

## UK Health Departments Infected Blood Payments Scheme Reform

Friday 17<sup>th</sup> April 2015

Meeting Room 2. Richmond House, 79 Whitehall, London.

### Attendees

Robert Girvan - [Robert.Girvan@](mailto:Robert.Girvan@) GRO-C

Gareth Brown - [Gareth.Brown@](mailto:Gareth.Brown@) GRO-C

Jenny Thorne - [jenny.thorne@](mailto:jenny.thorne@) GRO-C

Seamus Camplisson - [Seamus.Camplisson@](mailto:Seamus.Camplisson@) GRO-C

Lynsey Lauder- [Lynsey.Lauder@](mailto:Lynsey.Lauder@) GRO-C

Rowena Jecock – [Rowena.Jecock@](mailto:Rowena.Jecock@) GRO-C

Kypros Menicou – [Kypros.Menicou@](mailto:Kypros.Menicou@) GRO-C

Naomi Balabanoff - [naomi.balabanoff@](mailto:naomi.balabanoff@) GRO-C

Siobhain McKeigue - [Siobhain.McKeigue@](mailto:Siobhain.McKeigue@) GRO-C

Philippa Snape – [Philippa.Snape@](mailto:Philippa.Snape@) GRO-C

First Part of meeting: Ailsa Wight – [Ailsa.Wight@](mailto:Ailsa.Wight@) GRO-C

### Minutes

#### Item 1: Welcome and Introductions

#### Item 2: Consideration of The Penrose Inquiry Final Report

##### Scotland

- The Scottish view of the Inquiry Final Report is that it is a thorough review of events, however the report is not necessarily what those infected wanted.
- Scotland is committed to reviewing the payment schemes. While some affected patients in Scotland would like the new scheme to be a Scottish scheme, the Cabinet Secretary (Shona Robison) has recognised that a UK wide scheme will avoid duplication of administration,

reducing service delivery costs. Scotland is going to appoint an independent chair for the review (likely from the 3<sup>rd</sup> Sector).

- Scottish Ministers would probably like to increase the total amount of money paid out, however this is more likely to be through annual payments rather than one-off payments.
- Terms of reference will be drawn up for the Scottish payment review group and when complete Scotland will share with all. Part of the work of this group will be to take views from people within Scotland, international views, engage with UK partners and consider other payment schemes (the risk of setting a precedence with this payment scheme which may then have wider implications has been raised with Scottish Ministers).

**ACTION (1): England has looked at other schemes previously and will share that information.**

#### **Wales**

- Wales have not discussed any increase in payments, although Ministers have said that they want to increase support flexibly.
- Wales want to ensure that there is a UK wide approach.

#### **Northern Ireland**

- It was expected that the Northern Ireland Health Minister would want parity with the rest of the UK.

#### **Scotland**

- 12,000 people a year are tested for HCV in Scotland annually.
- A task group is working on whether and how Lord Penrose's recommendation could be implemented. Options being considered include whether to target people to be tested for HCV or whether this should be a 'passive' drive. This is likely to be announced in August 2015, when the Sexual Health & BBV Framework will be updated.
- The Scottish Government has provided extra money to Health Boards for the new HCV treatment. Anticipated competition between the two drugs companies Gilead and AbbVie should hopefully lead to price reduction.

#### **England**

- The Department of Health is also keen to have a UK wide approach to payment scheme reform, however need to confirm this with new Ministers.

#### **Item 3: Discussion of each country's litigation challenges and concerns**

- Disability Discrimination: England is facing a potential claim on the grounds that the current schemes are discriminatory. This is in the public domain. This claim lies in the fact that individuals with HIV (which is specified as a disability under the Equality Act 2010) all receive an annual payment under the structure of the current payment schemes, however that is not the case for all individuals with HCV.

- Public Sector Equality Duty: under the Equality Act 2010, in every decision made, Ministers and officials need to give due consideration of (i) the elimination of discrimination; (ii) the advancement of equality of opportunity; and (iii) fostering of good relations between individuals who share a protected characteristic and individuals who do not. There has been recent case law against Government Departments where it is not clear that Ministers have given due consideration, including where detailed discussion was included in papers for Ministers. This is something that is applicable to Scotland, Wales and England, and similar provisions are in place in Northern Ireland under the Northern Ireland Act 1998, and we will all need to bear in mind for each decision on this policy area.
- Negligence Grounds: Westminster lawyers are currently looking into the potential risk of legal challenge on negligence grounds because of the delay in the introduction of HCV testing highlighted in the Penrose Report. The Consumer Protection Act has a 10 year cut off which means that those coming forward after 2011 couldn't claim compensation under Burton but could therefore choose to claim negligence.
- Coroner's Inquest in England: there is a family asking for an Article 2 Inquest i.e. extended powers of investigation under Article 2 of the European Convention of Human Rights (ECHR). This is being considered by the coroner.

**ACTION (2): England to send out a note on the legal issues to all.**

#### **Item 4: Discussion of payment situation across the four countries currently and ideas for what the new scheme could look like**

##### **England**

- As in the note that was circulated prior to the meeting, there is an expectation that responsibility for HIV payments will transfer to the devolved administrations in due course.

##### **Wales**

- Unaware of an agreement or any discussions between UK health departments at the time of devolution about the HIV scheme.

##### **Scotland**

- Also unable to find any record – however not too much of a concern as so few with HIV in Scotland.

#### **General Discussion Points:**

##### **General ideas for payment scheme reform**

- It is important to be clear about rationale for payments under a reformed scheme. Initial discussion focussed on *“financial assistance to help with additional costs of living with an infection or any residual consequences from the side effects of the infection”* as a possibility.

- All agreed that this proposed rationale will need to be discussed further, potentially alongside other options to be developed. Some general points discussed included:
- Any approach needs to be seen to be an improvement for those that have been infected, however more financially sustainable over the long term for UK Health Departments.
- All agreed that there should be ongoing support for infected individuals and those previously infected who continue to suffer side effects/symptoms as a result of infection/treatment.
- Secondary infected people are currently treated the same as those that are primary infected. In the future it would be worth considering whether anyone with a new secondary infection should be eligible for support via the schemes.
- Scotland had considered, as one option, raising people's annual income to £23,000 (in line with average wage).
- It is crucial that whatever reforms are made, the process is streamlined for those using the system.
- All widows of infected partners irrespective of the cause of death are currently eligible for support – discussion around continuing with this system.
- There will need to be a very clear appeals process built in to any new system.
- Potentially suitable to have a 'one off pot' which is based on need which is not covered by the annual payment.
- Question of older people – if people are pension age with no side effects or infection, it was discussed whether their payment should be stopped (over time) if they no longer have any additional living cost requirements.
- Important that we also discuss other options for schemes
  - Do nothing (legal challenge)
  - Do nothing to the schemes but set up a mediator who will have a pot of money to give out money when required (legal challenge)
  - Modify the current system

#### **Concerns with payment scheme reform**

- The cost of bringing all payments in line with that of the Macfarlane and Eileen Trusts is currently unaffordable/very expensive. As a consequence, any reform means that some people will lose out.
- Discussion of individual assessments – concerns that a system of individual assessment can be open to both abuse and challenge.
- Concerns with CPI linkage – is this sustainable? Do we want to maintain CPI rates? Instead there are other systems that could be used (e.g. the system used by DWP)

#### **ACTION (3): S.M. to work out how much money would be released by uncoupling the regular payments from CPI and share with all.**

- Discussion of means testing – this is extremely unpopular with campaigners.

#### **Important payment scheme reform considerations**

- Any new scheme needs to look forward and to what people need now rather than considering past payments/losses/etc.

- For the dependants of infected it is important to note that payments can't be stopped abruptly, instead they would need to be phased out
- It will be important to legitimise any changes through public consultation.
- The existing charities can't be closed down, however funding could be stopped.
- It is important that we set out the principles and rationale of the schemes as all changes will be subject to judicial review.
- The consultation document should focus on consulting on the principles of payment scheme reform, rather than the details, so that Ministers can make well informed decisions.
- We should move towards referring to financial assistance, not financial support.

#### **Further information required**

- How many people are actually unhappy with the current level of support?
- What is the range of income levels?
- How many families/beneficiaries are there in each country and what support do they receive?
- What do the Caxton Foundation get claims for, what do they pay grants for, and what are the average amounts that they give?
- Information on the additional living costs for those that were infected, including those that have cleared the infection but are living with side-effects. This question can be posed to the Scottish consultation group – Scotland is establishing a patient reference group; they have a lot of face time with Ministers and Civil Servants.

**ACTION (4): England to send a flow diagram to all which contains the tiers of different groups**

**ACTION (5): N.B. to update the payment slide and circulate to all**

**ACTION (6): Scotland to add questions to consultation group goals.**

**ACTION (7): Scotland will send up the Terms of Reference once a Chair has been appointed and they have been set.**

#### **Key Dates**

Scotland, Wales and NI elections: May 2016

World Haemophilia Day: 17<sup>th</sup> April 2015

World Hepatitis C Day: 28<sup>th</sup> July 2015