Independent Review of Children's Cardiac Services in Bristol Revised Terms of Engagement (May 2015)

Introduction

1. The Bristol Review is an independent review of the safety and quality of children's cardiac services in Bristol from March 2010 to the date of the Review. It was established by the NHS Medical Director, Professor Sir Bruce Keogh, and is chaired by Eleanor Grey QC. The Review's work is governed by its Terms of Reference. It will examine the services provided by the University Hospitals Bristol NHS Foundation Trust (the Trust) in Bristol and at outreach clinics in the South West and South Wales.

Contributing to the Review

- 2. Anyone who has experience of children's cardiac services in Bristol from March 2010 to date is encouraged to contact the Review. This includes families and carers, older children and young people, staff and former staff of the Trust, and other professionals and managers involved in the provision of the services. The Review will be greatly helped by hearing from anyone who has used the services or been involved in delivering them, whether their experiences were positive, negative, or a mixture of both.
- 3. Contact can be made with the Review:

• by email: enquiries@thebristolreview.co.uk

• through the Review's website: www.thebristolreview.co.uk

• by telephone: **0300 0134 754** □ by post:

The Bristol Review 5th Floor, One Temple Quay Temple Back East Bristol BS1 6DZ

4. The Review is adopting a collaborative approach with the aim of exploring concerns and indicating where opportunities for improvement in children's cardiac services and care may lie. As explained in its Terms of Reference, the Review does not have legal powers to compel witnesses and obtain documents, but works in the expectation that parents, members of staff of the Trust and others are willing to take part. The Review expects cooperation from staff and other healthcare organisations in line with their professional and employment responsibilities, and

considers that these responsibilities extend to anyone receiving, or who will receive, an NHS pension.

Period of time covered by the Review

- 5. The Review will primarily examine events from March 2010, although it recognises that events leading up to that date may also be relevant. Information about earlier events can be submitted, or the Review may ask for it.
- 6. The Review will generally consider events up to July 2014, the date at which the Review started its work. The Review will decide whether information provided to it is relevant to the Terms of Reference.

Principles for Receiving Information

- 7. The Review may receive information in a number of ways, including written documents, accounts written with the assistance of its legal advisors or staff, or by meetings held with the Review's Chair.
- 8. There will be no public hearings.
- 9. Written information is just as important to the Review as oral information. There may be circumstances where a person taking part in the Review is asked to provide a written account when a meeting with the Review is not necessary. When full and complete information has been sent, the Review may simply ask the participant for confirmation.
- 10. If, from the information sent in, it seems that more detailed information could help the Review or the writer wishes to add more, participants may be asked to provide a fuller written statement. If this happens, a member of the Review's legal team will be in touch to help them to do this.
- 11. A meeting with the Review's Chair (Eleanor Grey QC) will be arranged where this appears helpful to the work of the Review. The meeting will be arranged, as far as is possible, for the convenience of the person or persons attending the meeting. It will take place in Bristol, or at another agreed venue.
- 12. Before any meeting with the Review, it would be helpful if the person attending the meeting could send to the Secretariat:
 - a. A short written account of the main points that they wish to raise (there is a template on the website which may help); and
 - b. Copies (not originals) of any documents which the participant would like to be read before the meeting.
- 13. The participant can also bring to the meeting any further documents which they think are relevant, but which were not sent earlier.

- 14. If the Chair proposes to have anybody else at the meeting (such as experts assisting the Review), participants will be told in advance and asked for their consent. If an expert is present at a meeting, the Chair may invite them to ask questions.
- 15. The Review may decide that it is important to examine further documentation, including clinical records. Where required, this will be discussed with the person taking part in the Review, who will be given time to decide whether to agree or not. The Review's experts will on occasion be asked to consider any relevant further documentation including clinical records and where necessary the participant will be asked if they agree to this.

Confidentiality and Information Sharing

- 16. Any information received by the Review, including personal accounts and the information discussed in meetings with the Review's Chair, will be held securely and in confidence subject to the possible circumstances outlined in paragraphs 17 19 and 36 41 below. However:
 - a. An independent note-taker may be present during a meeting, to help ensure that all the information given is available later for analysis. Alternatively, an audio recording may be made and later transcribed into a note. In either case, the person or persons who attended the meeting will be given an opportunity to review the note, and to correct it and add additional information if they wish;
 - b. Written information and evidence received, including the note of any interview, will be made available to Professor Sir Ian Kennedy (Consultant Advisor to the Review), to any other independent expert appointed by the Review, and to other members of the Review team (including Secretariat staff and the Review's legal advisors). The purpose of making information available in this way is to enable the Review to carry out its work;
 - c. Information from accounts and documents may be used to question other participants, for example information provided by parents may be used to question staff of the University Hospitals Bristol NHS Foundation Trust. This will be done in a way that does not identify the original participant or patient concerned, unless they have agreed to be identified in advance, or the patient (or those speaking on a patient's behalf, such as parents) agree that the patient may be identified.
- 17. Whilst the precise content of a participant's documents, account or any note of a meeting will be treated as confidential information by the Review, as outlined above, the Review's Report will draw on the information gathered from all these sources. It will do this both in describing factual events, and in supporting the Report's findings. However, if direct quotations are used, even anonymously, the source and any individuals mentioned will have the opportunity to review the relevant part of the draft Report before publication, to check for factual accuracy.

- 18. If serious allegations are made about an individual, this information may be passed to the police, or to any employer as appropriate, or to any relevant regulatory or statutory body (such as the General Medical Council or the Nursing and Midwifery Council), as the Review sees fit or as required by law. The Review may also disclose information to the Coroner if the Coroner is in the course of investigating any death in respect of which the Review holds information of significance, or to safeguarding authorities if there are serious concerns about the wellbeing of a child or vulnerable adult.
- 19. The names of all those who have participated in the Review will be listed in a confidential appendix to the Review's Report. The Review does not anticipate publishing the names of patients, parents, carers or junior members of staff in any Report, unless they have given prior consent. However, the names of senior managers and senior staff at the Trust or other NHS body may be considered for publication, if relevant.

Support for Participants

- 20. Anyone asked to attend a meeting may be supported during the meeting by a friend, relative or colleague, or, in the case of staff, a trade union or other representative. As the Review is not part of a legal process, participants in the Review will not be legally represented, and the Review will not deal with anyone other than the person taking part in the Review. Similarly, a trade union or other representative attends as a supporter or friend, and not in a representative capacity. Staff selecting a colleague as their supporter are encouraged not to choose a person in a direct line management relationship with them.
- 21. The Review's Secretary should be informed when the meeting arrangements are being made if a supporter will be attending, and given their name. The friend or supporter will accompany those attending the meeting and may be present in the room during the meeting, but will not take part.

Evidence from Staff and Other Professionals

- 22. Trust staff and other professionals and managers involved in the provision of the children's cardiac service in Bristol are encouraged to contact the Review. Both current and former staff are encouraged to take part in the Review. It is expected that NHS employers will make reasonable arrangements for staff to attend meetings, including cover for their clinical commitments.
- 23. In addition, the Review may write to the Trust and other healthcare bodies, seeking information from current and former staff (whether in writing or via a meeting or both). Where the Review asks for information, it will, so far as is reasonably possible and in advance of any meeting or for the purpose of producing a written account:
 - a. Identify the topic or topics about which it is seeking information; and

- b. Draw attention to relevant documents.
- 24. The Review will liaise and co-operate, so far as possible, with the Trust and other healthcare bodies to ensure that the most suitable staff and professionals are invited to provide information. It will take account of professional and other commitments when scheduling meetings.

Further Meetings

25. If new matters come to light after a meeting with the Review Chair, or after an account has been prepared, it may be necessary to call a further meeting or to ask for further comments in writing.

Attendance at meetings

- 26. Information about the practical arrangements for a meeting will be sent in advance.
- 27. If a person attending a meeting has any particular needs (as a result of ill health or disability, for example) which may affect the arrangements for the meeting, please let the Review's Secretariat know in advance.
- 28. Anyone attending a meeting is able to attend for a brief introduction by the Secretariat and will be given the opportunity to familiarize themselves with the meeting room.
- 29. All those attending a meeting will be asked to switch off their mobile phone, laptop computer, tablet, camera or any recording equipment while the meeting is taking place. Such equipment may be given to the Secretariat for safekeeping while the meeting is taking place. Because the Review will arrange for a note of the meeting to be produced which will be checked and can be amended by the person being interviewed, there is no need for any other recordings and these will not be permitted.
- 30. Appropriate refreshments will be provided for those attending meetings and any supporter who accompanies them.

Expenses

- 31. It is expected that staff of the Trust and their supporter, and any other professionals and managers asked to attend a meeting will have reasonable expenses incurred as a direct result of attending the meeting met by their employer, in accordance with their employer's expenses policy.
- 32. Parents or carers, older children and young people, and their supporter, asked to attend a meeting may claim reimbursement of reasonable travel expenses, in line

with the Review's policy, which is published on the website. A claim form will be provided on the day of the meeting. Receipts will be required for all claims.

Possible Warning Letters

- 33. The Review team will send a warning letter to any person who may be criticised in the Review's final report. If the person wishes to respond to the points in the letter, he or she must do so in writing within 14 working days of receiving it, unless a time extension is agreed with the Review.
- 34. A warning letter will set out the criticism or proposed criticism and its basis. No significant or explicit criticism of a person will be included in the Report unless the person has been sent a warning letter and has been given a reasonable opportunity to respond and the Chair of the Review has had an opportunity to consider the representations made.
- 35. The existence and contents of any warning letter must be treated as confidential, both by the Review team and by the letter's recipient. The recipient and any advisor owes that obligation to the Review Team. This obligation ends when the Report is published. Further information on the warning letter process will be provided in the Review's website closer to the publication date of the Review.

Disclosure requests

- 36. Subject to the operation of the Freedom of Information Act 2000 and any other obligation to disclose information required by law, the notes of meetings, documents and any written accounts will remain confidential, except as described above.
- 37. If any other person asks for access to a participant's account, to notes of interview, or to documentary evidence submitted to the Review, whether under the Freedom of Information Act 2000 (FOIA) or otherwise, the Review will seek legal advice on whether or not it is subject to disclosure obligations under FOIA. This is because these obligations are imposed only on "public authorities".
- 38. The Review would generally regard documents it holds as exempt from disclosure by virtue of the confidential setting in which the information was given, and also because the content would be likely to be 'personal data' of the person participating in the Review and others, under the Data Protection Act 1998. In addition, when patients are interviewed, or the care of a living patient is discussed, information about their care or treatment will amount to 'sensitive' personal data under the same Act. As a result, and subject to any legal advice on individual cases, the Review believes that it would generally be in the public interest to resist disclosure requests. However, if it appears that an exception should be considered, the individuals concerned would be asked for their views.
- 39. Please note that any decision by the Review on non-disclosure will be subject to rights of appeal and to decisions by the Information Commissioner, courts or

tribunals service. Their decisions concerning the application of FOIA or the Data Protection Act will bind the Review.

- 40. Each individual request will be considered on its own merits at the time when the request is made.
- 41. There may be circumstances where the Review receives a Court or Tribunal Order ordering disclosure of statements or documents. For example, it is possible that information might be sought from the Review by the police, or as a result of civil proceedings, or because of action taken by regulatory authorities such as the General Medical Council or Nursing and Midwifery Council. In those circumstances the Review will be obliged to disclose that information to comply with any court order made.

Declaration

I/We have received a copy of, read and understood the Terms of Engagement set out above.

We understand that the information we have supplied to the Review will be treated on a confidential basis, subject to the exceptions required by law outlined above.

 (signature)
 (name, print in capital letters)
 (signature)
 (name, print in capital letters)
 (date)

Note:

The Terms of Engagement are to be sent to each person taking part in the Review, to ensure that all participants clearly understand how their information will be managed.