

20183101 Standing down of DHSC Infected Blood Reference Group – January  
progress report  
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Standing down of DHSC Reference Group	
Name of core programme/ supporting work stream	Infected Blood Scheme Reform
Lead organisation	DHSC
SRO	Nick Adkin/Emma Reed
Programme leads	Donna McInnes Ginny Belson
Oversight group/ board	Transition Board
Aim of programme	Standing down of the Infected Blood Reference Group
Objectives	<ol style="list-style-type: none"> <li>1. To ensure a considered and managed closure of DHSC's Infected Blood Reference Group</li> <li>2. <b>Brief background note:</b> The Reference group was set up by the DHSC policy team to support and advise on the development and roll out of the new infected blood support scheme. The Reference group is made up of a range of expert medical reps and stakeholder groups representing beneficiary groups; <b>see Annexes A and B for more detail.</b></li> </ol>
Delivery partners	Reference group members and stakeholder organisations NHS BSA, the administrator of the EIBSS
Key stakeholders	Beneficiaries, reference group members, APPG
Resources	DH: 0.1 x DD, 0.5 x G7, 0.2 x SEO
Outcomes required	<ul style="list-style-type: none"> <li>• Agreement by TB that the current Reference group should be stood down</li> <li>• Agreement by NHS BSA to set up a NHSBSA are setting up a beneficiary led group for transparency and help them with the running of EIBSS</li> </ul>
Outcome measures	<ul style="list-style-type: none"> <li>• Scrutiny from MPs through oral PQs and correspondence</li> </ul>

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<b>Delivery confidence</b>	This month	G
	Last month	N/A
<b>Assessment of RAG rating</b>	DHSC policy team are agreed that this is the correct course of action as we are now in the final stages of implementation of the policy Reforms and have little we need to put to a group such as this.	

<b>Key deliverables</b>	<ul style="list-style-type: none"><li>• Managed closure of the DHSC coordinated reference group</li><li>• Ensure any functions of this group that are still needed are carried forward by NHS BSA</li></ul>
<b>Key milestones:</b>  <b>TB to agree closure of the Reference group</b> <b>Assurances that NHS BSA will take this area forward with a new advisory group</b> <b>Decision to be communicated to the members of the Reference group</b>	
<b>Milestone</b>	<b>Date</b>
TB to agree closure of the Reference group	31 <sup>st</sup> January 2018
Assurances that NHS BSA will take this area forward with a new advisory group	After 31 <sup>st</sup> January 2018
Decision to be communicated to the members of the Reference group	w/c 5th February 2018

<b>Progress last month</b>	<ul style="list-style-type: none"> <li>N/A The last meeting of the existing Reference Group took place on 23rd November 2017</li> </ul>
<b>Key activity next month</b>	<ul style="list-style-type: none"> <li>Provide support to NHS BSA in setting up their advisory group</li> </ul>
<b>Risks &amp; mitigation</b>	<p><b>Risk:</b> Stakeholders are concerned about the closure of the Reference group - reputational damage</p> <p><b>Mitigation:</b> Working with NHS BSA to ensure plans regarding their new advisory group will reassure stakeholders that there will still be an opportunity to be involved in consultation regarding the running of EIBSS</p>
<b>Issues</b>	The current DHSC Reference group is no longer needed to advise on operational matters regarding the EIBSS in the future as these issues mainly fall to NHS BSA

## **ANNEX A**

### **Background**

The Infected Blood Reference Group is an advisory Panel of relevant subject matter experts and other key interested individuals. The purpose of the Infected Blood Reference Group is to provide expert advice, insight and input to support and advise the Transition Board on developing the decisions following the outcomes of the *Infected Blood: Reform of Financial and other Support* consultation and the *Infected blood support: special category mechanism*. It has helped officials are to understand the impact of decisions that will inform progress of the implementation of a reformed payment support scheme leading to robust outcomes.

### **Remit**

The Panel was set up to adhere to the 7 principles of public life<sup>1</sup> to reflect their independence and not attend these meetings as representatives of their organisations. They will meet to:

- Provide a 'safe' space for members of the infected blood policy team to test early policy development to inform delivery of the work that shapes and drives implementation;
- To confidentially feed in the general views of key stakeholders and the affected community to help us to understand the priorities for delivering reforms and the impact any decisions made will have on these communities;
- Provide ad hoc advice, challenge and support as and when needed on specific issues to ensure a joined up approach on delivery;
- Share views and knowledge to help shape final policy/delivery decisions.

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<sup>1</sup> The 7 principles of public life are selflessness, integrity, objectivity, accountability, openness, honesty and leadership and these all apply to anyone who works as a public office-holder. They were first set out by Lord Nolan in 1995 and they are included in the Ministerial code.

**ANNEX B**

**INFECTED BLOOD REFERENCE GROUP – TERMS OF REFERENCE**

**Purpose**

The Infected Blood Reference Group is an advisory Panel of relevant subject matter experts and other key interested individuals. The purpose of the Infected Blood Reference Group is to provide expert advice, insight and input to support and advise the Transition Board on developing the decisions following the outcomes of the *Infected Blood: Reform of Financial and other Support* consultation. It will ensure officials are transparent and help them to understand the impact of decisions that will inform progress of the implementation of a reformed payment support scheme leading to robust outcomes.

**Remit**

The Panel will adhere to the 7 principles of public life<sup>2</sup> to reflect their independence and not attend these meetings as representatives of their organisations. They will meet to:

- Provide a 'safe' space for members of the infected blood policy team to test early policy development to inform delivery of the work that shapes and drives implementation;
- To confidentially feed in the general views of key stakeholders and the affected community to help us to understand the priorities for delivering reforms and the impact any decisions made will have on these communities;
- Provide ad hoc advice, challenge and support as and when needed on specific issues to ensure a joined up approach on delivery;
- Share views and knowledge to help shape final policy/delivery decisions.

**Expectation**

Members may have access to privileged information, as discussions could focus on areas of policy development and/or implementation that are not yet approved by Ministers and so not in the public domain. We expect members to respect the confidential nature of such discussions. It is understood and agreed by members of the group that such information shared during meetings and via correspondence must be kept confidential. Members of the Infected Blood Reference Group agree not to disclose the confidential information obtained through this group to anyone unless required to do so by the Chair.

**Membership**

The Membership of the Panel will comprise the following:

- a. **Chris Pond**, (Chair) Chairman of The Caxton Foundation
- b. **Steve Winyard**, (Deputy Chair) Independent
- c. **Jan Barlow**, CE, The Caxton Foundation
- d. **Charles Gore**, Chief Executive of The Hepatitis C Trust
- e. **Jeff Courtney**, Policy and Public Affairs Manager, The Haemophilia Society
- f. **Peter Stevens**, Chairman of The Eileen Trust & The Skipton Fund
- g. **Alasdair Murray**, Chairman of MFT
- h. **Professor Keith Palmer** – Clinical/DWP Expert
- i. **Professor Howard Thomas** - Hepatology Specialist
- j. **Siobhain Butterworth**, Trustee, Caxton Foundation

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- k. **Matthew Gregory**, Trustee, The McFarlane Trust
- l. **Margaret Kennedy**, Trustee, Caxton Foundation
- m. **GRO-A** Trustee, The McFarlane Trust
- n. **Ailsa Wight**, Deputy Director, Emergency preparedness and Health Protection Policy Directorate

### **Observers**

- a. Paul Bridges, Government Legal Department
- b. Joanna Musgrove, Government Legal Department

### **Relationship with other Committees**

The Group will provide an advisory function to support the Transition Board and respond to specific requests and challenges.

### **Timing**

The Reference group will provide advice and support to the Department of Health until the new Scheme Administrator is established and firmly embedded in a reformed system.

### **Timescale / Frequency of Meetings**

**Monthly or as needed** – although the group can agree off-line communications such as emails or other correspondence. It may be that specific expert advice is required and so only those qualified to provide advice will be able to input and therefore the entire group will not be required.