

## **Reference Group on Infected Blood**

### **Independent Facilitator's Report**

#### **1. Background and Purpose of the Reference Group**

1.1 During the 1970's, 1980's and early 1990's thousands of people who were given NHS supplied blood or blood products were infected with HIV, Hepatitis C (HCV) or both infections as well as many different genotypes of these viruses. People were also infected with other Hepatitis viruses, vCJD and may well have been infected with viruses and infections which are unknown about at the present time.

1.2 Lord Robert Winston has called this "The worst treatment disaster in the history of the NHS".

1.3 Currently the Government provides financial assistance and support services to those affected and infected, as well as to some uninfected family members. These payments are made on an ex gratia basis. Delegates argue that the existing approach is inconsistent varying by different viral infections and treatment of comparable groups. They further argue that it fails to address the full impact experienced and the various degrees of poverty endured.

1.4 Payments for infected and affected individuals vary significantly and delegates at the meeting made reference to this.

1.5 The Government has committed to reforming the current schemes and plans to launch a public consultation by the end of 2015.

1.6 To help inform the development of the consultation document the Department of Health organised a one-off Reference Group Meeting on 5 October 2015.

1.7 The purpose of this meeting was to hear the views of some of those affected in preparation for the formal consultation process.

#### **2. Reference Group Structure and Composition**

2.1 The Reference Group Meeting was hosted by an independent facilitator who had no previous knowledge of, or involvement with, this subject. The Department of Health did not attend or send an official note-taker. This was to ensure delegates felt able to speak openly.

2.2 In the absence of an official note-taker notes of the various discussions were kept by the facilitator. While this helped create a sense of openness it also limited the amount of detail captured. In addition the lack of specialist knowledge on the part of the facilitator slowed down some of the discussions while additional clarification of points raised was provided.

2.3 Delegates are thanked for their willingness to provide such clarification and for sharing some of their own contemporaneously-kept notes which provided important detail not captured by the facilitator on the day.

2.4 The following three groups were invited to nominate 5 delegates each or 15 in total with the purpose of providing an opinion on seven affected categories identified by the DoH:

The Haemophilia Society

Tainted Blood

Contaminated Blood Campaign

2.5 To provide a focus for the discussion delegates were asked to consider and offer their views on the following four questions

- What financial assistance or support services would people value in a new scheme?
- Why would they value these things?
- How would they prioritise their suggestions?
- To whom would they prioritise and how?

2.6 The event was attended by eighteen delegates. Five delegates from each of the three invited groups plus three delegates from Wales. Representatives from Northern Ireland were also invited but were unable to attend. The DoH indicated that Scotland is already consulting separately with them.

2.7 A delegate expressed the opinion that the meeting was unrepresentative of the whole blood community as only a very small number of delegates came from that group. It was noted that in part this was exacerbated when two delegates from the group were unable to attend.

2.8 Discussions were highly participative, wide ranging and multi-faceted throughout the whole day. Issues were discussed in as much detail as possible and it is highly likely this would have happened to a much greater degree had there been more time.

2.9 The discussions also explored differing views and differing perspectives between delegates. There was widespread agreement on many points, and understandably, less so on others. This is entirely valid in the circumstances given

the very wide range of issues and circumstances that exist both for those infected and affected.

2.10 All of this is reflected as much as possible in the report which seeks to capture the key elements of the discussions which took place throughout the day with a view to informing the development of the consultation process. It is imperative that the design of the formal consultation process takes full account of the very wide and diverse range of circumstances and requirements - medical, financial, social, familial, geographical, to mention just a small number - that obtain for those affected by this issue.

2.11 To provide the most accurate summary possible of the discussions that took place, the report lists the points raised by delegates, rather than taking the more usual approach of writing a continuous narrative.

2.12 Additional documents submitted to the facilitator are appended to this report. These provide further information on aspects of the overall discussion that may not have been fully captured given the absence of an official note-taker, or that may not have been explored in sufficient detail, given the time constraints, the overall size of the group, the need to give all participants an opportunity to comment, and the facilitators lack of specialist knowledge.

### **3. Question 1 - Financial Assistance / Support Services**

3.1 Delegates rejected the way this question was posed; the interpretation of the wording was perceived as suggestive of a 'tweak' to the current arrangements, rather than a commitment to achieving a full and final financial resolution.

3.2 Delegates also emphasised that it is impossible to anticipate what issues might emerge over time, No one knows what the full impact of the viruses might be, or what might emerge from any unidentified viruses contained in the infected blood. The issues may be due to the identification of further viral/prior infections, long-term detrimental effects from antiviral therapies, and viral effects. Co-morbidities associated with ageing or other as yet unidentified, but associated, influences may become relevant.

3.3 With regard to financial settlement, delegates felt that three mechanisms should be put in place to take account of individual preferences

- A future-proofed, full and final lump sum settlement
- A part settlement, part ongoing payment linked to the Retail Price Index
- A regular enhanced payment linked to the Retail Price Index

3.4 All payments must be tax free. They must also be sufficient to lift individuals out of the need to claim benefits (but failing this should not be a bar to claiming benefits).

3.5 Delegates unanimously favoured the provision of a final, conclusive and future proofed financial settlement. Those affected want full account taken of the difficulties and damage caused by contaminated blood and the future implications of living with the consequences. The vast majority of delegates want lump sum and enhanced on-going payments linked to the Retail Price Index.

3.6 All payments must be tax free and must not be a bar to claiming benefits. However the priority must be to ensure that those affected and infected become financially secure enough to not have to claim means tested benefits.

3.7 It is vital that any new approach is future proofed and takes full account of the possibility of further infected blood-related difficulties emerging in the future for affected people. A public health expert should be consulted to help identify how to deal with this.

3.8 Delegates emphasised that there must not be any immunity or exemption from Governmental responsibility that would preclude future litigation. It was also emphasised that if the lump sum and/or on-going payments are high enough this would cover many issues which might emerge over time without the need to have to continually ask for more support.

3.9 The impact on all those affected whether alive, bereaved or deceased must be taken into account when computing any settlement. This includes spouses, children, partners, parents and extended family members, whether infected or not. It must also address fairly those who are classified as 'self-clearers'.

3.10 It was also made clear that the carers of living infected individuals have been forgotten and that carers need to be fully included in any settlement.

3.11 People must have enough to buy a house, live comfortably and securely and not be reliant on benefits. Financial and housing insecurity is a major difficulty for many. Independence, not dependence, must be the priority

3.12 Access to the best possible physical and mental health support, social care and nursing help, travel and life insurance is essential. Lack of access to insurance and mortgages creates enormous difficulties for a large number of people. Many affected and infected people cannot get accident, sickness or critical illness cover or premiums are excessively weighted so as to be unaffordable so this should be incorporated into any settlement.

3.13 It is essential that those who do not benefit under the current arrangements or who are simply unknown at this time, are found and advised of their entitlement. For example, spouses or partners whose condition was not recognised initially or until much later, children and/or parents who have died or lost touch with the trusts that provide support. Any contact must be sensitive to individual preferences of privacy and anonymity. Those exposed to viruses but currently excluded from support as 'natural clearers' must be recognised and included in any settlement arrangements.

3.14 A full and final financial settlement and/or ongoing payments for parents whose children died of conditions caused by contaminated blood products must be

provided. There must be a similar provision for widows, widowers and bereaved partners. Recognition, support and financial redress should be offered to parents and close family carers of those affected, but still living.

3.15 In calculating any type of final settlement, full account must be taken of the lack of educational accessibility due to interrupted/disrupted/curtailed education resulting from ill health and/or psychological impact of being infected/affected, and particularly the associated stigma experienced.

3.16 Full account must also be taken of the impact ill health has on infected and affected people to have a career or earn a living. Many are physically unable to work or have had to stop working due to their health or the stigma they face at work.

3.17 It is also essential that full account is taken of the loss of ability to have any, or further, children as a consequence of being infected by contaminated blood or blood products. This loss is further amplified by the fact that infected people are denied the sense of joyful anticipation that is very much part of normal life for parents-to-be.

3.18 Whatever new approach or settlement arrangements are put in place must be designed in such a way as to take account of any future issues that may not be apparent at this time. However reassessment or on-going appeals for further support must not be required should any such issues occur. The possibility of future issues arising should be incorporated into a final settlement.

3.19 Payments must not be income related or subject to means testing. Parents, partners and/or the household must not be required to meet any costs arising out of illnesses or conditions caused by infected blood and neither their income nor joint savings should be taken into account. Payments must not be discretionary.

3.20 Parents, partners and/or household income must be completely disregarded when calculating any payments including benefits. The affected individual must be at the centre of all arrangements put in place..

3.21 The current arrangements whereby financial support is administered by trusts and charities must be terminated.

3.22 The reference group considered that many infected and affected individuals want the personal impact of infection on their health, finances and quality of life recognised in a way that does reflect lesser or greater damage/losses incurred, especially where multiple or super-infection exists. However, some feel that any differentiation on the basis of diagnosis, illness progression or prognosis is discriminatory and unacceptable. Those with Hepatitis C believe that arbitrary stages are discriminatory and want them abolished. Opinions on this issue should be explored within the consultation process to establish a way forward.

3.23 It was stressed at the meeting that attaining an SVR post-treatment must not impact eligibility or level of pay-out. Delegates emphasised that the cumulative risk of cancer and previous health impact still remains in such instances.

3.24 Any new mechanism must not be “charitable” as such arrangements are both denigrating and devastating to those affected.

3.25 The trusts and charities having arrangements linked to loans, some of which are secured against registrants’ houses, should be required to immediately rescind these arrangements. Any request addressed by a loan, or charge against the registrants house, should be repaid and converted to a grant. Loans secured against the registrants home should be written-off and any interest charged should be reimbursed to the beneficiary.

3.26 No existing charge on a property should be required to be repaid or included in any settlement.

3.27 An entirely new, non-charitable organisation totally separate from and independent of government, the current mechanisms, staffing teams and bodies must be established to administer funds and work pro-actively on behalf of everyone affected. Delegates stressed that this organisation must work in an empathetic and considerate manner at all times. This is crucial. Many felt that both empathy and consideration have been especially lacking up to now. This has caused a great deal of unnecessary additional difficulty and suffering for many people.

3.28 The reference group were all in agreement that the staffing of any such organisation should not include any of the current personnel and should start afresh with completely unconnected staff.

3.29 The new organisation must be fully representative of those it purports to serve. The financial system should be kept as simple as possible and there was a suggestion that the finance and support services should be kept separate and distinct from each other.

3.30 There must not be any grant or charitable element within any new payment structure and access to the new arrangements should be a simple and straightforward process

3.31 Any new arrangement must, of necessity, have the capability and resources to anticipate future needs, enable priority access to new therapies and treatments for everyone affected by this issue.

3.32 The new organisation must engage actively with the joint HCV/HIV task force being set up by NICE.

3.33 In its work the new organisation must obtain the widest views available of co-infections such as CJD and other pathogens in addition to HIV/HCV. Its membership should include representatives from HS,TB, CBC and leading haematologists who were not practising at the time of the original infections, as well as hepatologists and infectious disease experts. It should also include a representative cross section of the infected population as well as independent campaigners who can ensure that the day to day realities of those living with illness and infection remain central to the functioning of the organisation at all times.

3.34 Infected/affected individuals, including independent campaigners, other campaign groups such as 'The Forgotten Few' and 'The Manor House Group', must be included in the consultation process as it develops.

3.35 Any medical experts assigned to assist the consultation process must have not been practising at the time of the contaminated blood & blood product infections occurred and must be seen to be independent from government.

3.36 The new organisation must also be sustainable in the long term and independent of any spending review. It is essential that its workings and deliberations are transparent with publicly available, complete and un-redacted, board minutes

3.37 All financial mechanisms and support services must be holistic and not limited to a prescriptive list. Any treatment paid for by victims, linked to their infection should be reimbursed. Reimbursement must not be limited to virus related treatment. For example: fibroscans, HCV treatment, IVF and surrogacy.

3.38 All affected individuals must not be subjected to any form of reassessment. Repeated assessment and unnecessary form filling is distressing, unhelpful and disrespectful to the personal dignity of people enduring difficulties not of their own making.

3.39 Although assessments linked to new financial arrangements were not favoured by many, others were concerned that extreme financial or health impacts would not be captured by a standardised scheme and some form of optional assessment may offer a solution in those cases.

3.40 The infected community must receive the same priority access to comprehensive medical care as that available in the Republic of Ireland through their Health Amendment Act Medical Card (HAA). This card provides priority access to the latest drugs/treatments, dieticians with specialist knowledge of HIV and or HCV; access to on-going tests and monitoring together with testing for infections associated with any virus regardless of whether an individual has developed an SVR. It was stressed at the meeting that attaining an SVR post-treatment must not impact eligibility or level of pay-out. Delegates emphasised that the cumulative risk of cancer and previous health impact still remains in such instances.

3.41 The Irish HAA card also gives its holders access to an advocacy service providing back up support and advice and ensures that the cardholder receives all the services they are entitled to as someone who received infected blood.

3.42 A number of delegates mentioned that the 2009 Archer Inquiry recommended setting up such an advocacy body in the UK. It was further mentioned that in 2014 the Science & Technology Committee also said one should be established to represent bleeding disorders and provide authoritative support on health and medical access/treatments/issues.

3.43 The Government must use financial resources such as the Contingent Liability Fund or other non-departmental source not subject to the spending review. Funds must not come from the DH budget. Delegates were strongly of the opinion that it would be wrong to deprive other ill people of the money needed to meet their health requirements.

#### 4. **Question 2: Why would you value these things?**

4.1 The current schemes are seen as paternalistic, divisive and indifferent to the overall needs of those affected, their families, spouses, partners, children and dependants

4.2 The dignity, self respect and quality of life of those infected and affected and their families and dependants is paramount and should form the basis of any new arrangements.

4.3 Insofar as existing arrangements are concerned there is no evidence that full account is being taken of the wide range of difficulties that infected and affected people are dealing with, the extent to which their quality of life has been diminished, the losses they have to contend with such as the inability to have any, or further children, the everyday facilities and opportunities that are denied them by virtue of their illnesses, and the severity of the conditions they are enduring and have endured for the majority of their lives. Many infected and affected people have been either marginalised, stigmatised, forgotten or ignored. This includes those who are considered natural clearers, those who have achieved SVR and those with secondary infections.

4.4 It is essential that the needs of all are responded to. There are many variables to consider so a fresh start and a much more comprehensive and flexible set of arrangements needs to be put in place. No single solution has been identified that addresses all issues adequately – such an approach would not work. Any new set of arrangements must be flexible, offer choice and provide for extremes

4.5 Delegates agreed that the current system needed to be dismantled and replaced. The differences and variations (level/qualification of payments) between existing mechanisms must be addressed in any new arrangements so that everyone experiences an uplift in financial terms.

4.6 Those who have been infected through no fault of their own must no longer go through long, complex and embarrassing benefit application processes.

4.7 There were differing views on the issue of whether previous payments of any type should be taken into account or any similar reduction imposed within any new payment structure. A number of delegates were in favour. Others argued that the issue of correction of past inequality should be explored in the consultation and the community should be asked how they want to see past lump sums, ongoing payments, grants and loans - whether from ex-gratia payments or legal settlements -

treated in any new arrangements. Should a line be drawn under the past or should any disparities be seen to be rectified before new arrangements are introduced?

4.8 There was unanimous agreement that any new payment structure must recognise and respect the dignity of those affected as a priority.

4.9 Payments must be excluded from any computation of benefits for other purposes and must be tax free. The point was also made that this should only become necessary if any new arrangements fail to remove the continued need for such benefit claims.

4.10 The social care and insurance benefits of the Irish system, and the dignified and respectful manner in which they are provided, are particularly valued by its beneficiaries. Delegates felt the infected/affected community may want a similar approach here in the UK and this should be explored within the consultation

## **5. Questions 3 and 4: How would you prioritise your suggestions and to whom?**

5.1 Both questions were considered inappropriate. Individual needs vary widely and it is unfair to prioritise one group over another.

5.2 The list of groups invited by The Department of Health is not inclusive of everyone that needs to take part in the wider consultation. That situation must be rectified as a priority. See para. 3.34 also.

5.3 Rather than include a limited number of groups in the consultation process, it was widely agreed that everyone in the community should have the opportunity to take part in any consultation process.

## **6. Additional issues**

6.1 The official consultation process must be well thought out, thorough and targeted correctly. It must be totally confidential and carried out in a sensitive and considerate fashion.

6.2 It was also felt that there was insufficient official expertise/specialisms at the meeting to furnish in-depth comments on the specialist requirements of the consultation process. Concern was also expressed that actuaries, independent lawyers and health experts specifically are not part of the process at this stage. They must be included in the consultation process and any forthcoming decision-making.

6.3 Legal advice and financial advice through accountants/actuaries should be provided to the infected and affected community throughout the consultation process on the same basis as similar advice is made available to those in Scotland.

6.4 Delegates want their own particular organisation, plus a representative cross section of affected people to participate in helping design the consultation document/process. The reference group also recommended they be allowed to beta-test the consultation questionnaire in good time to make amendments before it is distributed.

6.5 It is essential that, whatever the precise format of the data gathering process, any questionnaires used are well designed, include a high proportion of open questions, offer the option of free text responses, and provide plenty of space for answers. There must not be any 'either/or' questions or other types of limited option questions.

6.6 Whatever form the consultation takes steps must be taken to ensure inclusivity and anonymity as far as is possible. There were concerns that surveys can be tracked on-line in particular or in a paper exercise if the process is not run entirely independently. It was suggested that some might prefer the option of face-to-face meetings rather than online or postal surveys. A conference to glean views was also suggested as many members of the community want to have the opportunity to speak for themselves, similar to the regional meetings conducted in Scotland.

6.7 The consultation must be mindful that individuals are fearful of their details being exposed and their privacy compromised. Some delegates would be prepared to test the consultation process prior to release to ensure there are no bugs / inadequacies.

6.8 Delegates were unhappy at the amount of time they were given to prepare for The Reference Group Meeting. They want to ensure sufficient time is allocated to the consultation exercise to ensure that all stakeholders are engaged. This is imperative given the very wide spread and diverse constituency of affected individuals and their families.

6.9 Without adversely affecting the thoroughness of the consultation process delegates want this entire matter to be brought to as early a conclusion as possible in the circumstances, given the length of time that affected people have been dealing with this entire matter. It was also suggested that the government should make interim payments to the infected/affected community..

6.10 An acknowledgement in the form of a permanent, public memorial was also suggested as were two official apologies - one for the tragedy and one for the resulting lack of recognition over many years. It was further suggested that these ideas should be included as options within the consultation process.

6.11 A delegate expressed concern during the meeting that the views gleaned at Reference Group Meeting would not be acted upon. This would, in turn, impact adversely on the design of the consultation process and diminish its capacity to deliver substantive change. Delegates again stressed the need for substantive change rather than a modification of the existing arrangements, and the implementation of a full and final financial resolution.

## **7. Facilitators Recommendation**

7.1 While it does not form part of his formal remit, the independent facilitator recommends that the formal Consultation Document which will be written in due course is made available to those who attended the Reference Group meeting prior to its publication so that any suggestions they may wish to make can be considered for inclusion .