



**Improving everyday life for adults
with congenital heart disease**

A review into NHS services - we want your views

Foreword

There are now more adults living with congenital heart disease in England than ever before and the number is growing each year. Congenital heart disease can affect all areas of a person's life and those living with the condition need very specialist advice, support and care. In this country specialist care for adult congenital heart disease (ACHD) has not always developed in a planned and systematic way and excellent service provision is not always available everywhere. There are examples of very good practice in some areas but we need to make sure that this quality is available to all, regardless of where they live. We want to ensure that every patient with this condition receives a world class standard of care.

The NHS has been speaking to patients, their families, clinicians, NHS staff and commissioners. It is clear that there is a disparity in the way services are provided across the country. Some patients have said that they receive excellent care but many feel that things could be better. Some patients have said access to specialist ACHD care and clear advice about living with their condition has been lacking.

We want to change this. It is important that we enable all adults living with this lifelong condition to live their lives to the full, reassured by the fact they have the best possible care available to them.

With the full support of NHS commissioners (in charge of organising services), those involved in reviewing services have been working with a group of expert clinicians, professional organisations and ACHD patient representatives to assess the specialist services currently provided and explore how excellent care can be provided across England. We believe care should be organised within coherent networks covering the entire country and that those providing services should meet minimum standards to ensure the best quality care in the future.

The NHS wants to hear from all of you – patients, families, carers, clinicians and anyone else with a particular interest – to ensure we develop a service that meets your needs and delivers the best care for all.

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Professor Sir Roger Boyle CBE
Chair, ACHD Advisory Group

Former National Director for
Heart Disease and Stroke

ABOUT THIS DOCUMENT

This document sets out the challenges faced by adults with congenital heart disease and areas for improvement identified so far in the review process. Pages 4 to 6 set out what patients have told us about what it is like to live with the condition every day.

We have been working closely with an expert group of clinicians, patients and commissioners (the ACHD Advisory Group) to identify areas for improvement and to develop a model of how ACHD services could be organised in the future. On pages 9 to 14 we summarise this proposed network model of care and the draft minimum standards (draft national designation standards) which we believe would help the NHS deliver excellent care in the future.

We would like to know if you agree with the potential improvements we are suggesting. Please share your views by Friday 27th July. Pages 16 to 17 describe how you can get involved and have your say on the future of ACHD services.

WHAT IS ACHD?

Adult congenital heart disease affects people aged 16 and over living with a heart defect that developed in the womb and was present at birth. The condition is relatively rare, affecting 1 in 133 people. Congenital heart disease is sometimes diagnosed in the womb, but often it is not identified until after birth, or may even remain undetected until adulthood.

Thanks to medical advancements over the last few decades most people born with congenital heart disease now survive into adulthood, so there is a growing population of adults in this country living with the condition. Major heart operations are most commonly carried out during childhood. People with congenital heart disease will need ongoing care throughout their lives from services that specialise in the needs of adults.

THE REVIEW

This review into adult congenital heart services is separate to the *Safe and Sustainable* review of children's congenital heart services. Although there are obvious connections between both patient groups, the support needs of adults and children with congenital heart disease are different. For instance, whilst many children with congenital heart disease require surgical and interventional care, significantly fewer adult patients require surgery. All adults with congenital heart disease do however need ongoing expert care and support and as you will see in this document many patients have emphasised this.

While this review will take the outcome of *Safe and Sustainable* into account, ACHD services will be subject to an in-depth objective review process and consultation before any decisions are made on the future configuration of services.



Life as an adult with congenital heart disease



GROWING UP

People with ACHD have told us that the transition between children and adult services is often the hardest part about growing up and can span several years. Doctors have described how teenagers with congenital heart disease are often at more risk of emergency hospital admissions and deteriorations in their health, as well as psychological problems, in some cases leading to feelings of isolation.

Services should be age appropriate and take into account the different needs of patients across different age groups and cultures. Those with ACHD need accessible, clear and seamless transition arrangements in place so that they can move into adult life with reassurance that the care they receive will be responsive to their changing needs.



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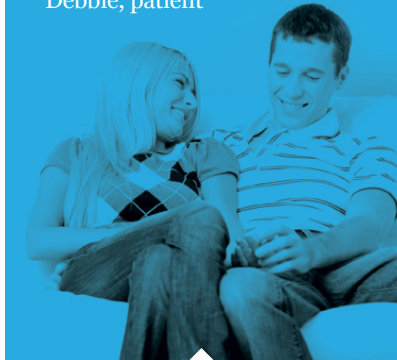
Transition was one of the most difficult periods for me. You often feel so isolated and I didn't really have anyone when I was growing up to support me psychologically through the process.

Susan, patient

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“It will be hard work physically and emotionally but like most women I want to have children as it’s a natural thing to want. We will just see if I am able to cope with it when the time is right.”

Debbie, patient



EDUCATION, WORKING AND SOCIAL LIFE

There are aspects of life many people take for granted, such as going to school, holding down a job and socialising with friends. People with ACHD often have very complex conditions that require regular follow-up care, which can have a significant impact on every aspect of their lives.

Those with ACHD in full time education may require regular time away from school, college or university, which can be very disruptive. Patients have told us that when coming out of education and entering working life the demands of regular employment can be very challenging. A readily available, comprehensive service which includes access to ACHD experts and occupational therapists would help adults with ACHD to address the additional challenges they face in their everyday life.

“I have always wanted to be a nurse and still now would like to be however I know this isn’t possible as I get far too tired and being on my feet running round in that type of job wouldn’t be suitable for me.”

Debbie, patient



SEX, RELATIONSHIPS AND BUILDING A FAMILY

Living with ACHD means that when those with the condition have new sexual partners, they often need to consider the implications on their heart and overall health. For some women with ACHD conditions it is perfectly safe to have children and raise a family. However, for others, the risks of complications associated with getting pregnant and giving birth are significant. For those women, pregnancy requires careful assessment and monitoring as their heart condition, combined with the physical stresses of pregnancy, can present very real health risks.

Unplanned pregnancy can be extremely serious for some women with congenital heart disease and the contraceptive pill needs to be carefully prescribed.

The NHS should provide adults with congenital heart disease with advice and support tailored to individuals’ needs to guide them through the process and help them understand the potential complications.



LOOKING AFTER YOUR BODY AND HEART

Keeping active and maintaining a healthy diet is vital to the long term health of people with ACHD. Being over or underweight can put significant strain on the heart. For most individuals with ACHD regular, moderate exercise is encouraged but it is important that they receive expert advice on sensible activities that will not put too much strain on their heart.

Dental hygiene is very important, as conditions such as gum disease may result in bacterial infections which can damage heart valves and cause complications. People are also advised of the possible risks of infection posed by simply getting their ears pierced or getting a tattoo.

People with ACHD should have access to the right advice to enable them to make informed lifestyle choices.

“When growing up I experienced issues around Games sessions at school. I was told that I was not able to compete or participate in many of these sessions. It felt like there was a lack of knowledge around my condition”

Janet, patient



“There is a need for appropriate psychological and emotional support. The emotional impact of living with congenital heart disease generally begins pre-birth. Therefore a cradle to grave approach in providing emotional support should be given to individuals and family members.”

Wendy, patient



EMOTIONAL WELLBEING AND COUNSELLING

Living with congenital heart disease can impact on a person's wellbeing and happiness. Many people have told us that they often feel anxious and find it hard to come to terms with their condition and the limitations it places on their lives.

A patient's experience doesn't just constitute surgery and physical care. People have told us that proper mental and psychological support can have a very positive effect.

Specialist psychological support and counselling should be regularly available to those with ACHD who need help to come to terms with the condition and understand it better.



GROWING OLDER

As we age, secondary conditions can develop including acquired heart disease (such as coronary artery disease), diabetes, arthritis and dementia, and for those with ACHD this can present new and complex challenges.

With a growing ACHD population we need to ensure that specialist care is available to deal with these complications and the impact it will have on an individual's heart. Services should be carefully designed to take account of the development of acquired heart disease and the increasing level of other medical conditions associated with ageing.

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As I have grown older I've had to visit hospital more often with other health complications. I want to be able to have full trust in the care that I receive and know that staff understand my condition.

Susan, patient

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Why improve things?

People with congenital heart disease need specialist care and the NHS has a duty to ensure that these needs are adequately met.

TRANSITION FROM CHILDREN'S SERVICES

At present, many transition services are inadequate and people are often lost in the system during the process. This means people either don't ever see an adult congenital specialist or are left to make their own enquiries on follow up care.

UNPLANNED AND INCONSISTENT PROVISION

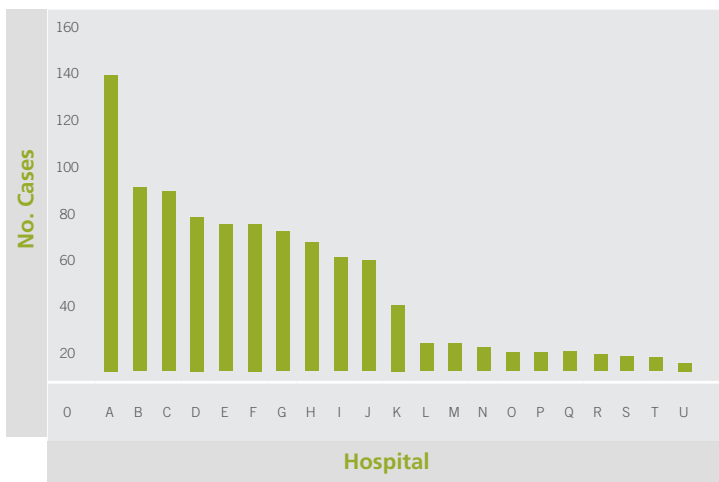
Specialist ACHD services have developed in an unplanned way in some parts of the country. People have told us that access to specialist ACHD care is not consistent and there are few areas where formal networks are in place. In some areas of the country people have access to certain ACHD services which are not always available in other areas. Services are not always joined up and people tell us that the lack of communication and clear referral pathways can be frustrating.

LOW PROCEDURE NUMBERS

Some hospitals are carrying out just a handful of surgical procedures on adults with congenital heart disease. This is known as 'occasional practice' and means that some clinicians may not be carrying out enough procedures to develop their skills and

2010/11 ACHD Cardiac Surgery Activity By Hospital

(data from the Central Cardiac Audit Database, Feb 2012 – anonymised)



This graph shows the variation in the number of cases performed by 21 hospitals currently providing ACHD surgery

continually improve outcomes for patients. The graph shows the wide range in the number of procedures taking place across the country. (Please note that not all centres performing ACHD surgery submit data to the Central Cardiac Audit Database).

MONITORING QUALITY

Experts agree that the care and ongoing support that patients receive need to be monitored more effectively through better data collection and reporting on patient outcomes. We are aware that currently a significant amount of information is not submitted to the national audit by some hospitals caring for people with ACHD.

CAPACITY

There has been an increase in demand for specialist ACHD services which will continue to rise as the population living with this condition grows. We want to ensure services are being managed effectively and people with ACHD are seen within appropriate timescales. Clinicians need to have reasonable workloads to allow them to spend enough time with their patients so they always get the care they need.

NETWORKED SERVICES

Current services have developed in an ad hoc way which means that some adults with ACHD do not have access to all the services they need. People with ACHD often require care from other parts of the NHS. Women with ACHD may need maternity care and as they age people with ACHD may develop secondary health conditions. The specialists caring for these patients need to work together to ensure care is appropriate to the patient's need. Integrated care pathways need to be established in all areas with links to other associated services and the highly specialised national services such as transplant surgery.

DEVELOPING EXPERT SKILLS

Clinicians have told us that the training of staff for the growing ACHD population has not developed in a planned or systematic way. Surgical procedures and treatments for ACHD patients are very complex and specialist training is required. It has been suggested by some secondary care cardiologists themselves that the ACHD patients they currently care for would be better cared for within a specialist ACHD service.

Ensuring excellent care for adults with ACHD

We should ensure that all patients get a service that is excellent. Ongoing care needs to be geographically convenient and part of a strong and dependable patient support network. By reshaping services we will improve access to care, develop strong networks of care and better meet the demands of a growing ACHD population.

HOW SHOULD SERVICES BE ORGANISED?

The ACHD Advisory Group has developed a proposed model of organising care in the future and draft national designation standards that centres would need to comply with to ensure excellence in the future.

We believe services should be organised within a network of care, built around three levels of specialist ACHD expertise. The ACHD Specialist Centre would lead the network, working closely with ACHD Intermediate Centres and ACHD Local Centres to deliver excellent care at a local level.

Clear referral pathways between the different ACHD centres and defined relationships with children's heart services and non-cardiac services would allow patients to access the care they need seamlessly. Centres would carefully monitor patient outcomes and submit data to the national audit process.

THE ACHD NETWORK

The three types of centres would form networks of ACHD care, with leadership provided by the Specialist Centre. There would be clearly defined policies and pathways established within each network and working links to other types of specialised care, such as obstetrics, transplantation services and palliative care.

YOUR THOUGHTS

We are very keen to hear your views on the proposed model for organising care in the future.



ACHD LOCAL CENTRES

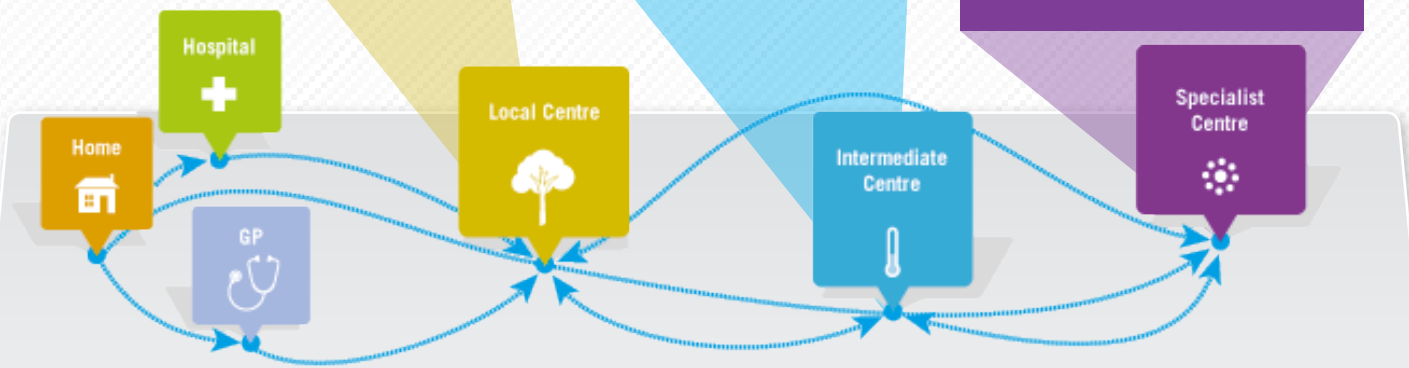
will be responsible for the ongoing provision of an ACHD patient's care including regular check-ups and monitoring.

ACHD INTERMEDIATE CENTRES

will be responsible for specific areas of heart health management that do not require surgical support. Specialist cardiologists, nurses and other clinicians will deliver ongoing care and a range of imaging and diagnostic procedures.

ACHD SPECIALIST CENTRES

will be responsible for leading the networks of care and undertaking all interventions including surgery and therapeutic catheterisation. All ACHD interventions will be carried out at these specialist centres by specialist ACHD surgeons and cardiologists. Concentrating interventional expertise into these specialist centres will improve patient outcomes and remove the risk of occasional practice at other hospitals.



WHAT HAPPENS TO YOUNG PEOPLE DURING TRANSITION?

The young adult's pathway between children's congenital heart services and ACHD services will be managed by specialist-led transfer clinics.

ACHD model of care	ACHD Local Centres	ACHD Intermediate Centres	ACHD Specialist Centres
Surgery			
Hybrid procedures (surgery and interventional catheterisation)			
Lead pathways to other highly specialised services			
Interventional cardiology			
Complex electrophysiology			
High risk pregnancy			
Cardiology (Specialist ACHD Cardiologist input)			
Simple electrophysiology			
Management of pregnancy			
Cardiologists with an interest in ACHD			
Ongoing care			
Assessment and diagnosis			

WHAT SHOULD FUTURE SERVICES LOOK LIKE?

BUILDING BETTER NETWORKS OF EXPERTISE

Specialist Centres would need to provide leadership to all the services within their network and ensure that patients receive world class ongoing care.

- Surgical expertise should be concentrated in a smaller number of specialist centres. Specialist centres should be responsible for supporting local hospitals in providing ongoing care for patients.
- Patients should be able to receive expert ongoing care from clinicians at a local hospital in the area in which they live. Cardiologists at local hospitals need the support of ACHD specialists.
- The network needs to be robust and sustainable to ensure that women with congenital heart disease receive specialist pre- and post-natal support.

“The availability of specialist expertise for women with ACHD before, during and after pregnancy is essential to ensure these women make informed choices and have access to the very best multidisciplinary care. The Royal College of Obstetricians and Gynaecologists welcomes this review and supports the proposals to develop networks of specialist adult congenital cardiac care.”

Professor Catherine Nelson-Piercy, Royal College of Obstetricians and Gynaecologists



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Adults with congenital heart disease face many challenges - among them the need for informed integrated care with advice from specialist teams. Much more needs to be done to ensure that those who move from childhood to adulthood with heart disease receive the co-ordinated and specialist care that they require. The proposed regional congenital heart networks will ensure that hospital cardiologists know where to seek advice both from local ACHD centres as well as specialist centres.

Professor Keith Fox, British Cardiovascular Society

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- As they age people with ACHD suffer the same burden of acquired diseases as the general population. Expert ACHD clinicians need to be readily available to advise non ACHD health professionals involved in the delivery of care. For example a patient with ACHD and acquired coronary heart disease may be managed by general cardiothoracic surgeons, or require joint working from both general and ACHD surgeons.
- Effective liaison between specialist ACHD centres and other specialist health services is needed e.g. pulmonary hypertension, genetics and transplantation services.

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Adults with congenital heart disease need holistic, multidisciplinary care. The Association of Cardiothoracic Anaesthetists supports this review, particularly the proposal to develop networks of specialist care which will ensure all patients have access to specialist ACHD anaesthetists for surgical procedures.

Dr Ravi Gill, Association of Cardiothoracic Anaesthetists

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GREATER ACCESS TO SPECIALIST CARE

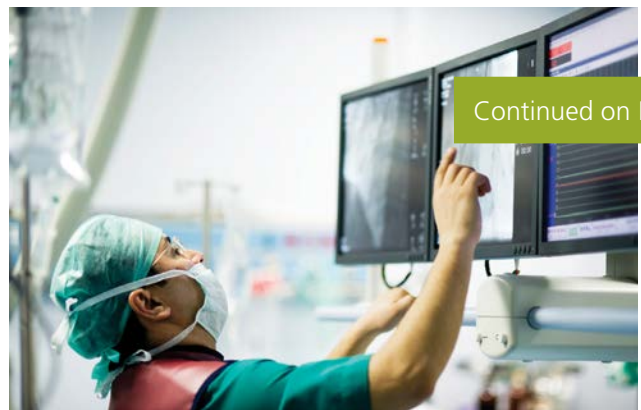
People with ACHD need access to specialist care. All patients, including those with less complex needs, should have the opportunity to be seen at least once by a specialist.

- To ensure that care is provided to people with ACHD in the most effective way there is a need for all specialist centres to have formally constructed multidisciplinary teams of cardiologists, cardiac surgeons, interventional radiologists, anaesthetists and intensivists.

CONCENTRATING SURGICAL EXPERTISE IN SPECIALIST CENTRES

All adults with congenital heart disease should be able to access excellent, world class standards of surgical care that is consistent across the country.

- There is strong advice from clinicians that operations and interventions should only be performed by congenital heart specialists who are part of a recognised team, have appropriate training and experience, and carry out a minimum number of procedures per year including complex surgery. It is important for clinicians to carry out enough procedures each year to be able to maintain and develop specialised skills.



Continued on Page 12

APPROPRIATE CARE CLOSER TO HOME

It is important that patients are able to access excellent ongoing care as close to home as possible.

- Patients should be able to access ongoing care at their local hospital where trained staff are able to provide expert care for their condition, without the need for regular journeys to a specialist centre.
- Patients need to have a robust care plan in place. GPs should have access to all relevant information about a patient's condition to ensure they receive the most appropriate care.
- In the case of a non-cardiac medical or surgical emergency, arrangements should be in place for the specialist congenital cardiology team to advise the clinician in the local hospital who is responsible for the patient's care.
- Families need to have better access to accommodation near specialist centres. Adults with ACHD who also have learning difficulties may be more dependent on their family and carers so adequate accommodation should be available.

IMPROVING REFERRAL PROCESSES AND PATIENT PATHWAYS

Clear pathways for patient care, including investigation, treatment and follow up should be standardised throughout the country. Patients need a more co-ordinated service that recognises that congenital heart disease is a lifelong condition which affects people's quality of life.

- Stronger networks with clear protocols will ensure that patients are referred appropriately and in a timely manner. Patients should be supported throughout by their ACHD Specialist Nurse.
- Local hospitals are not equipped to deal with the more complex needs of an individual with ACHD and should refer patients to specialist centres for specialist advice and treatment.

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The British Heart Foundation fully supports the aims of this review. All adults living with congenital heart disease should have access to highly specialised care. Services for adults with this lifelong condition need to improve and care should be consistent across the country irrespective of where a person lives.

Dr Mike Knapton, British Heart Foundation



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IMPROVING THE TRANSITION FROM CHILDREN TO ADULT SERVICES

Improving the transition from children to adult services is critical to providing high quality care.

- Relationships between GPs, local hospitals and specialist centres should be better organised to ensure that transition is smooth and efficient.
- It is proposed that specialist transition clinics are put in place to ensure that transition is effectively co-ordinated and uninterrupted and that patients are referred on to the appropriate specialist services.

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As more and more children born with heart conditions reach their teenage years and adulthood, preparing them for these critical parts of their lives is vital. Part of that preparation is ensuring that they are at the centre of their care moving forward. These standards, and the model of care, are a vital step forward in ensuring that this happens.

Paul Willgoss, Children's Heart Federation and ACHD patient



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This review and the proposal to develop strong networks of specialist ACHD care is welcomed by the BACCNA. Clearly defined roles and pathways should enable specialist ACHD nurse practitioners to provide more effective care throughout the network.

Sheena Vernon, British Association of Congenital Cardiac Nursing for Adults



INFORMATION AND COMMUNICATION

A successful network of care requires good communication between GPs, ACHD centres, local hospitals and the wider patient support network.

- The growing ACHD population has resulted in some ACHD Nurse Specialists being overworked and sometimes unable to respond to and care for the needs of patients. People with ACHD should have access to a named nurse in order to ensure that patients receive better communication, co-ordination and advice.
- There should be better support and access to information for partners, families and carers, and improved guidance about where they can access specialist advice.
- Information from specialists should be delivered to patients or GPs in a timely manner without delays.
- Centres need to be more proactive in publicising the wealth of information and support available from patient groups, such as the GUCH Patients Association, the British Heart Foundation and the Children's Heart Federation.
- Around 47% of people with Down's Syndrome are born with congenital heart defects. It is vital that people with ACHD with learning difficulties receive information and are communicated with in a way that they will understand. There is also a need for these patients to have access to appropriate emotional support to help them understand their condition better.

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Patients with ACHD have complex needs and require specialist, co-ordinated care throughout their lives. To deliver the best quality care nurses and other clinicians need to work within strong networks of specialist and supporting services, with access to appropriate training and information. The Royal College of Nursing fully backs this review and the proposals to develop networks of specialist ACHD services throughout the country.

Dr Peter Carter, Royal College of Nursing



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“The standard of my overall care is good, but I have sometimes found the communication aspects of the overall process poor. Communication between local hospitals, specialist centres and GPs needs to improve.”

Janet, patient

The review process and next steps

WHO IS CONDUCTING THE REVIEW?

The National Specialised Commissioning Team, part of NHS Specialised Services, is carrying out the review and has convened an ACHD Advisory Group to provide expert advice. The ACHD Advisory Group includes ACHD patient representatives, clinicians and representatives from professional associations. The ACHD Advisory Group has developed draft national designation standards which build on work carried out by a separate expert group in 2009.

The draft national designation standards can be found at: www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease

An independent group of experts will visit hospitals looking to provide ACHD services in the future as part of an assessment of their ability to meet the draft national designation standards. No decisions have been made and at this stage we are seeking your views to help inform the development of the draft national designation standards.

Next year a decision making group will publish options on how to improve services for people with ACHD and we will hold a formal period of public consultation to ensure everyone has the opportunity to contribute their views.

TIMELINE FOR THE REVIEW

2011

July 2011 - April 2012

Working with professionals, patients and commissioners to develop a proposed model of care and draft national designation standards

May 2012 - July 2012

Engaging with patients and their families, NHS staff, clinicians and other groups on the draft national designation standards

Autumn 2012

Reviewing feedback from patients and clinicians and revising draft national designation standards

Winter 2012 - Spring 2013

ACHD centres will be visited by an independent group of experts and scored against their ability to meet the draft national designation standards

Development of different options for how ACHD services might be organised in the future

Summer - Autumn 2013

National public consultation on the options for how ACHD services might be organised in the future

End of 2013

A decision on the future of ACHD services to be made

2014

2014

Improvements to ACHD services to be implemented

HOW CAN YOU HAVE YOUR SAY?

WE WANT TO HEAR YOUR VIEWS ON:

- ❓ What do you think of our proposed model of organising care into networks of specialist centres, intermediate centres and local centres with links to non-cardiac care?
- ❓ Do you have any comments on the draft national designation standards?
- ❓ What other improvements can be made to the way the NHS organises care for people with ACHD?

HAVE YOUR SAY ON THIS REVIEW:

- ✔ **To download** the draft national designation standards and to find out more about the review go to <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

YOU CAN SUBMIT YOUR VIEWS BY:

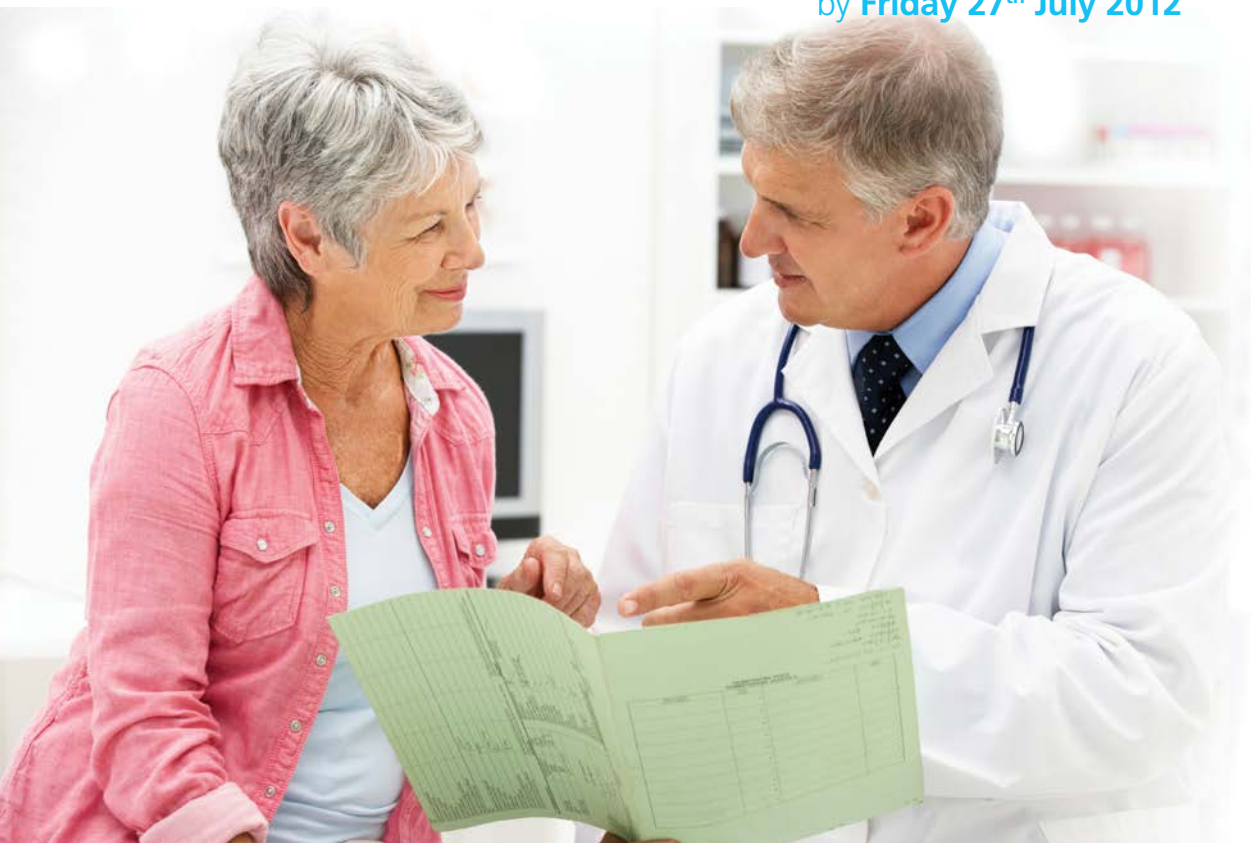
✉ **Letter:** Christy Rowley

NHS Specialised Commissioning Team
2nd floor, Southside, 105 Victoria Street
London SW1E 6QT

@ **Email:** adultheart@nsscg.nhs.uk


In person: We are holding a number of regional workshops for patients and people working with adults with congenital heart disease. If you would like to attend please contact the communications team on 020 7025 7520 for more details.

Please provide your comments
by **Friday 27th July 2012**



CONTACT US:

- Easy-read and large print versions of this document are available and other formats and languages can be provided on request.
- To request a copy or for further details on the engagement process please contact the NHS Specialised Services communications team on

 **Tel:** 020 7025 7520

 **Email:** nhsspecialisedservices@grayling.com

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As patients we spend our entire lives in close contact with the NHS and have a clear idea of how we would like services to be delivered. It is vital that people with congenital heart disease take this opportunity to help shape the future of their service.

Michael Cumper,
Grown Up Congenital Heart
Patients' Association



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Any questions?

Please find answers to common questions below.



Q Why are you reviewing services for adults with congenital heart disease?

A This review is designed to deliver improvements in the quality of treatment and care for adults with congenital heart disease. A review of services for children with congenital heart disease was initiated in 2008. Evidence shows that the number of adults with congenital heart disease is increasing as those with the condition are living longer. It is clear that the service needs to be developed to evolve with this trend. It is also apparent from feedback that we have received from clinicians and patients that the current service needs to be improved as it is not currently well provided in some parts of the country. There are no predetermined outcomes; at this stage we are gathering views from you and other patients on how the current service can be improved for adults living with congenital heart disease.

Q Does the review cover the whole of the UK?

A The review only covers ACHD services in England. Services are designated separately in Wales, Scotland and Northern Ireland. However patients in Wales, Scotland and Northern Ireland may use English specialist services (tertiary services). Representatives from Scotland and Wales sit on the Advisory Group as observers.

Q Who is carrying out the review of ACHD services?

A The review is being carried out by the National Specialised Commissioning Team (NSCT), part of NHS Specialised Services, and is advised by the ACHD Advisory Group. The NSCT is responsible for commissioning over sixty highly specialised services, often for very small numbers of people.

Q Who sits on the ACHD Advisory Group?

A The Group is chaired by Professor Sir Roger Boyle, former National Director of Heart Disease and Stroke. The Group is made up of clinical professionals with a variety of expertise relevant to the needs of people with ACHD, NHS commissioners and patient representatives. The Group is advisory, and it will not play any part in making decisions on the future shape of services. More information about the members of the Advisory Group can be found here: <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

Q Will I get a chance to have my say on the future of adult congenital heart services?

A Yes. We are very keen to hear from as many people as possible on how the current service can be improved and also what currently works well. A series of engagement events will be taking place in May and July 2012 and will be open to patients and people working with adults with congenital heart disease. We aim to hold a national public consultation on the proposals for improving the service in 2013.

Q Who will make the decision on the future of ACHD services?

A We are currently gathering views and evidence so that we can best shape the improvements that need to be made. We will publicise information about the decision making process throughout the course of the review.

Q When will any changes be implemented?

A Any changes to adult congenital heart services are expected to be made in 2014.

Q Will the proposed networks of ACHD care be aligned with the networks of care for children's heart services?

A The review will consider how adult networks may align with the children's networks that will be agreed by *Safe and Sustainable*. Services for adult congenital cardiac care will be designed around the specific and unique needs of adults and there will be clearly defined working relationships between specialist ACHD and children's congenital cardiac services. A dedicated transition process will manage the pathway of young adults between the two services.

Organisations involved in the review



BRITISH CONGENITAL CARDIAC ASSOCIATION



Royal College of
Obstetricians and Gynaecologists
Bringing to life the best in women's health care



British Cardiovascular Society



Royal College
of Nursing®

