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## **Infected Blood Roundtable**

### **Meeting Minute**

Cabinet Office, 70 Whitehall

**Tuesday 28th January 2020**

At 1300 PM

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#### Introductory Remarks

The Minister for the Cabinet Office (MCO) opened the meeting by thanking everyone for attending and for taking the time to meet. He noted that many had travelled long distances to be there, which was not easy for those suffering from long-standing health conditions as a result of infection.

The MCO began by repeating the apology made by David Cameron in 2015. He said that he had seen and read some of the evidence given by Participants in the Inquiry and that he recognised their struggle to obtain justice and closure. He stressed that he had wanted to hold this meeting sooner, just as they had, but was forced to delay due to the General Election. He also noted the recent sad passing of **GRO-A** over the Christmas period who had been due to attend this meeting, and for whom the meeting had been delayed out of respect, and offered his condolences.

Continuing, MCO briefly set out his role in relation to that of the Parliamentary Under Secretary of State for Mental Health, Suicide Prevention and Patient Safety (PS(MSP)). As Minister for the Cabinet Office, MCO is the sponsor Minister for the Inquiry on the Prime Minister's behalf. As such, he is responsible for safeguarding the integrity of the Inquiry and for providing the Chair, Sir Brian Langstaff, with whatever support he needs to complete his work as quickly as a thorough examination of the facts allows. To this end, MCO welcomed views from attendees on the progress of the Inquiry.

The MCO noted that the Department of Health and Social Care is responsible for matters of policy, which is why Nadine Dorries MP was invited to be at the meeting. MCO added that as the sponsor Minister at the centre of government he was also keen to ensure that the issues that mattered to attendees were being properly considered, and that he would ensure their views were conveyed to the Prime Minister.

In order to provide a focal point for the subsequent discussion, MCO provided a brief overview of three key areas that he understood were of concern to attendees:

1. First, on parity of support, MCO acknowledged concerns regarding the lack of progress towards achieving greater parity since January 2019. He highlighted the positive news that the Northern Ireland Assembly had announced £1m in funding to uplift payments to primary beneficiaries, but noted that there was still work to be done regarding Wales, and that he was engaging with the Secretary of State for Wales to address this.
2. MCO noted that there were other discrepancies in the level of, and eligibility to, support that must be addressed if the government was to make good the commitment made last July to achieve greater parity. He noted that, due to Devolution, there were four different health systems whose schemes must be respected and that progress in this space would require joint working. MCO said that he wanted to use this meeting to better understand from attendees where those disparities were, and to consider the value of a short piece of work, done in consultation with the Devolved Administrations (DAs) subject to their agreement, to address the most pressing issues.
3. Finally, on compensation, MCO noted that while he appreciated campaigners frustration on this, the government should wait for the Inquiry to report before considering compensation. While the Inquiry could not make a finding of legal liability, it could make a recommendation that the government fundamentally increases what it pays to the infected and affected, and that it does so on a different basis. For this reason, the government has decided to wait for the Inquiry to conclude.

The Parliamentary Under Secretary of State for Mental Health, Suicide Prevention and Patient Safety (PS(MSP)) said that she was primarily here to listen, and just as MCO would report to the Prime Minister, so she would do the same to the Secretary of State for Health, Matt Hancock. She added that finding a way forward with the Devolved Administrations would be key.

#### Roundtable on Campaigner Experiences

The MCO then invited all those who wished to speak to do so, and to set out the issues of concern to them. He noted that for this part of the meeting, he and the Health Minister would be in listening mode, and that he would like to give everyone the opportunity to speak first before responding to specific questions in wider discussion.

Attendees made the following points<sup>1</sup> in discussion:

#### **General**

- a) Campaigners highlighted their view that the government's task here was to identify need, confirm cost, and find budget. There were calls for the UK Government to take on a leading role.

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<sup>1</sup> Please note that these points do not reflect government policy, but rather the points raised by campaigners to Ministers:

- b) A number of campaigners noted that they had told their stories to Ministers previously, and that it was important that the government made progress to avoid raising expectations which were then not met.
- c) Campaigners also noted concerns about the pace of future delivery based on how the government had addressed the issue of parity to date.

### **Parity of Support**

- d) Campaigners raised concerns about the disparities in support across the UK, both in terms of who is eligible for support, the level of payments, and the application and assessment criteria.
- e) Payments to primary beneficiaries in Wales are still to be uplifted. Campaigners relayed that the Welsh Government had said that they could not find the funds within existing budgets.
- f) Widows and Bereaved Partners
  - i) A number of attendees highlighted concerns about insufficient support for widows and bereaved partners. Attendees asked Ministers and/or officials to engage with their Scottish counterparts on their approach.
  - ii) One campaigner commented that currently, in the Scottish Scheme, widows stop receiving payments if they remarry. Attendees said that this should be disregarded for all schemes as it is for widows of service personnel.
  - iii) It was also highlighted by attendees that infected widows should be considered as two separate entities.
- g) Bereaved Parents and Children
  - i) A number of attendees noted that none of the UK schemes make payments for bereaved parents and children. They noted that this is in contrast to the Republic of Ireland.
- h) Disparity between different categories of infected (HIV vs HCV)
  - i) Concern was raised over the disparities and anomalies in the English financial support system regarding the support given to women infected with HIV.
  - ii) It was noted that the English Infected Blood Support Scheme (EIBSS) had adopted the lump payment structure that dates back to 1991. Attendees asked the UK government to review this historical inequality, adopted from previous HIV schemes, where ex gratia payment was made on the basis of gender, age and marital status.
  - iii) It was also requested that EIBSS equalise payments such that HIV and Stage 2 HCV are recognised as equal.

- iv) Attendees raised concerns about there being no application form for HIV widows on the Scottish support site.
  - v) Attendees also raised concerns about the term ‘infected intimates’ being used for women infected with HIV by their partner.
- i) Means-Testing
    - i) Some campaigners said that there should be no means-testing for any beneficiary.

### **English Infected Blood Support Scheme**

- j) Attendees raised concerns relating to the English Infected Blood Support Scheme (EIBSS), including the capability of staff, process/administrative errors and insensitive customer service.
- k) It was suggested that means-testing and the EIBSS assessment process are unnecessary and burdensome, and that England should consider following the model of Scotland which have stopped assessments.
- l) Some attendees raised concerns about a perceived lack of understanding within EIBSS regarding HIV.
- m) In addition, it was requested that EIBSS provide funeral grants/expenses for infected persons, which would not be means-tested.

### **Psychological Support**

- n) A number of attendees highlighted concerns about a lack of bespoke psychological support for the infected and affected in England. They noted that this is particularly significant now that the Inquiry is underway and those infected and affected are having to relive particularly painful and difficult periods in their lives. They suggested that Wales presents a good example of how psychological support could be approached.
- o) It was suggested that funding could be provided for specialised psychology/counselling services, and there should be an increase in funding for Haemophilia Centres which should provide medical care and social work support.
- p) Proposals from attendees included that staff in Haemophilia Centres should be better educated on the history and infection of haemophiliacs and their resulting healthcare needs - physical and psychological.

### **Role of HMT**

- q) Many campaigners urged that HMT be brought into this conversation, and that any new funding to address disparities should come from the Treasury, rather from individual health budgets.

## **Compensation**

- r) Some campaigners said that the government should pay compensation now, following the tribunal model adopted in the Republic of Ireland (which covers infected and affected and bereaved children and parents). Campaigners added that compensation in RoI is paid out at accepted court level without accepting legal liability, and was paid before the conclusion of any tribunal.
- s) Some campaigners disagreed and felt that it was right to wait for the Inquiry to report.
- t) It was also suggested that the recommendations in Lord Archer's report of 2009 should be implemented.
- u) One campaigner put forward a new request that the government commit to commence work now on a framework for compensation, to be implemented if and when liability is established.

## **DWP Benefits Assessments**

- v) Some attendees said that they had experienced problems regarding DWP benefits assessments (e.g. for ESA and PIP); including receiving the wrong benefits, being refused benefits, or being required to regularly undergo reassessment.
- w) Concern was also expressed that intelligence and cognisance had been perceived to be taken into account during assessments to the detriment of claimants.
- x) To combat this, some campaigners suggested that the government should consider 'passporting' infected people through the system so that they don't have to undergo reassessment.
- y) It was also suggested by campaigners that the UK Government could consider the Green Card scheme used in the Republic of Ireland.

## **Communications**

- z) Some attendees raised concerns about responses to correspondence. They noted that it would be helpful for campaigners to have a direct channel of communication to Department of Health Ministers to facilitate dialogue on key issues.

## **Other**

- aa) One campaigner suggested that, rather than addressing the lack of support for those most in need first, total parity should be achieved in one hit.
- bb) Some campaigners urged that payments for the infected and affected should be for life.

- cc) One campaigner expressed concerns about the need for a consultation on parity of support.
- dd) Some attendees expressed concerns that the infected were not being monitored well enough. They said there was a need for continued testing of infected persons.
- ee) One campaigner requested that the Crown Prosecution Service be involved now to bring to account those who were responsible for the decision to use infected blood products.
- ff) Some campaigners suggested that planning for the meeting could have been more transparent and collaborative.
- gg) Concerns were raised by campaigners that there had historically been a lack of equal representation at meetings between government and campaigners whereby there was far greater representation for those with bleeding disorders infected by infected blood products over the 'non-bleeding' infected by whole blood. There was therefore a request for future meetings to aim for parity between the two groups.
- hh) Some attendees asked that carers of the infected receive support in their own right.
- ii) It was requested that the misdiagnosed should be recognised as a category in their own right.
- jj) One campaigner stated that no bereaved person should be made to pay 'bedroom tax'.
- kk) One campaigner suggested that infected and affected that receive ESA and PIP should be allowed to retire at 60.
- ll) One campaigner raised concerns that they had never received a response to their question of how and why the government arrived at the figure of £24m in funding that was announced by David Cameron in 2015.
- mm) One campaigner said that the Minister for the Cabinet Office should apologise for seemingly misleading the House of Commons on whether the Inquiry could determine liability. The Minister confirmed that he had written to the MP who raised this.

#### Concluding Remarks

In response to points raised by attendees, the Minister for the Cabinet Office noted the following:

- a) He and the Health Minister had heard their frustrations and anger, and it had been helpful for them to hear directly from campaigners and better understand the issues of concern to them.



- b) He recognised their frustrations at the pace of progress but noted that there had been an uplift to the English Scheme in April 2019, and a recent announcement of £1m in additional funding for Northern Ireland.
- c) He acknowledged that there remained more to be done towards achieving greater parity in support for the infected and affected across the UK.
- d) He noted that the UK Government would need to work in consultation and consort with the Devolved Administrations on this agenda.

The Parliamentary Under Secretary of State for Mental Health, Suicide Prevention and Patient Safety added that while the government's position on compensation was that it should wait for the Inquiry to report, she was keen to improve the support package for the infected and affected in the interim. She also committed to exploring what could be done regarding mental health support.

### Actions

#### **Ministers committed to the following actions:**

1. The Minister for the Cabinet Office to write to the Prime Minister setting out the points raised and next steps;
2. The Minister for the Cabinet Office to write to Her Majesty's Treasury to highlight the issue of parity and the need for funding to address disparities in support;
3. Ministers to write to the Devolved Administrations requesting urgent engagement at official level on proposals to achieving greater parity;
4. The Minister for the Cabinet Office to write to the Secretary of State for Wales regarding an urgent uplift to the Welsh scheme;
5. Ministers to revert to campaigners with proposals on how to achieve greater parity;
6. PS(MSP) and DHSC officials to consider the information provided by Birchgrove Group regarding their proposals on psychological support;
7. PS(MSP) to speak to Claire Murdoch, (NHS England's Mental Health Director) to discuss providing bespoke counselling and mental health support for the infected and affected;
8. Sue Gray to speak to DWP about 'passporting' infected persons through the benefits system;
9. Ministers to consider the proposal from a campaign group on a framework for compensation, prior to the Inquiry reporting;
10. DHSC officials to review EIBSS processes with the NHS Business Services Authority;
11. Ministers to consider how to improve communication between the government and those infected and affected;
12. A draft meeting minute to be circulated to all attendees.

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**ENDS**

## **PRESENT**

**The Rt Hon Oliver Dowden CBE MP**

Paymaster General and Minister for the  
Cabinet Office

**Nadine Dorries MP**

Parliamentary Under Secretary of State for  
Mental Health,  
Suicide Prevention and Patient Safety

**Sue Gray**

Permanent Secretary, NI Finance  
Department

**Lucy Noakes**

Special Advisor to the Minister for the  
Cabinet Office

**Alex van Besouw**

Deputy Principal Private Secretary to the  
Minister for the Cabinet Office

**Emily Dick-Cleland**

Private Secretary to the Minister for the  
Cabinet

**Timothy Davies-Bennion**

Private Secretary to Parliamentary Under  
Secretary of State (*cover*)

**William Vineall**

Director, Acute Care and Quality Policy,  
DHSC

**Tim Jones**

Deputy Director, DHSC

**Brian Williams**

Head of the Cabinet Office Inquiries  
Sponsor Team

**Kate Bell**

Senior Press Officer, Cabinet Office

**Will Warr**

Special Advisor to the Prime Minister on  
Health