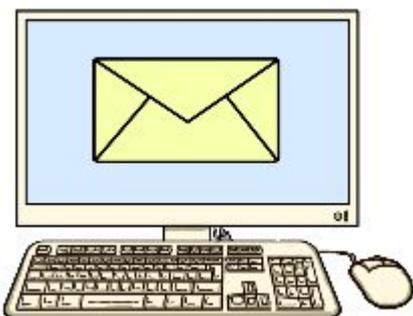
To tell us what you think



You can fill in our online questionnaire at:
<https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards>

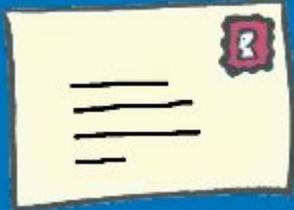


You can write to us at:
**CHD Consultation
Dialogue by Design
252B Gray's Inn Road
London
WC1X 8XG**



You can email us at:
**CHDconsultation@dialoguebydesign
.co.uk**

For more information about the
Congenital Heart Disease Review please
feel free to contact our Programme
Director Michael Wilson at:



**New Congenital Heart Disease Review
Team (5th Floor)
NHS England
Quarry House
Quarry Hill
Leeds
West Yorkshire
LS2 7UE**



or by emailing:
england.congenital@nhs.net



This paper meets the European EasyRead
Standard.



Artwork includes material from the
Valuing People Clipart collection
And cannot be used anywhere else
without written permission from
Inspired Services Publishing, Ltd.

www.valuingpeopleclipart.org.uk