
From: [text redacted]

Sent: 06 March 2015 16:45

To: zzzFirst Minister 2014 to 2016 <zzzFirstMinister2014to2016@gov.scot>; zzzCabinet Secretary for Health, Wellbeing and Sport 2014 to 2016 <cabsehealth@gov.scot>

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Subject: First Minister - Urgent - Penrose Inquiry - handling of publication of Inquiry report

First Minister / Cabinet Secretary for Health, Wellbeing and Sport

At a meeting with the Haemophilia Scotland on 25 February to discuss their expectations for the response to the Penrose Inquiry report (publication 25 March), they asked Shona Robison whether there was any potential for the First Minister to make the Ministerial Statement on the Inquiry report, given that she originally announced it in 2008. [text redacted]. The Ministerial Statement will be on 26 March and there will be a meeting with key patient representatives in the Parliament prior to it.

The recent handling submission enclosed below contains more detail on the proposed approach.

I would be grateful for your thoughts on the extent to which the First Minister would want to be involved in the response.

Thanks

[text redacted]

[text redacted] | Policy Manager- Population Health Improvement Directorate
(Health Protection: Blood policy)

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HEALTH AND SOCIAL CARE DEPARTMENT: SCOTTISH GOVERNMENT

From: [text redacted]

Sent: 03 March 2015 14:28

To: Cabinet Secretary for Health, Wellbeing and Sport

Cc: Minister for Public Health; Minister for Parliamentary Business; First Minister; DG Health & Social Care; Director of Population Health Improvement; Henderson D (Donald); Keel A (Aileen); Brown GJ (Gareth); [text redacted]; Matheson J (John); McQueen F (Fiona); Paterson J (John); [text redacted]; Ferguson SE (Shirley); [text redacted]; Hutchison D (David); Communications Healthier

Subject: CSHWS - Urgent - Penrose Inquiry - options submission for Govt response to publication of Inquiry report

CABINET SECRETARY FOR HEALTH, WELLBEING AND SPORT

I enclose a submission for decision that provides the Cabinet Secretary with an update on progress and preparations for responding to the Penrose Inquiry report and considers handling arrangements around the publication of the report.

We have a meeting with the Cabinet Secretary scheduled for 5 March where we can discuss this further.

Please let me know if you need any further information.

Thanks

[text redacted]

[text redacted] | Policy Manager- Population Health Improvement Directorate
(Health Protection: Blood policy)

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HEALTH AND SOCIAL CARE DEPARTMENT: SCOTTISH GOVERNMENT

From: [text redacted]

Health Protection

PHI Directorate

3 March 2015

PS/Cabinet Secretary for Health and Wellbeing

PENROSE INQUIRY – SCOTTISH GOVERNMENT RESPONSE TO PUBLICATION OF LORD PENROSE'S INQUIRY REPORT

Purpose

1. To provide the Cabinet Secretary with an update on progress and preparations for responding to the Penrose Inquiry report and to consider handling arrangements around the publication of Lord Penrose's report.

Priority

2. **Urgent** - to enable us to finalise the detailed handling plan and book a slot in Parliament. The report will be published on 25 March, [text redacted].

Background

3. The Inquiry was announced in the Scottish Parliament by the then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon, on 23 April 2008. Lord Penrose was formally appointed with effect from 12 January 2009.

4. On 5 February 2008, Lord Mackay of Drumadoon published his opinion that the decision of the former Lord Advocate not to hold a Fatal Accident Inquiry (FAI) into the deaths of the Rev. David Black and Mrs Eileen O'Hara was incompatible with Article 2 of the European Convention of Human Rights. Petitions for judicial review had been raised by the relatives of these people, who died after they had become infected with the Hepatitis C virus as a consequence of transfusion of blood and blood products. Lord Mackay also held that both the Lord Advocate and Scottish Ministers had statutory powers under which they could set up public inquiries into the deaths of the Rev. Black and Mrs O'Hara and that such inquiries would satisfy the Convention rights of the deceased.

5. Following careful discussion, [text redacted] to progress towards establishing a Scottish public inquiry under section 28 of the Inquiries Act 2005. [text redacted], however the 2007 SNP manifesto had stated that an SNP government would hold a full Public Inquiry to find out why people were infected with hepatitis C through NHS treatment. The

Department of Health did not consider a Joint Inquiry necessary, but it did make evidence available to the Penrose Inquiry.

6. The Penrose Inquiry ultimately had a remit to investigate the deaths of four specific individuals. More widely, it would investigate the circumstances of the transmission of Hepatitis C (HCV) and HIV from NHS treatment with blood and blood products and the consequences of the transmission of each of those viruses for all patients affected. A list of the core participants to the Inquiry is enclosed at **Annex A** and the full Terms of Reference are at **Annex B**.

Inquiry Report and Timescales

7. Lord Penrose wrote to you to confirm he will publish his report on Wednesday 25 March 2015. A lengthy, comprehensive and detailed report is expected, and the report is likely to attract significant media attention [*text redacted*]. The total cost will be published once the Inquiry has come to an end.

8. The vast bulk of the evidence which was given to the Penrose Inquiry was historic in nature (1974-1998). It is clear that great changes have taken place in personnel, facilities and procedures since the events which were investigated by the Inquiry. There have been very considerable advances in medical and scientific knowledge with regard to blood safety and the prevention/treatment of HIV and hepatitis C infection since the early 1980s. The transition has been made from clotting factors derived from pools of plasma with the potential to transmit viral infection to recipients, to safe recombinant factors to treat haemophilia. [*text redacted*].

Government's response to Publication

9. Before publication, an expert reading team will provide analysis and advice to Ministers on the content of the report [*text redacted*]. Our preferred option for responding would be:

- On the day of publication, following the report launch event, time will be set aside for media bids with the Cabinet Secretary at St Andrew's House, possibly also including a media briefing for journalists if that is considered necessary;
- A ministerial statement (draft outline enclosed at **Annex E**) on the first available day of Parliament after publication;
- A letter from Ministers to the Health and Sport Committee on the day of publication offering to attend a future Health and Sport Committee meeting to discuss the report and its recommendations. [*text redacted*].
- If necessary, depending on the content of the recommendations, write to the Health and Sport Committee with a view to providing a considered Government response in Autumn 2015.

10. The above proposed approach is discussed in more detail at **Annex D**.

11. [text redacted] we are considering an initial meeting with key patient representatives in the Parliament prior to the Ministerial statement.

12. Ministers and officials have held regular meetings with the most prominent representative groups and individuals over the last few years, and we have provided support and funding for various projects to support these groups. We would seek to meet with those affected more widely following publication and are taking advice from the relevant groups on how best to do this.

Conclusion

13. The Cabinet Secretary is invited to note the proposed handling in terms of the Scottish Government response to the publication of the Penrose Inquiry report and to agree:

- The proposed options for the Government's response to the publication of the report as outlined in paragraph 9, and as set out in more detail in **Annex D**;
- The proposed outline for the Ministerial Statement enclosed at **Annex E**;
- The handling arrangements around pre-publication/publication date and that a detailed handling plan will be sent up for approval;
- To meet with officials nearer the publication date to discuss the detailed handling plan.

[text redacted]

Health Protection

PHI Directorate

3 March 2015

The following were designated as Core Participants to the Inquiry:

Mrs Jeanie Black as personal representative of the Reverend David Black

Mrs Roseleen Kennedy as personal representative of Mrs Eileen O'Hara

Mrs Annie Laing as personal representative of Alexander Laing

Mrs Jean Tamburrini as personal representative of Victor Tamburrini

The Haemophilia Society

The Scottish Ministers

The Common Services Agency for the Scottish Health Service (on behalf of the Scottish National Blood Transfusion Service)

Ayrshire and Arran Health Board

Borders Health Board

Dumfries & Galloway Health Board

Fife Health Board

Forth Valley Health Board

Grampian Health Board

Greater Glasgow Health Board

Highland Health Board

Lanarkshire Health Board

Lothian Health Board

Orkney Health Board

Shetland Health Board

Tayside Health Board

Western Islands Health Board

Lord Penrose has also designated the following core participants to illustrate different groupings of interests as follows. Their names have been anonymised. One further core participant JM2 was designated by Lord Penrose to illustrate further the circumstances of the two groupings of interest under which the individual concerned is listed.

Transfusion cases up to and including 1979

JF

Transfusion cases in the 1980s

EF

KM

Transfusion cases in the 1990s

No designation [Mrs Annie Laing, as representative of Alexander Laing deceased, is already designated and covers that interest]

Hepatitis C cases associated with Haemophilia A up to and including 1979

FM

PD

Hepatitis C cases associated with Haemophilia A in the 1980s

MM

BW

JM2

Hepatitis C cases associated with Haemophilia B up to and including 1979

DB

IB

JD

Hepatitis C cases associated with Haemophilia B in the 1980s

RM

HIV cases associated with Haemophilia A or B

JM

GM

KM2

JM2

In addition, Lord Penrose designated Haemophilia Scotland as a core participant on 4 February 2014

Term of Reference 1:

To investigate the systems in place in Scotland for the collection, treatment, licensing, testing, preparation for supply and supply for use by the NHS of blood and blood products with particular reference to the risks of transmission of the hepatitis C virus and HIV to patients treated by the NHS in Scotland, including the role of government in regulation and setting guidelines and standards.

Term of Reference 2:

To investigate the systems in place for informing patients treated by the NHS in Scotland of the risks associated with the use in their treatment of blood or blood products, with particular reference to the risks of infection with the hepatitis C virus and HIV.

Term of Reference 3:

To investigate the systems in place in Scotland for obtaining consent from, and testing for infection with hepatitis C and HIV, patients treated with blood or blood products, and informing any patients found to be so infected.

Term of Reference 4:

To investigate the systems for recording and monitoring the numbers of NHS patients in Scotland treated with blood and blood products, with particular reference to the numbers exposed to risk of infection with the hepatitis C virus and HIV and the numbers contracting either or both such infections as a consequence of such treatment.

Term of Reference 5:

To examine the circumstances generally in which patients treated by the NHS in Scotland became infected with hepatitis C, HIV, or both through the use of blood or blood products in the course of their treatment, taking account of the development of scientific and clinical understanding and evidence internationally.

Term of Reference 6:

To investigate the deaths of Reverend David Black and Mrs Eileen O'Hara, Alexander Black Laing, Neil Mullen and Victor Tamburrini, with particular reference to the circumstances in which they became infected with the hepatitis C virus, HIV or both.

Term of Reference 7:

To investigate the steps taken by those involved in, and those responsible for, the NHS in Scotland, including NHS Boards and the Scottish National Blood Transfusion Service

("SNBTS"), their officers and employees and associated agencies, once hepatitis C and HIV were identified, to trace individuals who might have become infected with one or both of them as a result of receiving blood or blood products; and to identify any other or further steps that might reasonably have been taken to trace such individuals.

Term of Reference 8:

To investigate the steps taken by those involved in, and those responsible for, the NHS in Scotland including NHS Boards and SNBTS, their officers and employees and associated agencies, to prevent the provision of infected blood and blood products.

Term of Reference 9:

To investigate the steps taken by those involved in, and those responsible for, the NHS in Scotland including NHS Boards and the SNBTS, their officers, employees and associated agencies to inform individuals who might have received infected blood or blood products of the risks associated with their treatment for themselves and their families; and to offer treatment to any individual at risk, and to identify any other or further steps that might reasonably have been taken to inform and to treat such individuals.

Term of Reference 10:

To examine any particular adverse consequences for patients treated by the NHS in Scotland and their families of infection through blood and blood products with hepatitis C and HIV, including the treatment offered.

Term of Reference 11:

To identify any lessons and implications for the future, and make recommendations.

Term of Reference 12:

To report as soon as practicable.

SCOPE OF FINDINGS AND RECOMMENDATIONS

1. The key findings for Government will relate to the state of scientific and technical knowledge at the relevant time and whether we could have been legitimately expected to have discovered/controlled the blood product infections more efficiently. Pathogens are constantly emerging and evolving; new pathogens will therefore always pose a threat to the blood supply. In the past, it has often taken multiple cases of transfusion-transmitted infection before these threats have been recognised and mitigated.
2. [text redacted].
3. [text redacted].
4. The terms of reference for the Penrose Inquiry do not make reference to compensation, and do not permit the Chairman to consider payment of compensation either in relation to individuals or on a collective basis. However, it is possible that civil liability may be inferred from his findings and recommendations. Lord Penrose will also reflect on the experiences of those infected and their families, which may have resonance for the current financial support arrangements.
5. After the report publication we intend to work with the other UK Health Departments [text redacted] on potential reforms to the current UK-wide ex-gratia financial support system for those infected and their families. The Scottish Government has already contributed more than £30 million in payments to 705 Scottish recipients (133 known deceased) to date, via the Skipton Fund and Caxton Foundation.

RESPONSE APPROACH

Pre – publication

1. [text redacted]. We understand that members of the media/press will be provided with embargoed copies of the report on the morning of the launch, around 2 hours prior to publication (but these details have still to be confirmed). A dedicated “reading team” has been established and will work alongside our policy team. They will work under the guidance of a strict security protocol for handling the report. The team will have responsibility for identifying key issues arising from the report for Director General Health and Social Care and Scottish Ministers. This will also help to develop the framework for the Cabinet Secretary’s Ministerial Statement.
2. The publication of the report will likely attract significant media attention [text redacted].
3. [text redacted].

Day of Publication

4. Lord Penrose’s team has booked the auditorium at the National Museum of Scotland, Chambers Street, Edinburgh, for a launch starting at 11 am. The launch will be open to Core Participants to the Inquiry, interested members of the public, and the media. At the launch event, Lord Penrose will outline the background to the Inquiry, along with the Inquiry’s key findings and recommendations.
5. Copies of the Final Report and its Executive Summary will be available at the conclusion of the event. We have confirmed that Inquiry core participants will be provided with embargoed copies of the report one week prior to publication
6. On the day of the report’s publication we would recommend that time be set aside for media bids with the Cabinet Secretary at St Andrew’s House, with a media briefing included if necessary. Further details will be provided in the handling plan.

Post Publication

7. Dependent on timing, we would suggest the Cabinet Secretary provide Parliament with a **Ministerial Statement** on the first available day of Parliament following publication which will set out clear timescales for subsequent reporting arrangements. The statement will also provide an opportunity for the Scottish Government to acknowledge any failings within the system, the loss of life and associated grief, and also highlight the positive work already undertaken to ensure services are safe, effective and person-centred.

8. Timing-wise we would anticipate a **full Government response/report** to be provided in Autumn 2015. Given the historic nature of the Inquiry this may ultimately be unnecessary or limited in scope. Further consultation on the recommendations may be required with UK Government, the other devolved administrations and UK advisory committees such as the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO). There is also the possibility that opposition MSPs will seek a debate and this will be factored into our approach to an interim response. Motion S4M-12139 was lodged by Richard Lyle MSP on 22 January concerning the publication of the report. It has 53 signatures [*text redacted*].

9. Post publication we would ask the Cabinet Secretary/DG Health and Social Care to consider meeting/engaging with a number of key stakeholders, including those groups representing patients and families, in order to build positive relationships, seek buy in and empower them to be part of the Scottish Government's final response where appropriate. Again, the primary interest of those infected and their families is likely to be increased financial support arrangements. The previous Cabinet Secretary met regularly with key stakeholders including the Scottish Infected Blood Forum and Haemophilia Scotland, who are the major patient/family organisations in Scotland. The new Cabinet Secretary met with Haemophilia Scotland on 25 February and further meetings have already been scheduled with those organisations in early March, during which their expectations for the report can be discussed.

Parliamentary Handling

10. As required by statute, the report will be laid under section 26 of the Inquiries Act 2005 – "*Laid before the Scottish Parliament by the Scottish Ministers under section 26 of the Inquiries Act 2005.*" It will be the responsibility of the Inquiry Sponsor Team to take forward these arrangements and they will liaise with the Inquiry Secretariat and the Parliamentary Bureau. We have confirmed that the Inquiry report can be laid simultaneously with the launch and publication of the Inquiry Report.

Annex E

[text redacted].