

Confidential**Circulation: Board only****Caxton Trustee Ltd**

Report to: Board

Date of meeting: 10 February 2016

Report from: Chief Executive

Subject: Political developments

DH consultation

The Minister made a statement to the House of Commons on 16 December 2015, in response to an Urgent Question from Diana Johnson MP. In the statement, the Minister announced that the consultation would not now be launched until January 2016. On 21 January 2016 the Minister made another statement to the House, announcing the launch of a 12 week consultation period which will close on 15 April. The Chairs of the Alliance House entities and I were given advance notice the previous day in a meeting with Department of Health officials, which was called at short notice.

The key changes that the Government is proposing to make are:

- For those with Hepatitis C at Stage 2, the existing £14,749 annual payment which people currently receive from the Skipton Fund, and which is index-linked, will be increased to a flat rate of £15,000. There will no longer be a cost of living increase, so the £15,000 will never increase. This means that this money will decrease in real value over time.
- Those with Hepatitis C at Stage 1 will be able to apply for an individual health assessment, as a result of which they may receive some kind of annual payment, up to a maximum of £15,000 per annum, dependent upon how much the Hepatitis C infection is impacting on the individual's health.
- Payments for any new infected registrants with Hepatitis C (and/or HIV) will be determined through the same individual health assessment process.
- Those with Hepatitis C will be given enhanced access to treatment.
- Primary beneficiaries will no longer be able to access the range of financial and other support provided by the Caxton Foundation. For some Caxton primary beneficiaries, this could mean the loss of as much as £4,000 per annum in regular payments and winter fuel payments, as well as losing access to grants for support with such things as mobility issues and adaptations to property, and access to free expert advice and support on issues such as benefits, money management and housing. Primary beneficiaries will only be able to apply for discretionary support for travel and accommodation costs which relate to ill health.
- Anyone infected by their spouse/partner in the future, where the primary beneficiary was aware of their own infection status, will no longer be recognised as a beneficiary and will receive no financial or other support: the Government believes those who are infected have individual responsibility for taking steps to ensure they do not infect anyone else.
- Those who are already bereaved will be given the option of a lump sum (equivalent to three times what they receive under the existing Caxton policy, or £5,000, whichever is the greater). If they take the lump sum, they will not be entitled to any ongoing discretionary support. If they do not choose to take a lump sum, there may be some ongoing discretionary support, but it is not clear what form this will take, and may well not include the range of support that Caxton currently provides in the form of regular payments, winter fuel payments, grants, and free expert advice and signposting.

- Those who are bereaved in the future will continue to receive the payment their infected partner/spouse was receiving at the time of death for one further year. After this time, bereaved spouses and partners would not be eligible for any further support, including any discretionary support.
- There is no provision for any discretionary support for the parents or children of those infected.
- The existing five organisations which support people with HIV and Hepatitis C, including the Caxton Foundation, will be closed down and replaced with a single organisation.

Those who are infected with Hepatitis C at Stage 2 are likely to be worse off financially under the new proposals. Those with Hepatitis C at Stage 1, who would be eligible to apply for an individual health assessment, might be better or worse off, depending on the level of payment they were to receive as a result of the assessment. However, the consultation makes it clear that to receive a higher level of payment, people would have to demonstrate that the Hepatitis C at Stage 1 is having a significant impact on the individual's health. The health impact of living with haemophilia will not be taken into account.

With regard to the bereaved, beneficiaries may be better or worse off, depending on whether or not someone chooses a lump sum, and the level of this, and depending on what the Government is envisaging by "ongoing discretionary support" for those who opt not to take the lump sum.

We sent out a letter about the consultation on behalf of DH to 3500 beneficiaries/registrants across the five organisations on 27 January 2016. In spite of my advice regarding how to reach as many people as possible, DH decided not to send a hard copy of the consultation document to all beneficiaries. (Distribution of the letter was actually delayed because DH had put in the letter the wrong telephone number for people to call if they wanted to request a hard copy of the consultation document. They rectified this by putting a label on the outside of the envelopes giving the correct number!)

We have now sent out own letter to Caxton beneficiaries (on 29 January 2016) setting out what changes are being proposed and how people will be affected if the proposals are implemented.

We will also be preparing a response to the consultation, hopefully in conjunction with the other Alliance House entities. The Chairs and I had an initial meeting on 2 February 2016 to discuss the process for starting to prepare this.

Scottish Review Group

The Scottish Review Group, which was set up after the publication of the Penrose Inquiry, published its final report on 17 December 2015. The report makes the following recommendations:

- The annual regular payments for those who are mono-infected with either HIV or Hepatitis C at Stage 2 should be increased from the current level of £14,749 to £27,000 per annum.
- There should be annual regular payments for those who are co-infected with HIV and Hepatitis C at Stage 1 and Stage 2 of £37,000. At the moment, those who are co-infected and at Stage 2 receive £29,498. The recommendation would widen the regular payment to those at Stage 1 as well.
- The lump sums paid by Skipton are currently £20k at Stage 1 and £50k at Stage 2. The report recommends reversing this, so that those who are mono-infected at Stage 1 receive £50k, and those who reach Stage 2 receiving a further £20k. Those who are co-infected should receive the full £70k lump sum at Stage 1.
- When the infected individual dies, the proposed annual payments should convert into a pension for surviving spouses of those who were either co-infected, or mono-infected with HIV or Hepatitis C at Stage 2, at a rate of 75% of the relevant level of annual payments. For the first full year after death,

the widow/widower should receive the proposed annual payment in full. Widows/widowers of those who died at Stage 1 should also be able to apply for this payment where the virus contributed directly to the death of the infected individual.

- A new Support & Assistance Grants Scheme should be set up, administered in Scotland, either by an existing Scottish body, or via a new body established specifically for this purpose.
- Recipients of the ongoing annual payments should have the option of converting these into a one-off lump sum payment by way of final settlement.
- The payments should continue to be disregarded for tax and benefits purposes.

In a press statement on the day the report was released, Shona Robison MSP, the Scottish Cabinet Secretary for Health, Wellbeing & Sport, said that a "new and improved system of financial support for those infected in Scotland will be announced before World Haemophilia Day, next April".

I had a telecon with Robert Girvan and Gareth Brown at the Scottish Health Department on the morning of 20 January 2016. Officials are in the process of working on an options appraisal for the Scottish Health Minister, and wanted our input into the process.

They essentially wanted to know whether we thought it would be possible for the five Alliance House entities to make different levels of payments to Scottish registrants compared with those in the other three UK countries. Whilst a number of changes to existing arrangements might need to be made – eg the Skipton Fund agency agreement with DG would have to be changed; funds going to the charities would have to be restricted, with clear guidelines on how money was to be spent (without cutting across trustee discretion) – and the Scottish Health Department would have to agree changes with DH, my best guess was that it would theoretically be possible. However, I stressed that for a proper view they would need to take legal advice. We also flagged that it would be quite controversial for the organisations to be having to make differential payments, but that in itself wouldn't be a reason not to do so, if there was clarity as to how and why this was happening.

They confided in us that whilst there has been a lot of focus on setting up a Scotland-only organisation to make payments, they hoped that if additional money could be distributed to Scottish beneficiaries/registrants quickly, in a couple of years the appetite for a Scotland-only organisation would fade. They were aware of the cost benefits of not having to set up something separately, although I stressed that managing different arrangements for different countries may mean we would need more resources.

They said they would continue to talk to us as things progressed. However, in the light of the DH consultation, Scotland will probably have to rethink its planned approach.

Winter fuel payments

There have been no further developments regarding Shona Robison's suggestion to distribute some of the additional £25 million announced by the Prime Minister in March 2015 via increased winter fuel payments to beneficiaries. During the debate in the Commons on 16 December 2015, the Minister remarked that the administrations in Wales and Northern Ireland had yet to give her their responses to the proposal.