

# Consultation on Future Arrangements for access to Cord Blood Bank Services in Northern Ireland

March 2015

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## 1. CONSULTATION SUMMARY DOCUMENT

### Consultation on Belfast Cord Blood Bank

#### Background

Cord blood is blood that remains in the placenta and umbilical cord after birth. It is rich in stem cells and can be used to treat some blood cancers and rare blood disorders such as Fanconi Anaemia. Cord blood is one way of providing patients with stem cells for treating these conditions. Other sources include bone marrow and “ordinary” blood which is specially treated.

Cord blood that is used in the treatment of patients comes from two main sources:

1. **Public Cord Blood Banks:** These banks (of which there are two in the UK) hold stocks of cord blood taken from maternal volunteers’ cords at the time of delivery. Public cord blood banks place the details of their cord blood stock on an international register. This register is searched by doctors treating patients who require cord blood treatment to find samples which are the best possible match for the patient.
2. **Directed donations:** These are collected from the umbilical cord of new born siblings of children with certain blood disorders. They are arranged by the specialist doctor treating the child. The idea is that cord blood from a sibling is more likely to be a good “match” to the affected child. Often this sort of donation is collected “just in case” it is needed in the future. Often in these instances the child has responded well to drug treatment and the cord blood is stored just in case it would ever be of use in the event of a relapse.

If a child from Northern Ireland is going to have treatment with either a donation from a public cord bank or a sibling, the actual treatment will take place in a highly specialist unit outside Northern Ireland. This is because the treatment is so specialised only a small number of hospitals in the UK can carry it out.

### **Belfast Public Cord Blood Bank**

For the last ten years, Northern Ireland has had a public cord blood bank located in the Northern Ireland Blood Transfusion Service (NIBTS). Staff from the Belfast Cord Blood Bank (BCBB) arrange collection of blood from the umbilical cord from some volunteers giving birth in Belfast Health and Social Care Trust. If this is suitable it is processed and stored in a freezer in the BCBB. The details are put on an international register. This international register is searched for the best match when doctors want to treat a patient with cord blood.

Demand for the cord blood stored in the Belfast Cord Blood Bank (BCBB) has been very low. Only two of the stored donations made during the ten year period of operation have been selected for use. Neither of the donations were used on patients from Northern Ireland.

There are two main reasons demand has been low. The first is that the genetic makeup of the population of Northern Ireland is very similar to populations in other parts of Europe and the USA. This means that very large banks in other countries have many more samples, making it more likely to secure a match for the patient. The second reason for the low demand is that the size and scale of the BCBB means that the methods employed in the collection and processing have not been able to keep pace with the very large

banks in other countries. This means that many of the samples stored in Belfast are not of the required standard and are very unlikely to be used.

Changes in laboratory accreditation standards underwritten by the UK Stem Cell Forum (UKSCSF) mean that to continue to operate the Belfast Cord Blood Bank would require significant additional investment, bringing the annual cost of running the service to around £600,000.

Even with the additional investment, the genetic make-up of the population in Northern Ireland is such that the bank would end up collecting and storing samples of cord blood which is readily available from other banks therefore conferring no advantage either locally or internationally.

**For the reasons outlined above, we do not believe that this represents a good use of health service money and are planning to cease activity at the Belfast Cord Blood Bank. This means that volunteers giving birth in Belfast Maternity Units will no longer be invited to donate cord blood to the Belfast Cord Blood Bank.**

**The samples currently held in BCBB will be offered to the NHS cord blood bank. It is likely that only a small number will be suitable for transfer to the UK bank. The other samples which will be disposed of in line with NIBTS procedures.**

### **Directed cord blood donations from siblings**

There are currently around 70 cord blood samples stored in the Northern Ireland Blood Transfusion Service which are for use in named patients. These are the sibling donations described above. When the Public Blood Bank ceases operation, it will no longer be possible to store these samples in the

Northern Ireland Blood Transfusion Service but other arrangements can be put in place.

Cord bloods that may be used in the future for the named person for whom they were donated will be carefully transported to the National Health Service Blood and Transplant's (NHSBT) laboratory in England for continued storage.

The NHSBT is the national specialist authority who specialise in this field. Their laboratories hold the required accreditations to look after these donations.

If a stored sample is required to be used to treat the patient for whom it was collected, it will be sent to the treating hospital. As described above, the treatments are carried out in England so transport from NHSBT laboratories will be straightforward.

### **Collecting cord blood for use in siblings**

When the specialist doctor treating a child asks that cord blood should be taken from the new born sibling of a child with a blood condition, special arrangements are made. These arrangements are designed to make sure the process runs as smoothly as possible. Mothers are advised to have their baby in Belfast, usually by planned delivery. This means staff who know how to take a good cord blood sample are on hand at the birth.

At present staff in NIBTS who work for the public cord bank oversee this process. In the future the arrangement will be slightly different as the BCBB will no longer be operating. Ensuring that sibling donations can be obtained

locally is of paramount importance to the HSCB and arrangements are being put in place to secure this.

Mothers will still be advised to have their babies in Belfast by planned delivery. Nominated staff from the Belfast maternity unit will be responsible for the collection of the cord blood. Belfast Trust will have received notification of the planned cord blood donation well in advance of the delivery and an individual plan put in place to make sure the collection goes smoothly. Specialist staff from NHSBT will be available to support Belfast staff in this process. These mirror the current arrangements across England.

Once the sample has been taken it will be transported for processing and storage to NHSBT. Cord blood can be stored at room temperature for 48 hours. This gives plenty of time for transport to the specialist laboratory in NHSBT.

**The purpose of this consultative exercise is to inform the population in Northern Ireland of this change and to give people a chance to seek clarification and to raise issues they feel require further clarification.**

## **2 Responding to this consultation**

You can respond to this consultation by e-mail or letter.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises. If you require the documents in another format or language please use the contact details below.

Responses should be sent to:

E-mail: **BBCB@hscni.net**

Written: Consultation on Future Arrangements for access to Cord Blood  
Bank Services in Northern Ireland  
Commissioning Directorate  
Health and Social Care Board  
12-22 Linenhall Street  
Belfast BT2 8BS

Telephone: 0300 555 0115

**Responses must be received no later than 5.00pm on Friday 22 May 2015.**

The questionnaire can be completed by an individual health or social care professional, stakeholder or member of the public; or it can be completed on behalf of a group or organisation.

### 3 Your views - The Consultation Response Questionnaire

Please tell us if you are responding on your own behalf or for an organisation by placing a tick in the appropriate box:

I am responding: as an individual   
 on behalf of an organisation   
 (please tick a box)

Name:	
Job Title:	
Organisation:	
Address:	
Telephone:	
Textphone:	
Fax:	
E-mail:	

May we contact you should clarification be required on your response?

Yes  or No  (please tick a box)

Recommendation	Agree	Disagree	Comments
<ul style="list-style-type: none"> <li>• Cease the collection of all unrelated blood cord donations</li> </ul>			
<ul style="list-style-type: none"> <li>• Establish arrangements for the transfer and/or disposal of all current unrelated blood cord bank donations</li> </ul>			
<ul style="list-style-type: none"> <li>• Establish a formal mechanism through NHS Blood and Transplant to establish fully accredited arrangements for collection, storage and access for directed donations</li> </ul>			

Any Further Comments:

**Equality implications**

1. This proposal was screened for equality and human rights considerations. A full copy of the screening exercise is included as part of this consultation. Please let us know if you are satisfied with the content of the screening exercise and outcomes. If not we would be interested in your reasons for this.

Yes  No

Comments:

2. If you have any suggestions on how the proposals could better promote equality of opportunity, human rights or good relations please give details.

Yes  No

Comments:

3. If you have any additional evidence to support the equality and human rights screening activity give details below.

Yes

No

Comments:

**Responses must be received no later than 5.00pm on Friday 22 May 2015.**

**Thank you for your comments.**

#### 4 Appendix 1 - Freedom of Information Act 2000 – confidentiality of consultations

The Health and Social Care Board will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Health and Social Care Board can only refuse to disclose information in exceptional circumstances. Before you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Health and Social Care Board in this case. This right of access to information includes information provided in response to a consultation. The Health and Social Care Board cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

- the Health and Social care Board should only accept information from third parties in confidence if it is necessary to obtain that information in

connection with the exercise of any of the Health and Social care Board functions and it would not otherwise be provided;

- the Health and Social Care Board should not agree to hold information received from third parties “in confidence” which is not confidential in nature;
- acceptance by the Health and Social Care Board of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner.

For further information about confidentiality of responses please contact the Information Commissioner’s Office (or see web site at:

<http://www.informationcommissioner.gov.uk/>).