

Feedback from advisory / engagement groups

Introduction

The new congenital heart disease (CHD) review team held three meetings with:

- Patients and public chaired by Professor Peter Weissberg, Medical Director at the British Heart Foundation on 12 November 2013 to which a range of national, regional and local charities were invited;
- Providers chaired by Chris Hopson, Chief Executive of the Foundation Trust Network on 19 November 2013 to which Chief Executives (or their nominees) from all providers of CHD services were invited; and
- Clinicians chaired by Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital on 22 November 2013 to which clinicians from all providers of CHD services as well as representatives of other linked specialties were invited.

The purpose of the meetings was to provide an opportunity for the new review team to update everyone on its work (summarised in John Holden's weekly blogs) and to have an open discussion about work to date and to hear from the groups what they felt about the work to date, what was going well and not so well and what needed still to be considered as part of the new review. The meetings were well attended – a list of those who attended each is attached to the individual notes of the meetings.

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John Holden welcomed participants to each meeting and emphasised the importance of their contribution to on-going thinking. He gave an update on the review but emphasised that it should not contain surprises/new material. He noted that the aim was to build on work done to date particularly in those areas that were controversial or perhaps not fully worked through in the previous work. He identified the different strands of work:

- alignment of three different sets of standards dealing with any ambiguity and ensuring that they reflect the model of optimum care;
- analysis using latest data focusing in the first instance on specialist inpatient care and later on other aspects of the service and other interdependent services;
- using the analysis to enable modelling of functions and form to meet capacity requirements;

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- commissioning and change model – looking at how NHS England will commission for change ensuring that service specifications translate into practical improvements for patients;
- making sure information is provided that is understandable to all and is timely; and
- early diagnosis that will lead to better and less variable ante-natal detection rates.

John Holden emphasised that the new CHD review team are committed to making the process as open as possible. He also noted that the current timescale for this work is heroic given a number of factors including local government elections, and that the team will let people know if there are changes.

Key issues

There was lively discussion in all three groups. Some issues emerged in all three groups, some in two and some only in one. These are identified below – a fuller account of the points made is contained in the accompanying notes of the individual meetings.

Common issues that came up in all groups

- A desire to work more closely with the other groups and to be kept up to date with new developments and any changes to the timeline.
- An unease with the term ‘engagement group’ and a request for another title.
- Support for the scope of the review and bringing standards together across the whole pathway (not just surgery).
- A commitment to planning, developing and commissioning a world class service that is safe, sustainable and future proof and puts the child first, but recognition in the Clinician Group that this might come in steps – not all at once.
- A request to move quickly to ensure that services are not damaged in the meantime or in the words of the Provider Group risk ‘chronic stagnation’.
- A need to look at how training and workforce planning – in particular, the Clinicians’ Group noted that appointing new CHD surgeons would be a great achievement because there are not trainees coming through and there are similar concerns about the nursing workforce. They also noted that there are pressures on junior staffing and training particularly in the smaller units. The Provider Group noted that these elements needed to be planned and costed in.
- A need to consider how services are provided at the moment and how the work of different centres might change in the future (there was discussion around occasional practice and sub-specialisation in the Patient and Public Group and whether it would

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be possible that not all centres will do the same work in the future in the Provider Group).

- A need to have clarity when setting standards about what number of clinicians is required to ensure safe cover and a resilient service (there was also discussion in the Patient and Public Group around number of cases and case mix).
- Effective communications from the new review team – the Clinicians Group asked the team to explain simply and persuasively the case for change while the Patient and Public Group made a strong case for wider communication in a compelling and understandable format to all groups including in particular service users, children and young people and Black, Asian and Minority Ethnic (BAME) groups.
- The need to recognise co-dependencies in service provision - services need to work together when providing different elements of care. The Patient and Public Group noted that services need to be joined up and that this may be lifelong to care for those with different needs.
- Funding and the need to identify costs and where funding is going to come from.

Common issues that came up in two groups

- Support for the pathway to include prenatal care and the focus on improving early detection and diagnosis came up in the Patient and Public and Clinician Groups.
- A need to ensure that we do not reinvent the wheel. The Provider Group noted that many of the principles are the same as *Safe and Sustainable* and the Clinician Group supported not going back to square one on standards which are largely uncontroversial.
- Support for developing outcome measures that go beyond mortality and include morbidity. The Clinician Group were keen to be involved in the development of outcome measures and the Patient and Public Group considered among others patient experience
- Co-location – in the Patient and Public Group there was discussion about when it is essential and when it is desirable. The Clinician Group recognised the benefits particularly from an anaesthetic perspective but also the sensitivities involved
- Specialisation and referrals – in the Patient and Public Group there was discussion about the merits of hospitals making referrals where appropriate. There was no agreement in the Clinician Group as to whether there should be specialisation between centres
- Learning from others – in relation to clinical networks (Patient and Public) and to practice (Clinician)

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Issues discussed by one group only

- Transition from children's to adult services (Patient and Public)
- Not having a blame culture in the case of adverse incidents but learning (Patient and Public).
- Reasonable and safe distances to travel to service and associated costs perversity of any proposals which would require patients to travel past a congenital centre to be treated elsewhere – i.e. not for good clinical reasons, but simply to 'make up the numbers' (Patient and Public).
- Need to expand data collection (Patient and Public).
- Ensuring effective discharge and ongoing care (Patient and Public).
- Conflicts of interest and vested interests and the need to be aware of what people do and where they come from (Clinician).

Conclusion

The meetings provided an opportunity to discuss in detail some of the key issues. As noted above, a number of themes were common discussion points for all groups. The new review team is considering all the points made and will incorporate them into its thinking as it takes work forward. The team will continue to hold meetings with the groups and will consider further ways in which we can improve our communication generally, and in particular our working with children and young people and BAME groups.