

16th March 2017

The Lord O'Shaughnessy
Parliamentary Under Secretary of State
Infected Blood Consultation Response
Department of Health
Room 164, Richmond House
79 Whitehall
London
SW1A 2NS

Re: Infected Blood: Consultation on Special Category Mechanism and Financial and Other Support in England

I write in relation to the above mentioned consultation and further to Nicola Blackwood's Ministerial Statement to Parliament on the 6th March. I am responding to the consultation specifically on behalf of my constituents who are co-infected and I am not making a representation in relation to those with mono infections.

As you know, I have campaigned on behalf of victims of the Contaminated Blood scandal for many years, and received many assurances from the former Prime Minister David Cameron, as well as the current Secretary of State that no one would be worse off under this consultation. I have made numerous representations on behalf of my constituents about the importance of discretionary payments and how much these are relied upon, as well as the distinction between those who are infected with Hepatitis C and those who are co-infected with HIV/Hep C and other viruses.

Firstly, I welcome the decision not to outsource the payment mechanism. I would ask the Department to reflect carefully on concerns about the existing administration by beneficiaries and interested parties alike and to ensure that the causes of concern are not repeated in the new administration.

However, I read the remainder of the consultation paper with great alarm. It seems to me to disadvantage the co-infected quite markedly, particularly by taking away the expected annual payment increase, based on an 'expectation' of a rise in claims by those with Hep C for more substantial support. While I have no wish to affect the claims of others, it cannot be to the detriment of the co-infected victims.

The consultation proposes to more than halve the budget for discretionary support, which will cause great concern to many who rely on these regular top-up payments. I fully appreciate that many of the 'discretionary' payments tended to become fixed. This is not the fault of those who receive them, but of the system of finance set up after the events which caused them to be beneficiaries. I would urge the Department to consider, in greater detail, the level of discretionary support currently being utilised and to ensure this is, at the very least, maintained; preferably as part of a more permanent and transparent arrangement, to mitigate the cap-in-hand approach of the discretionary system, whilst allowing some flexibility.

The Impact Assessment attached to the consultation response, under 'Policy Objectives' states that the reformed scheme should "not financially disadvantage existing scheme recipients in terms of what they could reasonably have expected to receive under the old, unreformed scheme". I do not see how that objective could be achieved without the narrowest and meanest interpretation of reasonable expectation, bearing in mind my paragraph above in respect of discretionary payments.

The Impact Assessment also says that the scheme should be "acceptable to the majority of scheme recipients". This misunderstands the distinction between beneficiaries and must not be the case. The 'co-infected' group of victims are by their nature a minority; and great weight must be given to that. Of the 1243 originally infected, only 250 or so are alive today. If it is the Government's intention to form a scheme that is acceptable to the 'majority', then such calculation should not include the co-infected – who this consultation sets to unfairly disadvantage – within these reforms.

Finally the Equality Analysis sets out in paragraphs 6:10 and 6:11 the Government's belief that not guaranteeing the regular, fixed support received by some through discretionary payments is 'fair and reasonable'. And in 7:29, it relates this reduction to said discretionary payments to a requirement to 'ensure fairness to all groups of beneficiaries'.

This cannot be right. A number of those co-infected were effectively given death sentences, often when very young, as a result of contracting HiV. They have had to live with the combination of infections which has had a markedly different effect on their lives from many who contracted Hep C, a fact recognised by the distinction in payments for Hep C, but crucially also by the uplift in payment for those who developed the more serious consequences of Hep C.

The arguments for greater and more generous access to such payments, which I have supported, and have been made for many years, were never intended to be at the expense of those who are co-infected, and the equality statement shows a lack of awareness of the long term lifetime consequences of co-infection.

And I am genuinely astounded, and on behalf of those I represent, deeply hurt, by the final sentence in paragraph 7:29 which says that those who have their payments reduced 'could be expected to adjust to the change'.

Let me spell out what that sentence is saying.

Those who were infected with HIV/Hep C by the NHS, through no fault of their own, who have spent years pursuing answers as to why, which have been denied by the Government as it has refused a public inquiry, who have endured the misery of their illnesses and the impact on those around them, who have seen hundreds of their friends die- nearly 80% of those similarly affected-, who have sought and been promised help in a reformed financial system and accepted at face value an honest commitment from David Cameron that whatever happened they would not be worse off, are now expected to accept a reduction in their standard of living, for however long they have left, because they can be 'expected to adjust to the change'.

I am quite sure, that on reflection, you will appreciate the distress that such a phrase implies.

I would urge you and Nicola, as part of the consultation process, to review these considerations and either take the 'co-infected' separately, or, at the very least, ensure they are not disadvantaged by the rising numbers of those with Hep C making claims.

Kind regards

Rt Hon Alistair Burt MP