

**METHODOLOGY OF THE COLLECTIVE RESPONSE
ON BEHALF OF PAST AND PRESENT HAEMOPHILIA CENTRE STAFF IN
SCOTLAND ON TOPIC C5 SUBMITTED TO THE INQUIRY TEAM
ON 2 DECEMBER 2011**

TOPIC C5 –

C5a) The information given to patients (or their parents) about the risk of non A non B Hepatitis and the severity of the condition before their treatment with blood or blood products;

C5b) the tracing and testing of patients who might have been exposed to the virus through their treatment with blood or blood products; and

C5c) the information given to patients who might have been infected, or who were found to be infected, and their families.

To assist in the location, collation and provision of relevant information to the Penrose Inquiry Team, the Scottish Health Boards established the Haemophilia Directors Working Group (HDWG). The Group had its first meeting on 11 May 2010 and has met regularly thereafter throughout the duration of the Inquiry. The meetings were regularly attended by Professor Ludlam (former Haemophilia Director at ERI), Professor Lowe (former Haemophilia Director at GRI), Professor Forbes (former Haemophilia Director at GRI). These doctors formed the 'core' of the HDWG. Due to clinical commitments, many current Haemophilia Directors were unable to attend the meetings of the HDWG, however were kept abreast of discussions and developments by way of email exchange. These included:-

Dr Henry Watson – Aberdeen Royal Infirmary

Dr Elizabeth Chalmers – Yorkhill

Dr Brenda Gibson - Yorkhill

Dr Campbell Tait – Glasgow Royal Infirmary

Dr Ron Kerr – Ninewells Hospital

When considering the list of Topics to be addressed by the Inquiry Team, the HDWG formed the view that it would be of assistance to the Inquiry Team if they were to

prepare a paper collectively addressing Topic C5. The Haemophilia Directors had met regularly *during the period relevant to the Inquiry*, at meetings of the UKHCDO and Scotland and Northern Ireland Haemophilia Directors, to discuss amongst other things developments in practice, current issues and policy. Accordingly, they felt able to offer to the Inquiry Team a '*collective view*' on the matters to be considered in relation to Topic C5. As noted in the Collective Response, Haemophilia Directors in Scotland had been asked by the previous Scottish Government Inquiry into hepatitis C to collectively recall information given to patients with haemophilia about hepatitis. This decision to prepare this paper was taken during the summer of 2011, prior to the Inquiry Team advising which Haemophilia Directors they would be inviting to attend the Inquiry to give oral evidence on this Topic.

Professor Ludlam identified that he had, in connection with a separate matter, prepared a document in draft which included much of the information that was considered by the HDWG to be relevant Topic C5. Professor Lowe and Dr Brenda Gibson added to this their recollections of practice by themselves and their predecessors and colleagues, at Glasgow Royal Infirmary and Yorkhill Hospital respectively. This document formed the first draft of what came to be referred to as the '*Collective Response*'.

This first draft of the Collective Response was circulated to past and present Haemophilia Centre medical and nursing staff who could be located. The document was circulated with a covering letter dated 14 September 2011 (Appendix 1). The list of recipients of that document is set out in Appendix 2. It was subsequently realised that Mrs Patricia Wilkie had not been involved in giving information to patients on hepatitis and hence her name was deleted from the final version.

A number of comments were received in response to the letter of 14 September which saw amendments being made to incorporate the same into the original draft.

Amendments made and further appendices added, the Collective Response was circulated again to the original recipients by way of letter dated 16 November 2011 (Appendix 3). The document at this stage was sent to Mrs Billie Reynolds, former Haemophilia Sister at Edinburgh Royal Infirmary, who had been omitted from the original circulation list. A copy of the letter of 16 November to Mrs Reynolds is attached (Appendix 4). Mrs Reynolds made contact with the Central legal Office

upon receipt of the letter, and followed up the telephone conversation by way of email dated 23 November 2011 (Appendix 5).

Having incorporated the amendments the final draft of the Collective Response document was circulated by way of email on 29 November 2011 (Appendix 6). A deadline of 5.00pm, Thursday 1 December was set for comments to be received. The timescale set reflected the fact that the Inquiry was originally scheduled to commence hearing evidence on Topic C5 on Thursday 8 December. It was considered important that the Inquiry have the document in sufficient time, prior to the commencement of the evidence on that Topic. In response to the e-mail of 29 November 2011 further comments were received by way of email from Billie Reynolds dated 1 December 2011 (Appendix 7).

Due to the time constraints in place to allow the document to be submitted timeously to the Inquiry Team, further dialogue with Mrs Reynolds could not be entered into at that time. Accordingly, the name of Billie Reynolds was deleted from the list of recipients and hence endorsees when the document was submitted to the Inquiry Team. It was not considered appropriate that her name remain on the document when comments had been made by her which, at the time of submission, had not been the subject of discussion with the HDWG and where appropriate incorporated into the document.

The Collective Response was then submitted to the Inquiry Team by way of e-mail on 2 December 2011.

APPENDIX 1

Anderson House
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Bonnington Road
Edinburgh EH6 5JR
DX No: ED154

Telephone 0131 275 7800
www.clo.scot.nhs.uk

STRICTLY PRIVATE & CONFIDENTIAL

Date 14 September 2011
Your Ref
Our Ref CLO/9 TAT/JB
Direct Line
Fax No
Email

Dear

THE PENROSE INQUIRY

As most of you will be aware there is currently an ongoing Public Inquiry, The Penrose Inquiry, into the circumstances in which Patients became infected with HIV and/or Hep C as a result of treatment by the NHS in Scotland with blood or blood products. I enclose a copy of the Terms of Reference of the Inquiry together with the more detailed list of Topics to be considered by the Inquiry. More information pertaining to the Inquiry can be found at its website www.penroseinquiry.org.uk.

I am one of 3 Solicitors within the NSS Central Legal Office dedicated to representing the interests of the Scottish Health Boards before the Inquiry. It is likely that I have been in contact with many of you before in relation to the Inquiry.

The Inquiry is currently hearing oral evidence from witnesses. In December of this year the Inquiry will hear oral evidence in relation to Topic C5. This topic is stated in the following terms:

C5a) The information given to patients (or their parents) about the risk of non A non B Hepatitis and the severity of the condition before their treatment with blood or blood products;

C5b) the tracing and testing of patients who might have been exposed to the virus through their treatment with blood or blood products; and

C5c) the information given to patients who might have been infected, or who were found to be infected, and their families.

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Legal Adviser Ranald F Macdonald WS

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Martin Dowds
Melanie Golding
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Susan A Murray
Ian S Crerar
Elaine R Coull
Lorna E Kennedy
Lynne J I Greig
Morag Shepherd
Lorna McPhail
Robbie Wightman
Kerry Ritchie
Stefano Rinaldi

Norma A Shippin
Jill S Collinson
Joy A Atterbury
Catriona M Robertson
Tracey A Turnbull
Dianne Kane
Alison L Sargent
Neil D M MacLeod
Jennifer Inglis
Michael Stewart

Employment

Murdo A Macleod
Hazel F Craik
Norma A Shippin
Laura Ewart
Rhidian Davies
Chris Reeve (England & Wales)



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My purpose in writing to you at this stage is to provide you with a copy of a document prepared by Professor Gordon Lowe, Professor Christopher Ludlam and Dr Brenda Gibson. This document sets out their collective knowledge in relation to Topic C5. This document has not yet been submitted to the Inquiry, however, it is our intention to submit the same as the collective response of both current and former contactable haemophilia staff who are able to speak to this period.

I would be most grateful if you would review this document together with the associated appendices (**please note we do not have the appendices yet and these will be forwarded to you separately**) and either confirm to me that you endorse the content of the document or alternatively provide me with any comment you consider relevant.

This document is being circulated to those narrated on the Schedule attached. Should you consider that there are others who should have input into this document and who are contactable, please provide me with their details and I will arrange for the documents to be forwarded to them. Our objective in circulating this document is to have as many relevant practitioners as possible endorse the same as their recollection of events.

I would be most grateful if you could revert to me with your endorsement and/or comments no later than **Friday 30 September**. This will allow us sufficient time to finalise the document and submit the same to the Inquiry. My contact details are as undernoted. Please do not hesitate to contact me should you wish to discuss any aspect of this matter or require further information.

In the event that I do not hear from you by the 30 September I will assume that you endorse the document and have no additional comment to make. I should advise that unless I have already been in contact with you to indicate that you are may be a witness on this Topic, it is unlikely that the Inquiry will ask you to give evidence on this topic.

I am grateful to you for your assistance in this matter and would be happy to discuss further if required.

Yours sincerely

Tracey Turnbull
Senior Solicitor

Encls.

APPENDIX 2**RECIPIENTS OF C5 COLLECTIVE RESPONSE
Draft dated 14.09.11**

Gordon Lowe
Charles Forbes
Christopher Ludlam
Henry Watson
Bruce Bennett
Audrey Dawson
Brenda Gibson
Ian Hann
Anna Pettigrew
Liz Chalmers
Isobel Walker
G McDonald
Campbell Tait
Ron Kerr
Philip Cachia
Tom Taylor
Bill Murray
Patricia Wilkie
Sister McDougall (GRI)
Susan Hook (ERI)
Chris Murphy
John Morris (GRI)
Peter Hayes (ERI)

APPENDIX 3

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STRICTLY PRIVATE & CONFIDENTIAL

Date	16 November 2011
Your Ref	
Our Ref	CLO/9 TAT/PH
Direct Line	[REDACTED]
Fax No	[REDACTED]
Email	[REDACTED]

Dear All

**THE PENROSE INQUIRY
 COLLECTIVE RESPONSE ON BEHALF OF PAST AND PRESENT HAEMOPHILIA CENTRE
 STAFF IN SCOTLAND ON TOPIC C5**

I refer to my letter of 14 September when I sent to you the Collective Response on behalf of past and present haemophilia centre staff in Scotland on Topic C5 as prepared by Dr Brenda Gibson of Yorkhill, Professor Ludlam of ERI and Professor Lowe, formerly of GRI, and Kathryn McElroy's subsequent letter of 12 October when the various appendices were sent to you.

I am grateful to everyone for taking the time to read the document and, where appropriate, providing me with their comments. In light of the comments received, the C5 Collective Response has been revised and three additional appendices added (Annex 14, 15 and 16). I now take this opportunity to enclose the revised document together with copies of the three additional annexes. It would be our intention to submit this document to the Inquiry next Friday 25 November. Accordingly, I would be most grateful if you would read the document again, as revised, together with the additional annexes.

In the event that I have not heard from you **by 5pm on Wednesday 23 November** I will assume that you are satisfied that the revised document reflects an accurate picture of events and are therefore agreeable to having your name listed on the Collective Response as being one of the recipients of the response and have endorsed the same. In the event that you are not so agreeable to endorsing the revised document, I would be grateful if you would advise me as a matter of urgency, and indeed **no later than 5pm on Wednesday 23 November**. In the event of such non-endorsement of the Collective Response, your name will be deleted from the Response.

I am most grateful to you for your continued assistance in this matter but should you wish to discuss any matter arising from this document then please do not hesitate to contact me.

Yours sincerely

Tracey Turnbull
 Senior Solicitor

Encls.

APPENDIX 4

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STRICTLY PRIVATE & CONFIDENTIAL

Mrs B Reynolds

Date 16 November 2011
Your Ref
Our Ref CLO/9 TAT/PH
Direct Line
Fax No
Email

Dear Mrs Reynolds

THE PENROSE INQUIRY

You will recall that we met some ago at my Office to discuss the Penrose Inquiry and in particular your work with Professor Ludlam at Edinburgh Royal Infirmary. As you may be aware, the Oral Hearings of the Inquiry continue and have now moved on to consider the issue of non A non B Hepatitis and Hepatitis C. In December and January the Inquiry will hear oral evidence in relation to Topic C5. This topic is stated in the following terms:-

C5a) The information given to patients (or their parents) about the risk of non A non B Hepatitis and the severity of the condition before their treatment with blood or blood products;

C5b) the tracing and testing of patients who might have been exposed to the virus through their treatment with blood or blood products; and

C5c) the information given to patients who might have been infected, or who were found to be infected, and their families.

My purpose in writing to you at this stage is to provide you with a copy of a document prepared by Professor Gordon Lowe, Professor Christopher Ludlam and Dr Brenda Gibson. This document sets out their collective knowledge in relation to Topic C5. This document has not yet been submitted to the Inquiry, however it is our intention to submit the same as the Collective Response of both current and former contactable haemophilia staff who are able to speak to this period.

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I would be most grateful if you would review this document together with the associated appendices and either confirm to me that you endorse the content of the document or, alternatively, provide me with any comment you consider relevant.

The document has been circulated to those narrated on the Schedule attached. Our objective in circulating this document is to have as many relevant practitioners as possible endorse the same as their recollection of events.

It is our intention to submit this document to the Inquiry on Friday 25 November. In the event that I do not hear from you **by 5pm on Wednesday 23 November**, I will assume that you endorse the document and have no additional comment to make. If it is the case that you do not endorse the document and accordingly wish to have your name deleted from the schedule then again, I would be grateful if you would advise me of the same no later than 5pm on Wednesday 23 November. I should advise that it is very unlikely that the Inquiry will ask you to give evidence on this Topic.

I am most grateful to you for your assistance in this matter and would be happy to discuss matters further with you should you wish to contact me.

Yours sincerely

Tracey Turnbull
Senior Solicitor

Encls.

APPENDIX 5

Page 1 of 1

Hay Pamela (NATIONAL SERVICES SCOTLAND)

From: Billie Reynolds [REDACTED]
Sent: 23 November 2011 18:24
To: Turnbull Tracey (NATIONAL SERVICES SCOTLAND)
Subject: Haem . Centre Document

Dear Tracey,

Further to our telephone conversation this afternoon, (23/11/11) my statement is as follows.

When I first read this document, I thought it had been compiled by the Glasgow Consultants. However, not all Haemophilia Centres are exactly the same and I would say in essence it covered Edinburgh Royal Infirmary Haemophilia Centre.

Best Wishes
Billie

31/01/2012

APPENDIX 6

Page 1 of 1

Blackwood Jennifer (NATIONAL SERVICES SCOTLAND)

From: Turnbull Tracey (NATIONAL SERVICES SCOTLAND)
Sent: 29 November 2011 12:33
To: [REDACTED]
Cc: Turnbull Tracey (NATIONAL SERVICES SCOTLAND); McElroy Kathryn (NATIONAL SERVICES SCOTLAND); Murray Susan (NATIONAL SERVICES SCOTLAND)
Subject: PENROSE INQUIRY : TOPIC C5 COLLECTIVE RESPONSE
Attachments: PENROSE COLLECTIVE RESPONSE ON C5 TRACKED CHANGES 29.11.11.doc; Annex 16.pdf, Annex 17.pdf

Dear All

I refer to my letter of 16 November when I attached the Collective Response on behalf of past and present haemophilia centre staff in Scotland on Topic C5. In light of further comments received, further revisions have been made to this document including the addition of two further appendices, annexes 16 and 17, and the replacement of Annex 14 with the final document, as opposed to the draft guidelines.

It is our intention to submit this document to the Penrose Inquiry this coming Friday, 2 December. I apologise for the tight timescale, however should you have any comment to make on the recent revisions then I would ask you to have these with me no later than 5 pm on Thursday 1 December.

I am most grateful to you for your assistance in finalising this Collective Response and hope not to have to trouble you further.

Regards

Tracey

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03/02/2012

Appendix 7

Page 1 of 1

Hay Pamela (NATIONAL SERVICES SCOTLAND)

From: Billie Reynolds [REDACTED]
Sent: 01 December 2011 12:08
To: Turnbull Tracey (NATIONAL SERVICES SCOTLAND)
Subject: Penrose Enquiry

1st Dec. 2011 11:50am

Dear Tracey,

I received your document this a.m. just after 11am. As I have a very busy day today and am about to leave for an appointment, and won't be home until after 5pm (your deadline) I am afraid I do not have the time to read all of the document.

One thing, I must stress is that I was not a Clinical Nurse specialist. I did not have that title, neither was I paid as such. Considering the fact that I knew nothing about the speciality when I was asked to go and work there. Michelle Jones was not classed as a Clinical Nurse specialist and I don't think that Iona Philp was either but I am not certain about her.

Page three, first paragraph, line six, should have "Edinburgh" added to it.

Yours sincerely

Billie J. Reynolds

31/01/2012