New Congenital Heart Disease Review

What was said in consultation

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Consultation update

- 12 weeks of consultation – many events across UK both delivered by the review team and partners
- Key of consultation period was to make people aware of the proposed standards, the questions and how they could respond
- Met patients, families, carers, staff from units, clinicians from others services, charities and local community groups

The Report

- NHS England commissioned *Dialogue by Design* to receive and analyse consultation responses on their behalf.
- This involved setting-up and maintaining the response channels, processing, analysing and reporting on the responses received.
- Report published 02/03/15

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The response in numbers

- In total, **459** valid responses received
- An average of **335** responses to each question
- **48%** of responses were from people with CHD or their families and carers
- **21%** of responses were from staff working directly with people with CHD
- **20%** of responses were from organisations
- **95%** of the responses were from England
- **At least one** response from every county/unitary authority in England
- **92%** were from respondents who classified their ethnicity as Welsh / English / Scottish / Northern Irish / British / Irish
- **28%** of respondents had a degree of disability. Very few responses were from people with a learning disability

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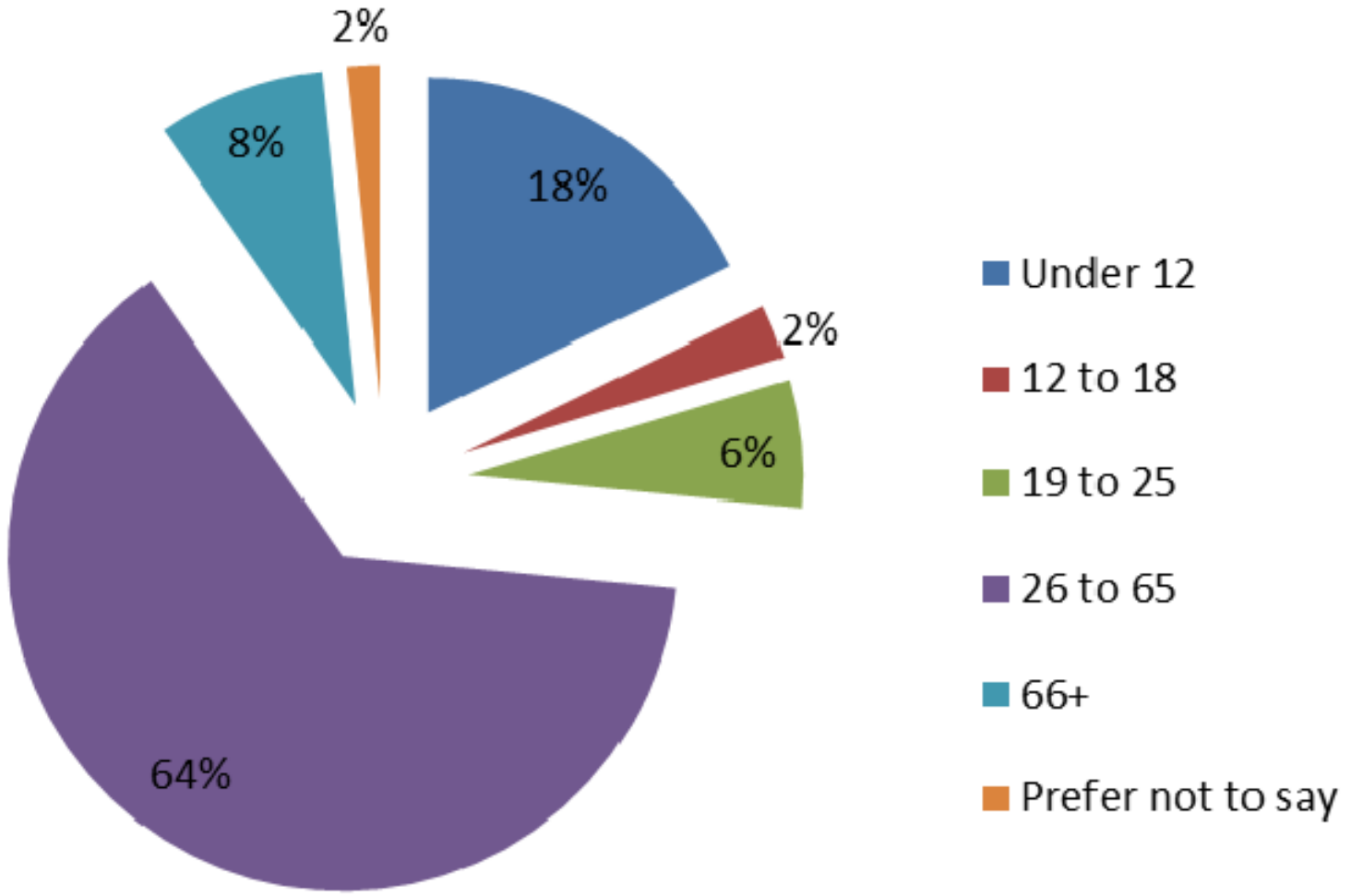
Respondents: age breakdown



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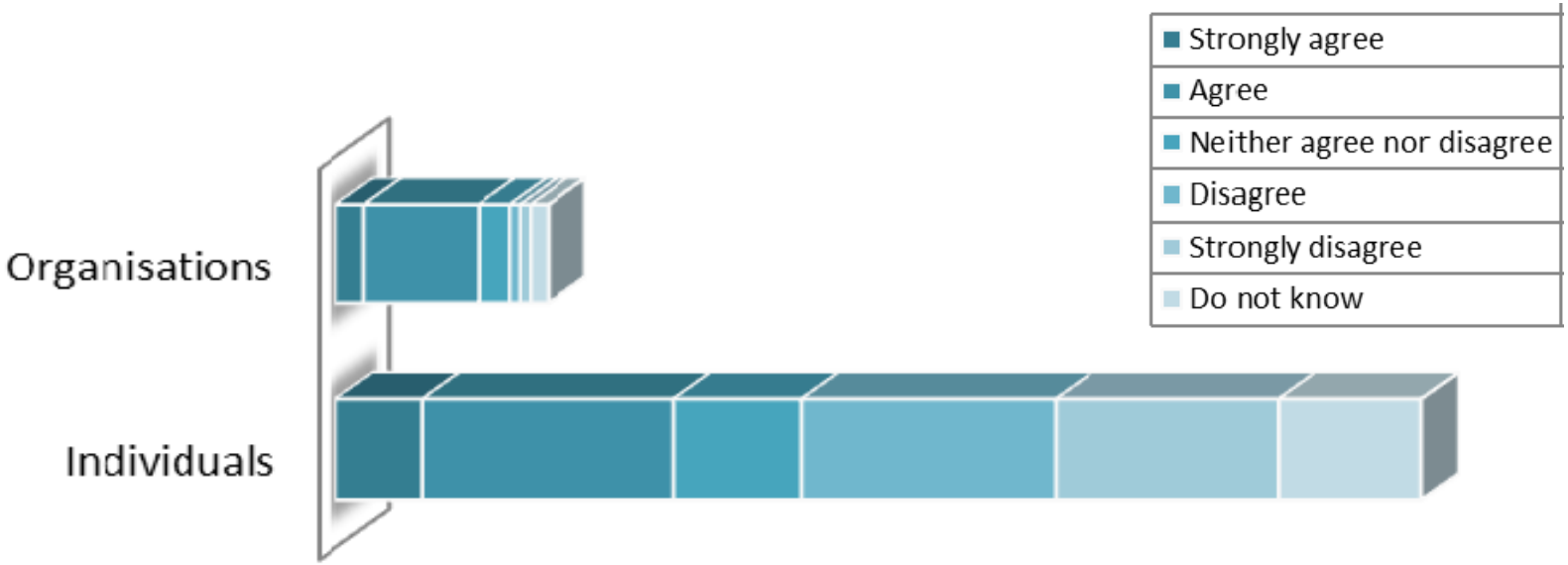
Overview

- Views on the standards are broadly positive.
- Many people think they will promote high quality, accessible, patient-centred care.
- Thought particularly beneficial to adults as this group not covered by existing standards.
- Most people also share their thoughts in more depth, not just whether they are for or against.
- Not everyone agrees with all the proposals.
- Many of the concerns focus on the challenges of implementation, particularly adequate funding and staffing or a fear that closure of centres will result
- Some people are concerned that the standards do not include all of the potential issues of CHD care.

Will the standards and specifications meet the aims of the review?



- Most people support the proposed model of care, and the standards
- People were divided in their opinions about whether the draft standards would meet the review's aims.
- Similar numbers think they will, as think they will not, with a slightly smaller number not being sure.
- Agreement that they will is higher amongst organisational respondents at around two thirds.

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Model of care

- Most respondents **support** the proposed model of care, seeing it as:
  - ensuring a UK-wide standard
  - leading to more joined up care
  - ensuring appropriate access to suitably trained staff
  - bringing care closer to home
  - concentrating expertise in larger centres
- Some respondents **oppose** the proposals. The main concerns are that the model could:
  - lead to additional travel time for patients and their families
  - cause care to become fragmented and inconsistent

Specialist cardiology centres – level 2

- Many respondents **support** the proposals - some unconditionally, some with reservations.
- Perceived advantages are: reduced travel time, increased access, quality and consistency of care.
- Some respondents **oppose** the proposals because they do not see the need for level 2 centres, question the practicality of the proposals, or prefer the current model of care.
- Specific **concerns** are raised about the future of existing 'non-specialist congenital' services that close ASDs.

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Development of networks

- The majority of respondents **support** the network approach, describing it in general terms such as ‘helpful’, ‘excellent’, ‘important’ and ‘fantastic’. Advantages described relate to:
  - Quality of care
  - Smoother transitions
  - Improving outcomes
  - Improving access
  - Reducing regional variations
  - Centralised system of care
  - Managed network boundaries
  - Staff development
  - Sharing expertise
  - Sharing resources
  - Working well together
- Many respondents have some reservations: that the approach will be hard to implement without proper management and funding or that some centres would not be included in the networks and close.
- **Opposition to the standards**: a few respondents oppose the standards describing them as unnecessary because existing networks work well.

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Staffing and skills

- The majority of respondents **support** the proposed approach on staffing and skills, though often with some reservations.
- Those with **positive views** focus on improving the quality of care, access to psychologists, increased numbers of nurses and 24/7 on call support.
- A few respondents **oppose** the proposed standards explicitly.
- Many express **concerns** including the cost of additional staff and training, whether the resources for this are available and whether there is sufficient expertise available to staff the proposals.
- Some respondents criticise the NHS strongly for not addressing what they see as a pressing and ongoing need for staff training, which some believe is the only way the proposed workforce requirements could be met.

Nurse staffing 1

- Nurses are seen as an invaluable source of support and information.
- Many respondents think that a higher number of nurses would ensure a positive patient experience.
- A few highlight the importance of a specialist nurse to support families during antenatal diagnosis and counselling.
- Views on the recruitment of specialist nurses vary. A couple of respondents think that if services are moved, nurses might be reluctant to relocate, leading to staff shortages in some services.
- Some respondents express concerns over the proposed working arrangements arguing that if specialist nurses are required to cover multiple locations they could be over-stretched and struggle to stay up to date.
- One respondent says that nurses working in CHD are excited about the proposed changes.

Nurse staffing 2

The number of specialist nurses generates particular interest from respondents:

- A few argue that the adult CHD population is growing rapidly and will require more resources.
- Respondents suggest alternative ways to determine the appropriate level of cardiac nursing staff.
  - Some respondents advocate linking provision with demand, or population and geography or taking account of patient dependency.
  - Some think the standard should set minimum number of nurses per network and each network should have the flexibility to decide how to distribute them across the different levels.
  - Some suggest nurse numbers should be equal to or higher than the consultant to patient ratio; another recommends one specialist nurse for each specialist (one nurse for each cardiologist, one nurse for each surgeon and one for each fetal specialist); another one nurse per two cardiologists with dedicated admin support for nurse specialists.

The ‘Infant deaths in the UK community following successful cardiac surgery’ study

The study found specialist nurses provide essential support and are often the link between local and specialist centres. Recommendations:

- At discharge all infants should have a named specialist nurse or a named specialist nursing team.
- All families should receive 'check-in' telephone calls from their named specialist nurse (team).
- A specialist nurse should attend all outpatient and outreach clinics.
- All families should have access to a telephone support service led by specialist nurses.
- All patients with a medical need should have access to community nursing which should be supported by the specialist centre.
- There should be cardiac trained nurses in the community and training links with local hospitals.
- Home monitoring should be provided for all high risk patients.

Surgical teams and caseload 1

- Many respondents mention advantages or concerns without expressing explicit support or opposition.
- Many who support the proposed size of surgical team also support the proposed surgical caseload. A few prioritise surgical caseloads.
- Many, without opposing the proposals, state their preference for three-surgeon teams noting their excellent track record.
- Some consider that not all hospitals could meet these requirements working as they do now.
- Some think that centres may need to share on call duties.
- Some respondents who support the proposed standard say that NHS England should implement it, even if this leads to the closure of centres.
- There are differing views on whether the standards are too stringent or not stringent enough.
- Some consider the implementation timetable too strict.

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Surgical teams and caseload 2

- The perceived **advantages** include: quality of care, cover for absence, promotion of safety and quality and exposure to a wide range of different cases.
- Perceived **disadvantages** include the potential for changing working practices to change to meet what is seen as a demanding target:
  - Surgeons might split operations that are currently performed as one appointment, recommend surgical treatment for borderline cases or focus on simple, shorter procedures instead of complex, time-consuming ones in order to meet their targets.
  - Centres might be unwilling to refer cases to other teams, even if these other teams were better placed to perform the surgery and which could result in some patients being sent far from home.
- Other **concerns** include: a perceived lack of evidence for this standard, that the caseload targets do not take account of complexity of operations or seniority of surgeons, and a fear that the proposals may lead to centres closing.

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Subspecialisation 1

- The majority of respondents are positive about the proposed approach but often qualify their support with a caveat.
- Few respondents oppose the proposed standards explicitly.
- Most comments on perceived disadvantages focus on implementation, rather than the standards themselves.
- Many respondents agree that surgeons should undertake only those cases for which they have the appropriate skills and that centres and surgeons must acknowledge their limits
- Some respondents advocate mandated sub-specialisation, with each centre having its own specialism. This is considered to:
  - allow surgeons to develop their knowledge and expertise, helping to ensure patient safety
  - allow patients to be assessed only by surgeons who have the necessary specialist knowledge
  - enable efficient allocation of resources.

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Subspecialisation 2

The perceived **advantages** of the proposals include:

- Surgeons gain wide knowledge of the disease allowing them to respond to any unexpected complications during surgery
- Helps compliance with on-call requirements
- Help provider financial stability as simple treatments help offset the losses centres make from highly complex procedures
- Staff avoid the stress and emotional drain from overexposure to complex cases
- Consistent and high quality across all centres as the proposed approach would prevent the creation of a two-tier system
- Too much sub-specialisation is seen as stifling new developments and innovation
- Supports patients' choice.

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Service interdependencies and co-location 1

- The majority respondents **support** the proposed standards, some with reservations.
- Few respondents **oppose** the proposed standards explicitly.
- Some respondents query the evidence base for the proposals.
- The proposed standards are seen as patient-centred, giving CHD patients with multiple morbidities access to a wide range of expertise.
- Respondents make a range of alternative suggestions for the co-location of different services.

Service interdependencies and co-location 2

- Perceived **advantages** of the proposals are:
  - Quality of care and improved patient safety
  - Positive patient experience
  - Efficient allocation of human and financial resources
  - Knowledge transfer and communication

- Many express **concerns** about the implementation of the proposals.
  - The cost and time-scale for implementation and
  - The potential for co-location requirements to lead to closures

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What matters most to respondents?

1. **Quality and consistency of patient-centred care** including patient safety, experience and choice, good communication, improving mortality rates and support for patients
2. **Transport/travel** in particular the difficulties of travelling for treatment and the need for easy and fair access to CHD services,
3. **Standard of staffing** including the size, specialisms and skills of teams and recruitment, training and working conditions
4. **Funding and resources** to ensure the specifications are achievable. A level playing field is seen as important.
5. **Support for existing CHD units**, particularly that those known to produce great outcomes, are supported and perhaps expanded

Respondents also referred to the application of the networking model; monitoring of standards to ensure compliance, transition, fetal diagnosis, and interdependencies.

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Making it happen

- Many respondents express support for the specific approaches proposed, describing them as ‘appropriate’, ‘professional’, ‘comprehensive’ or ‘satisfactory’.
- Respondents specifically **support** the use of:
  - quality dashboard
  - peer review
  - commissioning.
- **Concerns** include the cost of implementation, whether a rigid or flexible approach should be taken to putting the standards in place, and how to ensure consistent quality of care across centres in the long term.

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Other standards

- The few respondents who comment on sections of the consultation document which are not the subject of a specific question agree broadly with the proposals
- Respondents identify areas which they see as lacking from the draft standards or feel need to be given greater consideration:
  - **Transplantation**: the majority of those mentioning transplant services express disappointment that the current review does not include transplant services.
  - **Learning disabilities**: respondents think that CHD patients with learning disabilities, need to be cared for and supported by staff with the appropriate training and skills.
  - **The role of primary care:** one respondent notes that role of primary care not been mentioned in the draft standards.
  - **Paediatric Intensive Care Units (PICU):** some respondents feel there is too little detail on this.
  - **Psychological impact of CHD:** some respondents think there is insufficient emphasis on the psychological impact of CHD.

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Consultation 1

- Many respondents praise NHS England for giving them the opportunity to participate in a consultation that is viewed by many as a great outline of plans to ensure high quality CHD care
- Some respondents challenge the way the review has been conducted and make some negative comments regarding the material of the consultation document.

Support for the consultation

- Many respondents show strong support for the consultation which they believe will contribute to securing the best outcomes for patients
- There is widespread acknowledgement of the amount of time and energy devoted by NHS England in the production of detailed standards.
- The consultation is praised for the way it has been conducted - honestly and openly with a transparent process from the start.
- Some congratulate the NHS on improving their processes to make this current review much more comprehensive and patient centred.
- Respondents make positive comments on the consultation workshops. These are seen as an example of good public engagement.

Consultation 2

Concerns about the consultation

- Several respondents believe NHS England should be spending their money on enhancing care, not producing consultations.
- There is a concern for the way the consultation will impact upon staff.
- Some respondents believe NHS England is using assumptions about future patient demand that are not based on enough evidence.
- Some worry that patients have not been fully involved in developing the new standards, and that decisions are likely to be made regardless of their input.
- Some question the purpose and motivations of the review.
- Some say there was insufficient awareness of the consultation, and suggest that many potential participants did not know it was happening.
- Some respondents found the content of the consultation document unclear or too long and not user-friendly.
- Some consider that the document was not comprehensive enough and did not provide enough information about what will happen in situations of non-compliance.

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What happens next

- **Standards**: consider the NHS England Response then decision making
- **Delivery models**: work with providers
- **Commissioning approach**: work with specialised commissioning colleagues and CCGs
- **Early diagnosis**
- **Better information**

Decision making

CAP
- Recommends any changes needed

TAFG
- Approves revised standards / specification entering assurance process

Assure
- Specialised commissioning assurance
- *Equalities; Engagement; Governance; Affordability; Strategic Fit*

Board
- Considers whole review
- Makes final decisions

Timetable: 2015/16

2015-16

April – September 2015

Deliver review objectives

Agree standards

Co-design commissioning model

October 2015 – March 2016

Procurement

Specialised commissioning; finance; comms & engagement; analytics

April 2016 onwards

Live

Contract & performance management

Transition from review to SpecCom

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Questions?