



Improving everyday life for adults with congenital heart disease



WELCOME

Welcome to the latest newsletter updating patients, families and clinicians on the review of services for adults with congenital heart disease (ACHD).

Thank you to everyone who wrote to us and attended workshops during the engagement period last year. We both enjoyed attending a number of discussion groups, in particular hearing first-hand about your experiences.

We received extensive feedback on the proposed model of care and draft designation standards and views on how you think services could be improved for the future. With issues ranging from tailored support for pregnant women, young people in transition and the management of networks, your views are being carefully considered by the Advisory Group as we develop the model of care and draft standards.

We are committed to developing standards that will improve access to care and develop stronger networks to ensure the best possible service for everyone in England, no matter where they live. Your feedback along this journey is absolutely vital.

Professor John Deanfield and Professor Sir Roger Boyle CBE
Co-Chairs, ACHD Advisory Group



Professor
John Deanfield



Professor
Sir Roger Boyle CBE

“The Somerville Foundation supports the NHS review into ACHD services. We are working closely with clinical experts on the Advisory Group to develop standards of care that will improve the lives of patients with ACHD – now and in the future. The Advisory Group has taken considerable time to amend the draft standards to reflect the views submitted during last year’s period of engagement. No decisions have yet been made. A full public consultation will take place on any proposed changes and we encourage everyone to take part in the debate. Your views are important.”

Michael Cumper

Chairman of the Somerville Foundation and member of the ACHD Advisory Group

THE ACHD ADVISORY 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 including The Somerville Foundation and British Heart Foundation. A full list of members of the Advisory Group can be found here:

<http://www.specialisedservices.nhs.uk/document/achd-process-terms-reference>

WHY ARE WE IMPROVING SERVICES

There are now more adults living with congenital heart disease in England than ever before and the numbers are growing each year. Congenital heart disease can affect many aspects of a person's life and people 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 someone lives. The NHS wants to ensure that every patient with this condition receives a world class standard of care. The document *Adults Living with Congenital Heart Disease* explains the background and aims of the review in more detail.

ENGAGEMENT PERIOD

During the engagement period we heard from many people with congenital heart disease, their families and carers as well as nurses, cardiologists, surgeons and other health professionals. Many of you wrote to us by letter or email and hundreds more attended workshops across the country. We also held specific discussion sessions to explore the views of people from black, Asian and minority ethnic groups and young people going through transition. We encouraged feedback from people with learning difficulties by distributing a shortened version of the engagement document in an easy-to-read format.

WHAT YOU TOLD US

Many of you told us what works well about the current system and described experiences of excellent care from specialist nurses and doctors. Many of you also highlighted instances where the current system doesn't work very well and how services could be improved. We also received extensive detailed feedback on the proposed model of care and draft designation standards. The issues that you raised are varied and you can find out more about what other people said in the reports on the website. [Here are just a handful of the comments:](#)

"I agree with the principle of providing 3 levels of care: specialist, intermediate and local provided that there is a mandatory requirement for a Cardiologist with special interest in ACHD to be located in every intermediate centre and preferably the local centre."

"Communication is the key. Formal structures in place would be great - need to have a standardised format of patient records, so instantly recognisable. Need not only access to clinician but access to clinician with the right information."

"I also think that there needs to be more awareness of ACHD at GP and practice nurse level. If I visit my GP/nurse I need the reassurance that if necessary I would be referred back to my cardiologist if it is a heart related problem."

"Decisions made in childhood can often influence the next decade of a patient's life and so integration of teams is essential."

"It feels comforting to be in a hospital you are familiar with and where you know the staff."

"Other services need to be together as this is a lifelong condition and people invariably need access to other services throughout life which need to be joined up."

"I am pleased to see that there is a requirement for psychological support in Specialist Surgical Centres."

THE ENGAGEMENT PERIOD IN NUMBERS

98

People wrote to us with their comments on the model of care and draft standards by letter or email

256

People in total attended seven workshops held across the country

85

We met with 85 representatives of national patient groups, professional associations, trusts and commissioners at a national workshop in London

144

Patients, families, clinicians and other NHS staff attended four regional workshops

31

People came to the workshop in Bristol on 19th June

45

People came to Manchester on 23rd June

25

People came to York on 27th June

31

People came to a workshop in London on 30th June

19

Patients and family members or carers attended a discussion workshop for people with congenital heart disease from black, Asian and minority ethnic communities to explore any cultural-specific needs

8

We worked with the children's heart federation to organise a workshop for eight young people, aged 15-22, which enabled them to share their views with a specific focus on the transition process from paediatric to adult services

THE SOMERVILLE FOUNDATION CONFERENCE

Recently the ACHD review team attended the annual Somerville Foundation conference in Glasgow to get feedback from patients about how they would like to be consulted with during the next stage of the review. The discussions were extremely useful, generating ideas about the best way to engage with adults with congenital heart disease in the future. People suggested several different channels including online engagement, social media, online questionnaires and emails to ensure as many people as possible can have their say. We also asked people whether there are any particular groups that should be actively targeted and it was widely agreed that it was important to reach people with ACHD who typically don't come along to conferences or consultation events, particularly young people going through transition. Many felt the best way to do this was by using celebrity ambassadors or by working with documentary makers and TV producers to help raise awareness among less engaged groups.

A full report with more detailed feedback from the event can be found on the website:

www.specialisedservices.nhs.uk/document/feedback-report-engagement-with-patients-at-somerville-foundation-conference-2012

WHAT NEXT?

All the feedback received during the engagement phase is being considered very carefully by members of the ACHD Advisory Group who are in the process of refining and reviewing the model of care and draft designation standards. We will publish the draft standards once agreed shortly.

NHS COMMISSIONING BOARD

On 1 April 2013 the new NHS Commissioning Board (NHS CB) will assume responsibility for the management of the review. The current ACHD advisory group will continue to advise the NHS CB on relevant clinical issues. The main aim of the NHS CB is to improve health outcomes for people in England. You can learn more about the NHS CB at:

<http://www.commissioningboard.nhs.uk/>.

FURTHER INFORMATION

For more information on the review of ACHD services, please visit:

<http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

More information on why the NHS wants to improve services is available in the document Improving everyday life for adults with congenital heart disease.

You can contact the ACHD review team in the following ways:

✉ Write to:

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

☎ Call the review team on:
020 7932 2645

@ Email:
adultheart@nsscg.nhs.uk

Are you on our email list?

If you would like to receive updates about the review please email:

nhsspecialisedservices@grayling.com

