

# Expert Report to the Infected Blood Inquiry: Psychosocial Issues

January 2020

The logo for the Infected Blood Inquiry, consisting of a white circle containing the text "Infected Blood Inquiry" in a bold, sans-serif font.

**Infected  
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## INTRODUCTION

This report has been written by a psychosocial expert group, which was appointed by Sir Brian Langstaff in 2019 on behalf of the Infected Blood Inquiry (Inquiry). The group's seven members were chosen on the strength of their psychosocial experience and expertise in many aspects of illness and healthcare. The names of the group members, together with their areas of expertise, are listed at the end of this document.

In the letter of instruction from the Inquiry, we were asked to respond to a series of specific questions, which are shown in the Appendix. The main part of this report provides the responses of the group to each of these questions. For some of these, particularly those focusing on communication and support, we have been asked to describe 'best practice' in healthcare for people and their families, who are faced with major health problems and the associated treatments. We were also asked to consider the consequences of failing to meet best practice standards of care, and to link this to the experiences of witnesses who gave evidence to the Inquiry. We have also tried to capture the range of experiences and impacts of infected and affected individuals, who gave witness statements, and to link this to what is known more generally about the psychosocial impacts of major illnesses on individuals and families. It is important to acknowledge that there is no such thing as a typical pattern of responses, since these will depend on many factors, such as the life-stage and coping patterns of the infected person, their social and cultural background and the healthcare settings, in which diagnosis, treatment and ongoing care took place. A consideration of these contextual factors is also embedded in this report.

Members of the group attended the hearings, read transcripts and watched YouTube videos of the witness statements presented to the Inquiry. The Inquiry team provided us with 41 transcripts and 47 witness statements, to reflect a range of psychological and social issues experienced by people who were infected and affected. In this report we have attempted to provide a picture of the evidence from those witness statements about the psychological and social impacts of the illnesses and treatments arising from infected blood, most of which occurred some time ago. We have been asked to express our views from today's perspective, regardless of what may have been the practice or known about these matters in previous decades.

### **13.1. Psychological impacts of infection on people infected and affected.**

All long-term illnesses have psychological impacts on those with the illness and those who are close to them. Any one illness will have effects on an individual's emotional state and their self-identity, as well as giving rise to adjustments to the pain, incapacity and demands of long-term treatment and lifestyle change (Stanton, Revenson & Tennen, 2007; Hegelson and Zajdel, 2017). For people who received infected blood or infected blood products, the psychological impacts were compounded over a long period of time by the experience of further serious medical problems and intrusive treatments, which in turn resulted in many debilitating symptoms and side effects. Although less is known about the cumulative psychological effects of living with multiple medical conditions (Suls, Green and Boyd, 2019), it was very clear from the witness statements that there was a wide range of serious psychological impacts, on both infected individuals and those caring for them over a long period of time. This is consistent with research evidence in other health settings, which has shown a close response relationship between the number of health problems a person experiences and the likelihood of depressive symptoms (Gunn et al, 2012), and impaired quality of life (Moussavi et al, 2007). Nevertheless, it also important to note that a large number of studies,

including those in people with hepatitis C virus (HCV) and human immunodeficiency virus (HIV), have shown that the psychological impact for any individual is only partly related to the clinical severity of their condition. Impacts on quality of life and well-being are strongly influenced by a number of psychological and social factors, such as the person's perception of their condition, their coping responses and the quality of their social support (for example, Castera et al, 2006; Gordillo et al, 2009). Although equally profound, the timing and pattern of psychological impacts may be different in people being treated for an ongoing condition, such as haemophilia, compared with those who were previously healthy and infected through blood transfusions following accidents or problems in childbirth.

The psychological impacts arose from a range of issues. Many witnesses report long-term physical and emotional changes due to the acquired infections and the associated treatments. Early treatments of HIV and hepatitis C led to very severe and multiple physical and mental side effects. These treatments were described by recipients and their families as “brutal” and as “a blunderbuss type of treatment” that often led to extreme fatigue, severe pains, nausea and feeling depressed, aggressive and in some cases, suicidal. For hepatitis C, even if patients and their families managed to cope with the side effects and completed the course of interferon (usually 48 weeks), this was not always effective, with the virus remaining active. If the treatment was successful, patients also continued to experience ongoing side effects, including depression and developed a variety of conditions associated with being immune compromised, leading to the view expressed by several witnesses that their treatments had probably done as much, or even more harm, as the hepatitis. Even when hepatitis C infection had cleared, witnesses still worried about fears of re-occurrence, which resulted in ruminative thoughts and surveillance of body symptoms, both of which can have detrimental effects on emotional well-being (Almeida et al, 2019).

At the time when this happened, infected and affected individuals also had to cope with considerable uncertainty about the infected person's condition, as well as their future health. The relative lack of knowledge at that time about the likely trajectory of infections from blood and blood products, combined with the limited information which was provided by healthcare professionals (see question 13.4), would have been a major source of stress for both infected and affected individuals. Fears of further complications and other possible conditions, such as vCJD (variant Creutzfeldt–Jakob disease; see question 13.9.1), would have given rise to heightened levels of anxiety about current and future health. As a result, there may well have been greater surveillance and checking for further worrying symptoms.

Although there is not a large research literature on the psychosocial consequences of HIV and hepatitis C contamination of blood products (Riva et al, 2017), the negative effects on academic, behavioural and social adaptation have been described (Colegrove and Huntzinger, 1994) and these were evident in many witness statements. Serious psychological impacts occurred in childhood and adolescence in relation to school, with many witnesses describing a range of very negative experiences, including social exclusion, bullying, and frequent periods of absence for both physical and mental health reasons.

The stigmatising aspects of HIV and hepatitis C, which are described in greater detail later (question 13.7), very often resulted in avoidance, secrecy and fears of negative reactions and rejection by others. While reacting in this way is understandable, this carries a psychological cost, since it has been widely reported that avoidant coping in the context of a long-term illness is associated with poorer mental health and worse illness adjustment (Stanton et al, 2007), and this was certainly apparent in many witness statements. While those who were placed in a school with a haemophilia unit reported initial positive effects of being in a safe environment with plenty of support, many witnessed serious health problems and death in

their peers at that time and later on. As one witness recounted: *“I’ve been to around 90 funerals in total but there was one heavy year where I attended 70 funerals of people who were part of the haemophilia community, one of them being my own brother’s. I was very close to my brother. He was like my right-hand man. The heartache was too difficult to cope with.”* These experiences, which resulted in grief responses and survivor guilt, have persisted into adulthood for many and left those who survived with enduring bad memories. For example, another witness said *“just think why me? Why am I still here? What have I done differently? I just don’t understand why I’m still here. Was it different Factor VIII? Was it different concentrates? Was it different lifestyle? We’re all in the same place, you know. Okay, I was there a couple of years earlier than others but, yeah, it’s just guilt of losing all those friends”*.

Many witnesses were not aware of having been infected as a result of treatment during childhood and often were not informed until late adolescence. For many, their parents lived with the knowledge and struggled with the challenge of keeping secrets from their children and siblings, as well as feeling guilty for allowing them to have received blood products. A major impact of being told about being infected was on self-identity and challenged their view of themselves as a vital young being and their ability to imagine a future. Many also talked about how the news made them question whether they would be able to have intimate relationships, have a family and how their career choices would be affected. Development of self-identity is a key developmental task for adolescents and can be significantly affected by the diagnosis of a chronic life-limiting illness, such as HIV and/or hepatitis C infection (Christie and Viner, 2005).

A close attachment with a parent figure is an important factor in the development of resilience and self-esteem in children and adolescents, particularly in those living with chronic illnesses (Doty, Davis and Arditti, 2017). Witnesses describe how the loss or potential loss of a sibling/parent/carer due to infection had a significant impact on their mental health. Parents described how they were unable to provide the emotional closeness they believed they should have been able to, as a result of frequent medical treatment and hospital admissions.

There is a significant psychological impact of serious and/or constant ill health in adolescence. Young people with chronic illness are more likely to develop emotional difficulties, which will include anger, depression, PTSD (post-traumatic stress disorder), shame, guilt, fear for oneself and of infecting another person, grief, survivor’s guilt, risk-taking behaviour, disbelief, shock, social isolation and/or helplessness. The development of mental health problems in adolescence is a significant risk factor for ongoing and enduring adult mental health problems, especially if not treated during adolescence.

For both infected and affected individuals, their psychological state was often exacerbated by deteriorating relationships with healthcare professionals (see question 13.4). Many witnesses describe poor quality communication, and receiving insufficient or misleading information, which resulted in even greater fear and uncertainty, as well as a loss of trust and respect, both of which are fundamental for effective healthcare.

For those who survived into adulthood, many described a range of negative psychological issues linked to working life. Frequent periods of ill health, together with fatigue, made it very difficult not only to attend work regularly, but also to perform well in the workplace. As a result, many infected adults reported reduced job opportunities and job prospects. In couples, this often placed an increased responsibility on partners to provide sufficient income. For the infected person, limited work capacity and the concomitant financial effects only served to increase feelings of low self-esteem (see question 13.3).

Although the great majority of witnesses describe negative psychological effects arising from their experiences in school, healthcare settings and the workplace, a minority describe positive reactions and support. Some were able to draw positive effects from their illness and treatment experiences, which led to personal growth and a willingness to support others who were coping less well. However, this was only reported in a small number of witness statements. The dominant picture is one of a wide range of negative psychological impacts, often with devastating effects on day-to-day functioning and quality of life. These impacts occurred in the context of many negative social effects arising from the relentless health problems and treatment side effects, together with the distressing levels of stigma that were experienced. In many ways, the negative social effects and stigma described in the witness statements provide the most powerful picture of the psychosocial impacts on both infected and affected individuals, and these are described in much greater detail in response to questions 13.3 and 13.7.

**13.2. The psychological impact, on people infected and affected, of having to continue to be treated by, or interact with, professionals or medical institutions whom they hold responsible for the original infection and/or the impact of a loss of trust more generally in the medical profession or the NHS. In addition, the impact on those who must continue to receive the same treatment that was itself the cause of their infection. (The Inquiry has, for example, heard from witnesses who no longer feel able trust clinicians or NHS bodies, but who continue to require treatment for lifelong conditions such as haemophilia or thalassaemia.)**

Many infected and affected witnesses describe a range of negative emotional and behavioural reactions towards individual healthcare providers and the healthcare settings where treatment resulted in infection with HIV and hepatitis C. These reactions were clearly exacerbated by the perceived failure of these individuals and institutions to be accountable, and to offer acceptable explanations and apologies (see question 13.4 for an overview of the communication problems). As one witness observed: *“no doctor has ever acknowledged the role the NHS played in infecting me with HCV”*. In other areas of healthcare, in which medical errors and patient safety problems have occurred, common emotional reactions included anger, mistrust and resignation (Elder et al, 2005), all of which have adverse effects on behaviour. In other areas of healthcare, a commonly reported behavioural response was partial or total avoidance but, given the seriousness and chronicity of the health issues, this was not possible as patients still needed to be treated for their original and acquired medical problem. Witnesses also report that the feelings of mistrust and suspicion often resulted in other related worries, such as being concerned about upsetting healthcare staff, and that this would have further adverse effects on the quality and availability of their care.

The psychosocial impacts described by witnesses are consistent with those reported in surveys of patient and family responses to adverse medical events (Southwick et al, 2015). These revealed a lack of both healthcare professional and system accountability, combined with deficient and often disrespectful communication as the major reported criticisms. These resulted in a range of negative outcomes, including post-traumatic stress, financial hardship, permanent disability and loss of trust in both providers and the system.

Breakdown in trust has been shown to have deleterious effects on quality of care across all serious health problems (for example, Ernstmann et al, 2017). Patients need to have trust in their healthcare provider's ability and willingness to provide the best possible treatment. When this trust is compromised or damaged, communication is adversely affected, together with the patient's willingness to follow treatment or advice. While a few individuals were able to transfer to another healthcare provider, this did not usually happen. Consequently, having to continue attending for healthcare in the treatment setting where the infected blood had been given was clearly a major source of distress for many individuals.

Research also shows that trust is one of the key factors determining the ability to follow treatment regimens in adolescents. Loss of trust in medical professionals will lead to failure to attend appointments and the ability to follow medical self-care strategies. Many witnesses describe the distress they experienced from having to continue to be treated by, or interact with, professionals or medical institutions that they held responsible for the infection with HIV and/or hepatitis C. For adolescents who continue to receive blood products to manage their bleeding disorder this was a particular challenge. For a range of social, psychological and biological reasons, treatment adherence is known to be problematic in adolescence across all health problems and was therefore particularly difficult in this context (Spinetta et al, 2002).

### 13.3. Social impacts on infected and affected individuals.

As noted above, most studies of the psychosocial social impacts of chronic conditions have focused on single diseases, whereas this Inquiry focuses on multi-morbidity which refers to the conjoint presence of multiple (physical and mental) health problems (Suls, Green, Boyd, 2019). Many infected individuals were already having to cope with a serious condition, and multi-morbidity arose in this context from transfusions of infected blood products, mainly due to haemophilia, leading to HIV-related illnesses and/or hepatitis C infection. Many people experienced both these groups of conditions and may also have been at risk of developing vCJD. This section examines the social impacts of infection and the additional side effects of drug treatments on the lives of those with HIV and/or hepatitis C infection and those close to them, also affected. The extent of the disruption and hardships experienced was influenced by individuals' social circumstances, including their age, life stage, economic situation and social support.

A key impact affecting younger people with haemophilia was the effect of their disease and treatment on schooling and educational achievement. This was sometimes affected by having a lot time out of school, especially if they suffered frequent bleeds with severe haemophilia. These gaps in education were described by one witness as resulting in being *"treated like a dunce"* and placed in a remedial class. He also felt on a number of occasions *"... as if I had been written off and that people were just going through the motions because there wasn't much point"*. Following a diagnosis with HIV, many children themselves questioned how worthwhile it was to devote themselves to their GCSEs if they had been told they would not live very long, including *"not reaching your 18th birthday"*. Others would have liked to go to college but knowledge that their life span was limited reduced their life goals.

A key aspect of adolescent development is a move away from depending on parents and the development of social relationships with peers. The development of positive social relationships was already adversely affected by haemophilia, but then this was clearly made even worse with a diagnosis of HIV for many. They describe how, as children and young people, the diagnosis significantly impacted their ability to develop close relationships with peers. The statements contain descriptions of abuse and bullying directed not just against the

infected child but also their siblings. Bullying is a key cause of mental illness in adolescents. Rejection (both real and perceived) by peers is a significant risk factor for the development of mental illness and suicide.

Witness statements describing experiences as children and younger adolescents (pre 13 years) gave many concrete examples of the impact on friendship groups and their immediate concerns about loss of current activities and relationships. As they got older, witnesses began to have significant worries about their loss of future, including the possibility of having a close and intimate relationship or family. Many young people became anxious about loss of friends and their experience of social isolation. The brain fog that was described, and extreme fatigue and other side effects, which resulted from hepatitis C and HIV treatments, had an impact on educational aspiration and achievement. Young adults also described how the burden of hospital visits and medical treatment, and ongoing fatigue, limited employment and career opportunities and resulted in financial hardship.

Health problems directly affected employment and career opportunities, but did so in differing ways. This sometimes involved not being accepted into their chosen career on health grounds, such as a witness who was rejected by the RAF and was eventually employed in a bank. Even when in employment, health problems often restricted career advancement, especially from the effects of severe fatigue. For example, a woman with hepatitis C who worked part-time explained, *“I have no chance of promotion and I can’t apply for full-time jobs simply because of my fatigue. I am not fit enough, and my health has dictated my career path”*. People offered promotion often declined because they felt their health state would not allow them to take on the additional responsibilities.

Witnesses describe how health problems also limited career mobility. For example, a witness who worked in the public sector would have liked to move to a job in the private sector and thought this would be beneficial for his experience and future career. However, he explained that this was not possible as he would not get through the pre-employment screening. Although he was glad to have his current job, he observed *“... my freedom of career, my ability to move was restricted”*. A further constraint arose when witnesses were offered a period working abroad as part of career progression, or were given the opportunity of a job that that required travelling abroad; this had to be turned down and was not an option for them due to HIV visa restrictions and problems of health insurance.

Deterioration in health over time sometimes led to taking up a less physically demanding job. For example, a woman with hepatitis C described how she loved nursing, and wanted to continue and progress in this career, but her physical condition did not allow her to do so. She therefore decided to change her job and worked for social services. Another way of coping with increased health problems was to work part-time, with some people working part-time for much of their post-treatment career due to experiencing extreme fatigue, although this had implications for their earnings and opportunities of promotion. Others found working on zero hours contracts was more helpful, as this gave them greater flexibility to work as and when this was possible in terms of their health. For some people deteriorating health resulted in difficulties undertaking aspects of their job, and led to their having to resign. Job loss was cushioned for some people by being able to retire early on medical grounds. However, many people did not have this option, particularly younger people and those running their own small business, who therefore experienced particular financial difficulties.

Even though each family’s circumstances and responses to HIV and/or hepatitis C infection were in many ways unique, there were also common themes. A major theme related to the impact of reduced health on the employment of the infected person and how this affected their partner’s employment and caring responsibilities. The infected person generally moved



from full-time work to part-time work and over time reached a situation when they had to give up work altogether. This reduction in work or need to give up altogether had a significant impact on family finances and as a result their partner sometimes worked increased hours to pay the bills. For example, a young wife whose husband had contracted HIV, worked at four jobs that required catching several buses and did split shifts, as well as taking on caring responsibilities. She described this situation as “... a *drudgery to try to keep us together as a couple and try to maintain some sort of normality*”.

Women in more senior positions sometimes increased their work to full-time to cope with the financial difficulties, but managed this by paying for assistance at home. For example, a witness in a higher managerial position describes employing a carer to assist her husband and a childminder to look after the children before she got home. However, with all her responsibilities she felt so tired when she got back from work that she would just fall asleep. Other partners managed the demands of care by either reducing their working hours or retiring altogether. For example, a witness with hepatitis C who had herself taken medical retirement, reflected on their situation and commented, “*My condition had a strong impact on my family. My husband had to retire to look after me because I wasn’t well. He didn’t need to retire; he could have carried on working. The fact that he had to give up his job to care for me affected us a lot, both personally and financially.*” Financial difficulties were particularly severe for young couples where both partners became unemployed due to the man’s illness. For example, a witness explains that “*Before his illness we had been comfortably off ... I had worked in retail but now with x (her husband) ill and two young lads I could not work. Finances became strained. It was very stressful.*”

Infected individuals were often very concerned about risks of infection to their partner and a few couples agreed to be celibate to reduce these risks. However, the considerable asymptomatic period between testing positive, and people being aware of their status and of the risks of transmission, meant that some partners contracted HIV and some women became pregnant. In this situation and with limited knowledge of mother to child transmission, medical advice was usually to have the pregnancy terminated, which several women agreed to. This had long-term effects, with the absence of children sometimes leading to marriage break-up, and caused lasting regret. The lack of children and grandchildren was particularly hard for one Asian couple given the strong cultural expectations of the importance of families, and their role in looking after the older generation. The couple decided not to have children as the husband was infected with HIV and reflected, “*how much of a price does one have to pay for somebody else’s mistake, you know? And it seemed huge ...*”. A few couples were able to undergo a relatively new procedure of sperm washing to reduce transmission to partner and subsequently the child, but this process was described as “*emotionally and physically hard*”, especially for the woman, as at the time embryos could not be stored, with subsequent attempts requiring new retrievals.

Many witnesses describe how their early expectations of getting married, buying a house, and building a future together, had been shattered by the effects of receiving infected blood or infected blood products. As one witness describes it, “*There were three people in the marriage, three individuals and one of them was this big virus. And it did, it just ripped us apart. From that day on ... nobody can ever be the same again.*” The diagnosis and demands of treatment impacted not only on the infected person, but also had major implications for their partners’ life and well-being, and on any children. As a witness states, “*... there is a huge impact on the family because they carry you ... but the focus is always on the person who is suffering.*”

Chronic ill health is known to have a very negative effect on family life and relationships (Golics et al, 2013; WHO Europe, 2005). This was endorsed by witnesses who describe how normal family activities, such as camping, walking on the moors, playing football with their father, and going on holiday as a family, were no longer possible, and were greatly missed. A man with hepatitis C explained how he felt very badly because *“I could do nothing with the children during the treatment, not even kick a ball around or go for a walk. I felt bad for them, that they were missing out”*. When one child was infected, this also occupied most of the parent’s time, and the other kids therefore *“lost their mummy and daddy, the other kids, because we weren’t there”*. A daughter explained that she did not feel she had a mum because she was so exhausted from hepatitis C and from the interferon treatment that she was asleep every second day. Moreover, as widely reported in relation to other chronic conditions, the severe illness and death of a child can affect a sibling massively (Christ et al, 2003). As a parent recounted, *“It was horrible to see the grief ... it was devastating on him”*.

Considerable emphasis has been given to the stress on children resulting from a parent’s illness and the consequent tensions at home (Beardslee et al, 1998). This was also commented on by witnesses who regarded their child’s behaviour, such as going to school late or homework not getting done, as due to the atmosphere in the house and the things that were happening. A mother observed, *“My son preferred going to his friend’s house rather than stay in our house because of the way things are”*. Older children often felt they needed to look after their parent and so did not go out with their friends. A parent also described the significant emotional burden of her illness on her children, because *“... when they were old enough to learn why I was sick, they then had to carry the burden of it, and that has ramifications for them in their own lives going forward ...”*

Strained relationships and tensions between partners often reflected the multiple social impacts involving financial problems, housing problems, worries about the future and the demands of care. For example, in financial terms, a woman described their situation in which her husband with hepatitis C had been required to give up work due to sickness absence and they were only just managing on her earnings. It was never her intention to work full time and she struggled with this and was taking anti-depressants, but *“I felt I had to work to provide for the family, I had no choice”*. She described their situation as having *“... a huge impact on our relationship. We could not buy a house and so lived on a ‘sink’ council estate ... We were just trying to survive”*. She also explained that as a result of treatments her husband, *“has a very short fuse and does struggle to have empathy”* which increased the stress of caring. This, combined with the demands of work and caring, and financial worries eventually led to her decision to move out with the children, as *“I could not cope”*.

Sometimes a specific trigger was important in contributing to a final breakup. For example, for some couples a partner’s role as a carer eventually led to a situation where they felt their marriage was destroyed, as with a husband who had supported his wife through two rounds of interferon treatment in which she experienced very severe side effects, but felt that he had turned into a carer and not a husband, and left. Another trigger was a situation where the infected partner was viewed as becoming a different person post treatment. For example, a partner explained that her husband had become *“totally different. He was moody, rowing with the boys ... It was awful”*. More generally, it was common for the infected person to suffer not just physically, but also from problems linked to their feelings of frustration at not being able to work and not able to support the family, as well as not having energy to engage fully with the children.

Another situation that led to tensions within the family was the early death of a child, which is known to be extremely traumatic for both the parents and any siblings (Christ et al, 2003). A mother explained, when her son, who had mild haemophilia, died from AIDS: *“I was quite suicidal ... I didn’t want to go on, it was so unfair”*. She also described this impact as affecting family relationships, as *“My husband said that when x (son) died he lost me too ... it has wrecked and totally broken me”*. The impact on mothers was particularly great as they often felt guilty for administering Factor VIII. Indeed, one mother felt she had killed her son by using Factor VIII. It was often mothers who treated very young children until they were taught to self-administer treatment. Mothers also felt guilty for being the carrier of the haemophilia gene. Sometimes their husband blamed them for this and hence the death of their son, leading to marital breakdown. Guilt and self-blame are both potent precursors of depression (Stanton et al, 2007), and both almost certainly contributed to the considerable levels of negative mood and depression described in many witness statements.

The types of social impacts of HIV and/or hepatitis C on individuals and families were similar in many ways to those experienced with other chronic conditions where partners have to take on major new responsibilities for the family and the provision of care (Rees et al, 2001; Ericksson et al, 2019). However, there were aspects of the witnesses’ situation that markedly increased the severity of the social impacts for both the affected individual and family members. These included the relatively young age at which some individuals contracted these conditions, leading to particularly severe financial difficulties and related problems. There was limited availability of effective treatments for HIV or hepatitis C infections and newly researched drugs had many unwanted side effects. Despite long periods of challenging treatment for hepatitis C, the virus was most often not successfully cleared. For both hepatitis C and HIV infection, unlike other chronic conditions, there were risks of sexual transmission and transmission from mother to an unborn child.

Whereas this section has focused purely on the adverse social impacts stemming directly from the experience of diseases and their treatment, in reality the impacts for both the infected person and their family reflect the stigma attached to HIV and hepatitis C in the 1980s and early 1990s (see question 13.7). Stigma and the public response led to experiences of discrimination that further reduced employment opportunities, increased social isolation and limited the availability of supportive networks to assist in coping with their current situation and an uncertain future.

#### **13.4. Psychosocial impact of poor, inadequate and/or insensitive communication of information about testing, diagnosis, infection and treatment.**

Good quality communication is an essential element of healthcare practice. For infected and affected individuals, the process of providing consent to undergo tests for life-changing conditions, and the process of being informed of the test results and their implications, have a significant impact on how individuals and those close to them respond emotionally in the short and longer term (Fallowfield and Jenkins, 2004; Stein et al, 2019). Effective and sensitive communication surrounding these processes involves the provision of accurate information in ways that are understood, in an emotionally supportive environment. Such communication contributes to the trust needed between patients and the healthcare professionals providing life-long specialist care.

Communication also plays a pivotal role in the origin, exacerbation or amelioration of the effects of medical error (Fallowfield and Fleissig, 2003; Fallowfield, 2010). The characteristic themes running through much of the evidence provided by witnesses are obfuscation, denial,

casualness and secrecy, denying appropriate explanations, information about the future, support or recompense. Witnesses provide very few examples of healthcare professionals or relevant others apologising or expressing regret, which resulted in additional distress to affected patients and their families.

### **13.4.1. What is the best way to inform a person that they are infected with a serious disease? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.**

Much of the published literature concerning communication of serious disease deals predominantly with end-of-life type discussions, especially in cancer, and is not directly relevant to the problems faced initially by the infected and affected individuals in this Inquiry. However, there are some important principles on which to draw. As soon as the positive results were available from the diagnostic tests performed (often on individuals oblivious to the fact that they were at high risk of contracting a serious illness such as HIV and/or hepatitis C from their transfusions or treatment), good practice would include:

- (1) A clear and honest description of which tests had been done and what the results meant
- (2) A thorough explanation as to the nature of the diseases contracted and the possible treatments or clinical trials that might be available
- (3) Truthful and sensitive disclosure of the likely prognosis with and without different treatments and help with decision making about the available options
- (4) Considerable help in planning new and plausible goals, which many individuals might also require, given the serious nature and probable life-limiting outcome from the disease(s)
- (5) Counselling and time for patients and families to discuss their worst fears and anxieties should also be an integral part of good clinical care

As with many of these types of sad, bad and difficult conversations, it is helpful if the healthcare professionals involved have received training to conduct them in a sensitive manner appropriate for the individual patient and/or families. There were countless witness statements that are elaborated in other sections of this report which would suggest that few of the principles listed above were followed, compounding the confusion and psychosocial damage sustained.

A good example of best practice regarding elements needed when discussing a diagnosis of serious illness can be found in the Serious Illness Communications Checklist (Bernacki et al, 2014).

Conversations about serious and life-limiting disease are never one-off events, but rather a process of giving supportive information and listening to the concerns of people affected as the illness progresses. In particular, the parents of seriously ill children require significant support relinquishing the goals they might have once had for their child's recovery, and his or her future prospects, together with help establishing plausible, more achievable goals, such as maintaining the best quality of life (Hill et al, 2014). This is not possible without trust and truthful disclosure about the seriousness of the acquired illness in the first place.

### **13.4.2. What is the best way to inform a person that they have been infected with a serious disease as a result of medical treatment they have received? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.**

Good practice (for example, Fallowfield and Fleissig, 2003) suggests that patients who are the likely recipients of harm following an adverse event, such as contracting a serious disease, need:

- (1) An immediate disclosure of the medical error and the probability of different outcomes that might occur from the event; in this particular situation, the likelihood of serious infection
- (2) An explanation as to what happened, as far as is known, with a clear commitment to keep the harmed person informed of any further relevant information
- (3) A sincere expression of regret and a genuine apology even if the healthcare professional administered or ordered the transfusion of blood products or blood unaware of their contamination
- (4) Information as to what the care-plan or future treatment will need to be
- (5) A discussion about possible future compensation and referral to relevant agencies
- (6) Overt recognition that the infected and affected might well need significant professional emotional support and how this can be obtained
- (7) Clear information about the measures being taken to prevent a similar occurrence of the transfusion of infected blood or blood products
- (8) Regular updating regarding any details concerning an investigation into the events that occurred

Many witness statements describe failings and omissions of all of the above components of best practice. Open disclosure by a clinician, or appropriate other, about the seriousness of harm and what can be done in terms of treatment, may initially cause distress and sometimes anger. However, disclosure permits patients and/or affected families to start marshalling together strategies for coping and adjusting to the situation in which they find themselves. Many witnesses attest to poor communication and delay or lack of disclosure about HIV and/or hepatitis C infection. Some witnesses, or their families, were told of their HIV and/or hepatitis C infection over the telephone. Others experienced denial by healthcare professionals of any problems, despite feeling unwell or hearing rumours that something was wrong with the blood products received. Openness helps people to retain or regain trust in the healthcare professionals treating them. Studies show that patients who perceive explanations to have been insufficient, lacking in sympathy or inaccurate, experience more disturbing recall of events and poorer long-term adjustment (for example, see Gallagher and Lucas, 2005). Patients may be unwilling to co-operate or accept necessary investigations, tests or treatment if they are unaware of the reasons for doing so (Lo, 1994).

Discussion relating to disclosure and explanation of error should involve someone who has knowledge and training to deal with this type of communication. For children and adolescents, developmentally appropriate healthcare also requires healthcare professionals to be trained in child and adolescent health approaches. Patients and families benefit from knowing that steps will be taken to ensure that such errors do not occur again, having details

of appropriate personnel to contact with further queries, and receiving guidance towards counselling and independent advocacy/support services, such as the AvMA (Action against Medical Accidents). Witness statements suggest poor communication and continuity between various healthcare workers and services who might have been able to offer this type of support. Some witnesses mention that their GPs were unwilling to visit them when ill or refused to inform them of the diagnosis. Others attested to the accidental disclosure of HIV and /or hepatitis C diagnosis. One woman discovered that she had hepatitis C infection when a senior house officer, during an annual review, asked how she was coping with her hepatitis C. Shocked, she then saw a consultant who said the *“diagnosis was unfortunate but ... not to worry about it”*. The witness was given a two-page leaflet about the disease. As she had never consented to hepatitis C testing she was uncertain when the hospital knew of the diagnosis. She has never received an apology, counselling or emotional support, and said that *“everything felt very blasé”*.

Another witness reports how a haematologist treating her 2-year old son with haemophilia *“came down a corridor and told us that he (her son) had HIV. He didn’t even take us into a room, he just told us in a corridor in front of other patients”*. She states they were given no information about the likely cause of infection and discovered the seriousness of the disease from information presented on the television. She explains they were not told that their child had been tested or found to be infected with hepatitis C either, or that he was being treated. Being told of a serious diagnosis, but being given little information as to how it occurred or how best to handle the situation practically or emotionally, violates good practice guidelines.

### **13.4.3. From a psychosocial perspective, has best practice in terms of communicating with patients changed over the years, and if so, how and why?**

There have been significant changes in best communication practice since the time that blood and blood products were known to be infected. Communication in medicine has shifted over the past three decades from a paternalistic model of ‘doctor knows best’ to more collaboration with shared-decision making. There have been a large number of national and international guidelines and programmes regarding the professional duty of candour and optimal communication that should follow any medical error (for example, the UK National Patient Safety Agency ‘Being Open’, 2009 and the Australian Open Disclosure Projects, 2003). Fundamental to most recommendations is a need for unambiguous open disclosure and an apology. The specific content of these discussions will vary and depend on the level of harm, what can be done, and the needs and preferences of patients and their families. Withholding information about medical errors was justified on the grounds that patients would enquire if they were worried or wished to have more information (Gallagher et al, 2003). This is now not considered good practice. One witness reports that his doctor had said it was up to patients to *“realise that they have received a contaminated batch and know they have developed HTLV III<sup>1</sup>”*. If the patient did not realise then it was because *“they did not wish to know”*.

In the past, healthcare professionals were often advised not to apologise directly to patients following an adverse event, as it might lead to a higher likelihood of litigation. There is little evidence to suggest that apology will lead to litigation and legal liability claims, even in more overtly litigious countries than the UK. The NHS Litigation Authority has advised

<sup>1</sup> Human T-cell Lymphotropic Virus Type 3

unequivocally that saying sorry is the correct procedure and they “will never withhold cover for a claim because an apology or explanation was given” (<http://www.legislation.gov.uk/ukpga/2006/29>).

Changes from secrecy to a climate of more open disclosure were motivated by the expectations, and better health education, of the general population, together with cultural, ethical and moral imperatives for more truth-telling and less paternalism. The common perception that what a patient did not know would not harm them, was shown to be incorrect. Silence usually results in a heightened state of fear, anxiety and confusion, not calm and equanimity (for example, Fallowfield et al., 2002).

The ability to work effectively with adolescent patients has also changed considerably through the introduction of adolescent health as a speciality apart from paediatrics, and the acknowledgement of adolescence as a unique and important developmental stage which requires special skills different to those of a paediatrician or an adult doctor. A number of guidelines now exist in relation to working with adolescents and transition to adult services (Christie and Glew, 2017).

#### **13.4.4. The Inquiry has received evidence from a range of witnesses who have described being told of their infection by letter, over the phone, casually or informally in a non-private setting, or being told of their infection by someone who has little knowledge of the disease, or being told in an indifferent, unsympathetic or callous way. Could the way in which a person is told of their infection affect the psychological experience of that individual and if so, how and why?**

There were many examples of poor communication of HIV and hepatitis C test results. Witnesses describe learning of their infective status in a range of unsatisfactory contexts, including corridors, in a clinic room with the door open, by phone, and by letter rather than face to face in a supportive manner and setting. For some, the healthcare professional had incorrectly assumed that the witness was already aware of their status. For one witness, the GP receptionist read out her result on the phone seemingly out of ignorance. One witness describes how, having received a letter that assumed the hepatitis C status of the infected child had been conveyed to the child and the mother, a doctor then argued with the mother alleging that she had previously been told about her child’s infection. Another described how she learned of her now deceased husband’s hepatitis C status when she called the hospital to find out about delays to a referral for a lung transplant. The information had been sent to the patient’s GP over a year before with a request to communicate the information. The GP had not done so.

Many witnesses recall callous indifference displayed by those informing of HIV and/or hepatitis C infection. Studies show that hurt and anger following disclosure is magnified if there is no manifest empathy displayed by members of the healthcare team. Incomplete explanations, untruths and evasiveness create additional distress (for example, see Gallagher, 2003). One witness statement exemplifies this point in a statement: his father was told by the treating haematologist “*that going yellow was quite normal and would not come back*”, and furthermore that it would be better “*to just let haemophiliac children go*”.

Another witness recalls lying on a trolley in an A&E department after fainting and a junior doctor said *“This looks like HIV developing into full-blown AIDS”*. The wife of this witness, pregnant at the time, decided to have a termination due to the possibility of HIV transmission to her and the child, as they had not had protected sexual activity. Many witnesses claim that doctors told them of their diagnosis in a blunt manner with no privacy, *“The door remained open allowing people behind me to hear the conversation. The doctor said, ‘Good morning, I see you are HIV positive’”*. Studies in the published literature show that the quality of disclosure of medical error correlates with psychological adjustment, specifically the hyper-arousal, post-traumatic impairment and re-experiencing the situation, often described as post-traumatic stress disorder (PTSD). Gallagher et al (2003) report that patients believe that the manner in which error was disclosed impacted on their subsequent distress. Incomplete or evasive explanations led to increased distress, whereas honest compassionate disclosure, with an apology, decreased their distress.

From the witness statements, a great deal of the communication surrounding HIV and hepatitis C testing was neither effective nor sensitive. It is likely that this made a significant contribution to the emotional consequences of infection for those infected and affected, including anxiety, depression, suicide attempts and family breakdown.

#### **13.4.5. The Inquiry has received evidence from a range of witnesses who have described not being told that the treatment which they were being given (whether with blood or blood products) might expose them to a risk of infection and/or who have stated that they did not give informed consent to such treatment. Could a failure to provide sufficient information about risks and/or a failure to obtain informed consent affect the psychological experience of the individual and if so, how and why?**

There is a legal imperative to seek consent for any procedures or administration of drugs and other products following a reasonable description of the known risks, harms and potential benefits. Patients should also have some indication of the probability of these risks.

Some studies, however, do show that retention of medical information is selective and furthermore that the expected benefits of a procedure are usually better recalled than potential risks (for example, Lemaire, 2006).

Many witnesses described being given no information about the potential risks of blood or blood products in general, or about the risks of infection. One witness describes being falsely reassured about the risk of infection from blood. She declined a transfusion following childbirth for fear of HIV, but reluctantly accepted following reassurance. The blood was contaminated with hepatitis C, a risk about which she was not informed. Several witnesses, who were children or teenagers when infected, mention that they and/or their parents were not adequately informed about either infections or about research being undertaken on extra blood samples, taken without consent. One witness says that when he queried why extra blood was being taken, he was told that they had *“lost our blood vials so needed to take it again”*. Another witness says she was unaware of her son’s hepatitis C infection for 4 years and then was told *“in the most patronising and condescending way”*. She has subsequently found out that various tests were routinely being taken to ascertain whether the child would be suitable for *“the heat treated trial”*. She says she has no recollection of providing consent



for any of this and thought all testing was associated with her son's mild haemophilia. She remains extremely unhappy with everyone associated with her son's care over the past 3 decades, from the GP, to the haematology nurses, to the haematologists, and feels that there was a collective "*conspiracy of silence*". A similar example is presented in an extract from a letter written by a doctor to a haematologist "*We note that he is HTLV III antibody positive, but is not aware of this and that you do not wish this to be divulged to him. We shall make every effort to comply with your wishes.*"

Experience of serious harm following any medical interventions which were not disclosed adequately to enable truly educated consent, leads to mistrust about advice from other members of the healthcare team who may be involved with treating the infected patient. An example can be seen in the statement from a witness who says his haematologist said that despite contracting HIV, he was lucky to be alive and being treated for haemophilia for free. "*From that day forward any trust in my treatment for haemophilia was inexplicably damaged, compounded beyond repair ... it dawned on me that I'd become a walking virus, a disease to be ashamed of and I knew I was in real trouble. This virus would define me, judge me and I will continually be judged for it. This fear continues to this day.*" This same witness also says "*I couldn't confide in doctors because they'd become the centre of my fear, highlighted by every syringe of Factor*".

#### **13.4.6. The Inquiry has received evidence from a range of witnesses who have described not being told that they were being tested for HIV and/or hepatitis C and/or hepatitis B (HBV). Could finding out subsequently that such testing was carried out without their consent impact on the psychological experience of the individual and if so, how and why?**

Many witnesses report learning they had been tested for HIV or hepatitis C having provided no consent. Results from tests undertaken without witnesses' knowledge were placed in medical records. Some witnesses were not offered testing and reported having to contact the hospital to be tested. One witness did so after reading a newsletter from the Haemophilia Society. Other witnesses discovered that samples were taken from them or their infected family member for research purposes without prior consent. While some were confused or even bemused by this, many were clearly angry and upset by these practices, and felt that they were being used as guinea pigs. At least one witness strongly expressed the feeling that the healthcare professionals involved were putting their own research/career interests ahead of their duty of care to the patient. All of this inevitably undermined the trust, which people had in both individual practitioners and the healthcare system, the effects of which have been outlined in other sections of this report.

Failure to initiate open disclosure as soon as possible and to apologise is damaging to individuals in many ways. It does not permit people to move on, they get stuck with their anger. That said, it is never too late to try and partially rectify, as might happen with this Inquiry. (Consider, for example, the reconciliation hearings following the ending of Apartheid in South Africa.) An apology, no matter how sincere or efficient, can never undo what happened to those impacted by events, but satisfying and effective apologies do help reconciliation. Some affected individuals may gain a sense of justice or solace from an apology, in that the healthcare professionals or others involved have been forced, during the act of apologising,

to face the pain that their behaviours have caused (for example, see Tavuchis, 1991). Several surveys show that the general population expect and would want doctors to admit to error and to apologise (Mazor, 2004 and Witman et al, 1996).

The nature of the apologies that the infected, if still alive, and affected require, is multifaceted. Firstly, good practice would suggest, at the very minimum: a need for someone involved to apologise for the infected blood products or blood having been administered; an apology for testing and treating without informed consent; followed by sincere regret for the physical and psychosocial harms caused to the infected and affected individuals' lives, careers and relationships with others. Especially striking has been the accounts of deliberate obfuscation, and missing or inaccurate hospital notes, about the sequences of events. One father of an infected child commented that *"we should be living our lives now, but we will never really be able to until we are given the full truth. I am not willing to have gone through all of this and be told they did nothing wrong"*.

**13.4.7. The Inquiry has received evidence from a range of witnesses who have described not being told of their infections for years after their infected status was known by clinicians. Could this withholding of information about their diagnosis impact on the psychological experience of the individual, and if so, how and why?**

Many witnesses explain that the delay in receiving information about HIV and /or hepatitis C infections caused injury physically, and also damaged relationships with the healthcare professionals on whom they depended for ongoing care and treatment.

Research studies show that the parents of children who have received no information, explanation of medical error, apologies, acceptance of responsibility or acknowledgement of the impact, experience considerable emotional distress, anger, behavioural changes, life-style disruptions and marital discord, for example. (See Mazor et al, 2010). Some of the witnesses express guilt that their children were treated with infected blood products, *"my mum has a deep sense of guilt that she was in some way responsible for the infections"*.

Further consideration of the effects of delay in providing key illness or treatment-related information is described in question 13.6.

**13.4.8. The Inquiry has received information from a range of witnesses who have described being given little or no information about their infection, prognosis and/or treatment. Could this impact on the psychological experience of the individual, and if so, how and why?**

There appears to be a huge variation in the information given to witnesses, some alarmist, some underplayed, some lacking – depending on the knowledge and experience of the health professional giving the information. Many witnesses describe how they were given little or no information about the consequences of infection. For example, one describes being given no information about risks of hepatitis C infection to her or her family when administering Factor VIII to her child intravenously. Another describes being given inadequate information about the risks of hepatitis C infection to her or a baby, given that she and her husband were attempting to conceive, something which was known to the GP.

There were also a number of reports from witnesses about not being given any preparatory information about the many unpleasant side effects of their treatments for HIV or hepatitis C. Clear preparatory information about treatment can allow recipients to anticipate and understand what will be happening to them. When this is not provided, people may become disturbed by painful and debilitating side effects, which they may interpret as a worsening of their condition. Similarly, without a prior understanding of the nature and duration of treatment side effects, people find it harder to cope with a treatment, and are less likely to adhere to it.

Some witnesses describe being given falsely reassuring information, making light of the implications of hepatitis C. One of these was then later told she would not see her 30th birthday, leading her to make a video by which her young children could remember her after her death. Other witnesses describe being given alarmist information about HIV infection, being informed that they were likely to have only months to live. For example, one witness was informed he was HIV positive over the phone by a nurse, just before going to university. He was encouraged to get his affairs in order as he was likely to have only 6 months to live. Another witness recalls being informed – aged 17 years old – that he had two years to live. He described being told this in a way that lacked empathy or sympathy. Neither of these witnesses were offered any counselling or support to manage the information they had been given.

### **13.4.9. Please consider and discuss whether the circumstances in which a person is infected, and/or the circumstances in which a person or their family and loved ones learn about that infection, may impact on the grieving process in the event of the death of the person infected.**

The death of a family member is a major life stressor, the adjustment to which may take months or years. The emotional changes and physical symptoms, which accompany the normal grieving process, vary considerably depending on a range of individual and situational factors (Stroebe et al, 2007). Since this process can vary so much, it is difficult to quantify the extent to which the bereavement experiences of affected individuals were impacted by the circumstances in which people were infected, or how this information was conveyed at the time. Research has shown that the grieving process can become much more intense and/or prolonged, which is usually referred to as complicated grief (Horowitz et al, 1997). This can happen for a number of reasons, many of which were embedded in the witness statements.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), factors resulting in complicated grief include whether the bereaved individual has trouble accepting the death, feels unable to trust others, and harbours an excessive bitterness and anger related to the death (Horowitz et al, 1997). When this happens, rumination is common and tends to be focused on angry or guilty recrimination linked to the circumstances of the death (Shear, 2015). Complicated grief reactions also are much more likely to happen in parents who lose a child (Meert et al, 2011). Two witnesses, whose two brothers had died, described how their father was *“riddled with guilt. He feels guilty. He thinks when they gave the boys, you know, their injections ... You know they thought they were helping their sons ... It’s just a living nightmare”*. Another witness recalled that his parents could not cope with their son’s death, describing it as *“obviously a horrendous thing for all the family”*, and that his father had sought solace in alcohol and his mother struggled to cope with the diagnosis, and was simply not able to talk about it.

Other factors which put people at risk of experiencing a more prolonged or intense bereavement response include the nature of the cause and circumstances surrounding the death, the quality of palliative care prior to the death, and the support provided both prior to and after the event (Stroebe et al, 2007). Concurrent stressors, such as financial hardship, are also known to exacerbate difficulties in adjusting to the loss. While any one of these factors can result in complicated grief, a combination of a number of them greatly increases the probability of this.

Bearing all this in mind, it does seem likely that there would have been negative effects on the grieving process of those who were left behind after deaths from the stigmatising conditions, which were the result of treatment with infected blood products or blood. Additionally, the psychosocial impacts and need for secrecy, described elsewhere in this report, will have created greater individual emotional vulnerability. For example, one witness in recounting the grief he felt as he knew that his brother had AIDS and did not have long to live, stated that *“... he wanted to talk about this, talk about his fears, how scared he was but I couldn’t. It was too close to home for me and I wasn’t there for him. I wasn’t there for him and 3 months later he died. The biggest regret of my life because he’s gone and I can’t do anything to make amends for that”*.

What was also clear from witness statements was that their losses had profound and enduring effects on their emotional well-being, their behaviour and family relationships. One witness, whose three brothers had died from AIDS, was very deeply affected, recalling that he *“... went AWOL. I ended up wrecking my marriage”* and would do anything *“... just to get away from the family mentally, so I spent most of my time keeping myself occupied away from the family”*. He also stated that his mother, who became very thin and frail, and had died of a heart attack, *“... would be alive if it wasn’t for what happened because she was a strong woman. The tragedy has ripped her heart out”*. Another witness, whose father had died, recounted just how much her mother had been affected: *“So it was just a really turbulent time of uncertainty because she was left with overwhelming responsibility”* – she was responsible for two teenage children and a business. *“She obviously also had the burden of the secrecy of it all, of the stigma that was attached to it. She really struggled. It affected her greatly ... It affected her personality, her behaviour, her mental health. She became almost reclusive, in that she liked to stay at home and do her own thing ... She didn’t socialise anymore.”*

Poor quality communication from many healthcare professionals may have also had negative effects on grief processes. From witness statements, it was not really possible to ascertain whether any support had been provided prior to or after the deaths of infected individuals. It is known that bereavement experiences can be strongly affected by the quality of palliative care. Communication and shared decision-making, aligned to the needs and values of the terminally ill person and those closest to them, is associated with less problematic bereavement outcomes (Sanders et al, 2018). Since witnesses revealed that serious news was often delivered in less than optimal ways, which resulted in distrust and dissatisfaction with their healthcare experience, it is probable that this would also have had negative effects on any ensuing bereavement experiences.

**13.5. Psychosocial impact of financial hardship and dependence: Please consider and discuss the psychosocial impact of financial hardship and/or of dependence upon financial assistance from the trusts and schemes established by central government. You will note from the material that is being provided to you that the Inquiry has received evidence from a range of witnesses about their experiences in dealing with the trusts and schemes.**

For those who survived into adulthood, many described a range of negative psychological issues linked to working life. Frequent periods of ill health, together with extreme fatigue and depression associated with hepatitis C treatment, made it very difficult not only to attend work regularly, but also to perform well in the workplace. As a result, many infected adults reported reduced job opportunities and job prospects. In couples, this often placed an increased responsibility on partners to provide sufficient income. For the infected person, limited work capacity and the concomitant financial effects only served to increase feelings of low self-esteem (see question 13.3).

The cumulative effects of limitations in employment potential arising from interruptions in education, together with the continuing health effects, have undoubtedly had negative financial consequences for many infected and affected individuals. Although the extent of this varied across individuals and families depending on their prevailing social circumstances and life stage, the overall costs have been high. A variety of financial payments were available, but they were neither universal nor considered sufficient. Many witnesses describe being ground down in their attempts to obtain financial assistance and then giving up. For many, this difficulty in both accessing and receiving financial payments from the trusts and schemes had a range of negative consequences. In addition to the effects of continuing financial hardship, many witnesses report feeling let down, angry and ultimately helpless. It is known that frequent unsuccessful attempts to change an adverse situation typically result in feelings of helplessness and hopelessness, both of which are likely to lead to negative mood and depression (Maier & Seligman, 2016; Miller & Seligman, 1975).

It should be possible to conduct a proper health economic analysis of the financial impacts of hepatitis C and HIV infections following the receipt of infected blood or blood products, but we did not have a health economist on the team. We recommend that this should be done as an addendum to this report and to quantify the full range of major financial impacts on the lives of both infected and affected individuals.

**13.6. Please consider and discuss the psychosocial impact for people infected and affected by waiting for many years for explanations, apologies, investigations and/or answers as to what happened and why.**

Many witnesses maintain there has been deliberate obfuscation, and missing or inaccurate hospital records conceal the truth about the sequences of events. As was discussed in question 13.4.6, having to wait for explanations, apologies and answers can have a number of negative effects on both infected and affected individuals. First, they are very likely to get stuck with their anger, and find it difficult to move on. Second, people are likely to feel rejected and abandoned by what they perceive to be an uncaring healthcare system. They

may well feel a strong sense of frustration and anger at the lack of responsiveness, which will exacerbate the erosion of trust in the individual healthcare practitioners and the system. If attempts at gaining information are delayed and constantly thwarted, then this can readily result in feelings of helplessness (Miller & Seligman, 1975; Maier & Seligman, 2016), which can lead to a sense of resignation, lack of control and depression.

Evidence from healthcare communication research shows that a lack of timely information or answers to requests for information is a potent source of anxiety, which emanates from the uncertainty about what has happened and will be happening. As was outlined in 13.4.1 and 13.4.2, even when the health information to be provided is negative, if it can be conveyed in a timely and patient-centric manner; then people can begin the process of coping and adapting. Long delays in waiting for important health information result in both infected and affected individuals not knowing what they are facing and are a major barrier, not only to open communication within the family, but also to planning for the future.

### **13.7. Stigma and discrimination.**

Many witnesses, both infected and affected, described experiences of stigma and discrimination, often arising from other people's misconceptions about HIV and hepatitis C. The impacts of medical conditions for individuals and families are profoundly influenced by whether they are imbued with a stigma. The term stigma describes a condition or behaviour that in the view of the wider society marks the individual as unacceptably different and inferior and elicits some form of community sanction (Goffman, 1963). Possession of a stigmatised condition and internalising its social meanings has been shown to have a negative impact on an individual's self identity, resulting in poorer illness adjustment and mental health (Corrigan and Rao, 2012).

The high level of stigma associated with HIV/AIDS was influenced by the rapid spread and awareness of HIV in the early 1980s. Transfusions with infected blood and blood products thus coincided with what was referred to as the AIDS 'epidemic' (Robertson and Richardson, 2007). In the absence of effective treatment, the public health response was to launch educational campaigns that aimed to reduce risks by promoting behavioural changes. However, these campaigns also contributed to widespread public fear and to the popular notion that HIV/AIDS could be 'caught' through normal social interaction, such as through coughing, kissing and shaking hands. Moreover, the stigma attached to HIV/AIDS was influenced in high income countries not only by fear of medical risks, but also by the concentration of HIV/AIDS among already stigmatised social groups, particularly homosexuals, sex workers and injecting drug users, who were seen to be to blame for bringing the condition upon themselves.

Hepatitis C as a stigmatised condition shares some characteristics of HIV, with its normal route of transmission through handling blood, particularly in the context of illicit drug use, linking it with publicly unacceptable behaviour. The main difference was that no major educational campaigns specifically targeted hepatitis C. The public therefore had very limited knowledge about hepatitis C and as witnesses commented, they therefore drew on their knowledge of HIV, which they thought would be very similar, and this frightened them.

As with other conditions that are stigmatised, both HIV/AIDS and hepatitis C can lead the possessor to experience 'felt' stigma. This describes an individual's awareness of possessing a condition that is socially disvalued in the community and which differentiates them from the normal non-stigmatised population in a deeply discrediting way (Goffman, 1963). For those who received contaminated blood products or blood their stigmatised condition was the result of medical treatment. However, notions of individual responsibility and blame are inherent to stigma and those with HIV and hepatitis C were assumed by the public to have

brought it on themselves. For example, one witness with hepatitis C, following treatment of mild haemophilia, explained, *“I felt that people looked at me and treated me as if I had been an alcoholic, as if I had wilfully brought the illness upon myself, and that is simply not the truth”*. Similarly, those infected with HIV were aware that people assumed they had contracted this feared condition through being a homosexual, prostitute or drug user, with these assumptions reinforcing felt stigma.

Many witnesses reported that when they were informed by the doctor that they had tested positive for HIV/AIDS or hepatitis C, they were also advised that they should keep this diagnosis secret, but were not offered any further advice or counselling. For example, a spouse who was present when the hospital doctor disclosed that her husband had tested positive for HIV, explained that *“we were advised not to tell anyone because of the stigma and that was really emphasised. Not even to tell our families”*. This advice about secrecy was common at the time and even occurred when a patient’s life expectancy was anticipated to be very short. For example, a man, when informed by a doctor that he was HIV positive and had about a year to live, stated that *“I was not to tell anybody, including my parents as the stigma associated with this infection would mean I would become a social pariah if anyone knew”*. This advice was again not elaborated on, but was followed by this patient, who did not disclose the diagnosis to anyone for a long time. However, like others in this situation, he experienced a very high personal cost from non-disclosure of this life-threatening condition and stated that *“the secret of being HIV positive became a crippling burden”*.

The advice to keep their diagnosis confidential was generally followed and was often reinforced by their own awareness of potentially negative responses involving discrimination and unfair treatment towards people with a stigmatised condition that is visible or otherwise known about, referred to as ‘enacted’ stigma. As a witness explained, *“I personally felt I had to keep it (HIV) quiet because of what I was seeing and the destruction that other people had at the hands of people finding out they were HIV positive, and the damage to their careers, the damage to their family units, and so I took the attitude and it was just that I had to be silent, I was silenced basically, and had to be silent about it”*. She noted that later she told people her husband had died of cancer, as she could never have told people that he died of AIDS and it is only in recent years that she was beginning to do that as it was previously such a stigma.

For some witnesses, keeping the diagnosis a secret was a choice without being recommended, as they were aware of the potential risks of disclosure. For example, a mother explained that she couldn’t tell her family about her son’s HIV or *“his life wouldn’t be worth living”* and he had already been tormented at school for being haemophiliac. Similarly, a witness, whose husband had contracted HIV following treatment with blood products for haemophilia and eventually died of AIDS, described being very reluctant to disclose her husband’s condition given the climate of fear and discrimination around AIDS that was mounting in the media which she found alarming. She described the thought of anyone finding out as unbearable and explained, *“we were so terrified that if people found out they would treat us badly so we kept silent”*. She went on to describe how being HIV positive in the 1980s and 1990s was terrible, as it was a harsh world full of fear and cruelty and she did not think she had ever recovered.

People in the Asian community appeared to feel that the costs of disclosure would be particularly difficult to manage as the community is *“... very tight-knit; so whatever you do the next door neighbour knows”*. As an Asian witness explained, *“... throughout our lives we have had to keep it (HIV) a secret because if people know we’d be ostracised, you know, and my*

*parents would feel the brunt of it ... so we had to keep everything hush-hush. We couldn't talk about it, we couldn't mention it when family was there".* As a result, he felt that he and his wife had experienced a very isolated life.

Witnesses who regarded disclosure as necessary often experienced uncertainties about when and how to disclose. This related particularly to disclosure to a girlfriend, potential partner and young children. In some cases, disclosure to a girlfriend/partner resulted, as feared, in the break-up of the relationship, as the potential partner felt they could not cope with the situation. However, others regarded this as a challenge that was manageable. For example, a witness who met his wife when they were both in their teens did not initially tell her about his hepatitis C, which was due to a transfusion following burns when he was very young. However, when this relationship started getting serious he was prompted to disclose the information and was fortunate that his girlfriend was very understanding. Another witness described how she was obliged to stop campaigning for AIDS to be seen not just as a "gay disease" but also as one affecting those infected by contaminated blood products. Such campaigning was conducted to attempt to stop the stigma that her family had been subjected to from her son's HIV infection. The witness stated that government compensation was conditional upon all those affected signing a waiver agreeing never to speak about how those infected had become infected with HIV.

Parents varied in their views about the appropriateness of disclosing their HIV or hepatitis C status to a child. This was influenced by their perception of the potential impact on their child and whether or not the infected parent was experiencing symptoms or visible evidence of their condition. In most cases parents tried not to tell a child until they were about 18 years old to spare them the worry of an impending death sentence and give them a normal childhood. However, keeping this secret was difficult if the parent began to have signs of illness and could therefore no longer 'pass' as normal. For example, a witness recounted that he was told by doctors not to tell the family and so they did not initially tell their son that his father was HIV positive and just used to say "*your Dad is ill*". Later on, his friends started to ask what was wrong with his Dad and the son was therefore told his Dad was dying of cancer. However, when the son reached 18 years of age he was told his Dad's true diagnosis.

In contrast to delaying disclosure, a few witnesses thought it was better to be truthful and disclose to a child. However, a recognised downside was that the child then had to carry some of the practical and emotional burden of this information and the injustice of it, and this could affect them in their own lives from a young age.

Witnesses recounted many instances of enacted stigma. This took various forms comprising avoidance, bullying and acts of physical abuse, with families often experiencing several types of discriminatory responses. This had profound effects on self-identity and the physical and mental well-being of the stigma bearer and their close relatives. For example, avoidance was a very common response to disclosure by infected individuals and was often extended to all family members, who thus experienced 'associative stigma'. A fairly typical example was a witness who explained how her husband was hepatitis C positive in 1998 following a transfusion after an accident and her husband's family responded in terms of fear, which was somehow connected to AIDS. She thought this was influenced by "*those horrendous adverts on TV in the 1980s*". The family therefore feared that having her husband "*in the house was just going to kill them all off, so it was out [of the house]*" with contact cut off.

Although witnesses often described not disclosing their condition to even close friends because of fears of negative reactions, a few people decided to disclose. For example, a mother who contracted hepatitis C following a transfusion after the birth of her baby was aware that friends knew she had been in hospital and she thought it was better to be truthful



and to tell them, so she did. However, she found that instead of being supportive the result was “... *sadly and to my shock, very, very quickly friends just disappeared. It was social events I wasn't invited to, children's birthday parties, different things at play groups and nurseries. It was like I realised I wasn't welcome or I wasn't even invited*”. Other forms of avoidance included refusing to let their child play with a child known to have HIV or hepatitis C. There was also a reluctance to let people with HIV or hepatitis C use their cups and plates, and a couple described how after they had stayed the night with some friends they were later told by others that their friends had burned the sheets after they left.

Problems of verbal abuse were also experienced particularly by children, who had tested positive for HIV. For example, a mother described her young daughter as receiving “horrific abuse” in terms of bullying and name calling when her diagnosis of hepatitis was leaked to the press, including being called “*HIV girl*” and “*AIDS girl*” at school. Her mother commented that people used to ask what was going on with her daughter and why did she have an STD at nine years old? Occasionally direct physical attacks were made on individuals or their property. An example is the case of a couple where the husband, who had haemophilia, was diagnosed with HIV and hepatitis C. Both were physically attacked, with the husband ending up with a broken nose which was operated on and he had various other bleeds. A mother also described her daughter as being bullied because her father was ill and used a mobility scooter following an amputation and transfusion which had led to hepatitis C. This took place in the playground at school where some girls threw stones at her and tore her dress off. As a result, her daughter disliked being at school so much that she often tried to hurt herself so she could go to the infirmary and be taken home from school. In some cases, the bullying and physical abuse was described as being so bad that families with young children decided to have a fresh start in a new area, although this move was demanding with the need to get new employment and accommodation.

There were also several cases of property being vandalised. For example, parents with sons who had HIV that led to AIDS, described trying to keep their son's HIV secret as the campaigns on television were “devastating”. One family described how relatives and a friend got to know and as a result did not visit anymore. However, early one morning the father found what was described as “... *AIDS dead written on the house, not little letters 6 foot letters on the side of the house, crosses on the door, car vandalised, people going across the street from us ... It was devastating*”. They also became known locally as “the AIDS family” and received constant abusive phone calls day and night. To avoid the stigma at school some of the younger members of the family changed their surname. The family tried to cope for as long as they could, but then decided they needed to move, which they did.

Several other witnesses had similar experiences of being punished by members of the local community. Examples included a mother whose son had HIV: her car was vandalised and the word ‘AIDS’ written on it. They also had to vacate the farmhouse where they had lived for 6 months because someone told the farmer that her son had AIDS and the farmer was then worried that his stock of turkeys would be contaminated. When they rented another property, they had further difficulties, as ‘AIDS’ was sprayed on the front door and someone tried to set fire to the house whilst they were in bed. Similarly, another man stated that it was reported in local newspapers that his brothers had died of AIDS and in response people came to the cemetery to throw stones and even wrote the word ‘shit’ on the grave. His family too was referred to in their local area as “the AIDS family” and to avoid the stigma at school some of the younger members of the family changed their surname.

These few examples illustrate the very negative community reactions to HIV/hepatitis C, with a desire to cut off contact, and in some cases to punish people with these conditions. This was generally a response to fears of contracting the condition that were shaped by public education campaigns, together with the belief that these conditions were contracted through individuals' own behaviour, with no awareness of their transmission through infected blood or blood products.

People in work settings were often fearful that they might contract HIV/hepatitis C by being in proximity to anyone with the condition, which sometimes led to situations where workers threatened "*either he goes or we go*". One witness also described turning up at a factory that had been her regular client for delivering training and "*... the union representative stood up in front of everyone and said, 'we understand you have got hepatitis C. None of us wants you here'*". He explained that they had a communal kitchen and didn't want her using the kitchen or their cups and saucers, and did not want her using the toilets, and would be boycotting her training.

Interaction in healthcare settings often reinforced felt stigma through instances of discrimination. For example, some witnesses described their medical notes as visibly identifiable through files with red stickers or yellow and black tape over them. As one witness stated, "*I do understand the need for caution, but it makes you feel like a plague victim.*" People also described how, despite notions of confidentiality of their HIV or hepatitis C status, this was sometimes communicated by hospital staff in a voice that was loud enough for everyone to hear. Another person reported that there was a sign above his bed and at the nurse's station saying, '*at risk of CJD*', which broke data protection rules and left him vulnerable to the abuse that followed. There were many reports of HIV or hepatitis C infected individuals being treated differently in a range of healthcare settings. The stigma felt by the recipients of such treatment was clearly distressing and most likely had negative impacts on subsequent dealings with healthcare professionals.

There were also many examples of healthcare staff jumping to conclusions that individuals had brought their condition on themselves, especially by being an alcoholic or drug user. As a witness with hepatitis C stated, "*the staff looked at me and treated me as if I was an alcoholic, as if I had wilfully brought this on myself and that is simply not true.*" A woman admitted for a termination also described being treated by nurses as a murderer, although this procedure was advised because it was established that she became pregnant when her husband was diagnosed with HIV although he had not at that point been told.

Witnesses also spoke of the ways in which risks of contamination were greatly overemphasised in hospitals, which had an adverse effect on their self-identity. For example, a woman with hepatitis C, who was admitted for a gastroscopy, described a lot of discussion conducted in front of her about how to decontaminate the scope afterwards, with the decision that they would use the old scope and destroy it after the procedure. She commented that this situation made her feel "*disgusted and alienated*". Similarly, a woman with hepatitis C found that when she went in for routine surgery, she was put last on the list and they "*virtually fumigate the place after you because you are like a plague victim*". A patient with hepatitis C, who was admitted to hospital due to a haemophiliac bleed, was also put in a side room and when staff came in they were "*in full medical gear, masks, gloves, gowns, the whole lot*", and he was "*even brought his dinner in full gear*". He described this isolation as "*just so draconian it was ridiculous, and I was – I was scared*".

The situation in relation to dental care was often similar, with some dentists refusing to see people when they knew they were positive for HIV and/or hepatitis C, and if they did agree to treat, took extreme precautions and were dressed *“like someone just come from Mars”* and *“in the room everything’s covered in plastic”*. In contrast, other dentists were viewed positively, and people did not experience any problem.

The high levels of stigma, avoidance and verbal and physical abuse towards HIV and hepatitis C described by witnesses were just one aspect of the impacts of HIV/hepatitis C, with individuals and families also coping with the adverse medical impacts of HIV/hepatitis C and their treatments. Not surprisingly, these dual impacts affected all family members and put considerable strain on relationships, as well as increasing employment difficulties and other social impacts. Burdens were therefore immense, although there was little informal or formal support. Lives were therefore described as *“ripped apart”* and *“wrecked”* and the infection as having a devastating effect, both on the infected individual and their family. As one witness observed, *“... well, how much of a price does one have to pay for somebody else’s mistake, you know? And it seemed just huge.”*

The situation of witnesses, who had been given infected blood in the 1980s and 1990s, was very different from the current context, where new drug treatments make HIV and hepatitis C controllable conditions with limited side effects. New legislation and campaigns also aim to protect people with HIV against discrimination, harassment and victimisation, and increase public knowledge and reduce fears (National AIDS Trust, 2016). However, some stigma still surrounds hepatitis C (Northop, 2017) and HIV (People Living with HIV stigma survey, 2015).

### **13.8. Access to treatment: The Inquiry has received evidence from a range of witnesses who have described difficulties in accessing treatment for the conditions with which they have been infected. Could this impact on the psychological experience of the individual and if so, how and why?**

A number of difficulties were reported by witnesses in accessing treatments for HIV and hepatitis C, or for related problems arising from issues, such as treatment side effects or the appearance of new symptoms. Problems in accessing healthcare can arise from both the characteristics of the healthcare delivery system and of the individual user (Aday and Andersen, 1974), and can have a range of negative psychological effects.

The reasons for these difficulties seem to vary from general problems of access to specialist centres because of travel factors, through to difficulties in arranging appointments and lack of co-ordination between different parts of the healthcare system. Having to travel distances to undergo investigations or obtain treatment when feeling fatigued and unwell can be a major challenge, both physically and psychologically (Lightfoot et al, 2005). Studies of access problems in relation to treatment for hepatitis C and HIV infections have also revealed more pernicious factors, arising from clinician low prioritisation, clinician discrimination, rationing of healthcare and cost-related issues (for example, Edlin, 2016). A number of witnesses described experiencing these sorts of difficulties in gaining the access to treatment and/or in having to persist in their attempts to receive treatment.

The psychological impact of access problems will depend very much on the nature of the access barrier which individuals encounter. For those who have to travel long distances, physical disruption and fatigue will both add to the ongoing illness burden (Lightfoot et al, 2005). For those who have experienced difficulties or delays in making appointments for

investigations or treatments, this may well add to any existing sense of perceived stigma or feelings of rejection by the healthcare system (Sayles et al, 2009). The effects of all this on infected individuals and their carers, are highly likely to include a range of negative mood changes (such as increased levels of uncertainty, anxiety and depression), further distrust, dissatisfaction and lack of confidence in the healthcare system, together with a subsequent reluctance in following treatment and advice. Difficulties in accessing healthcare, particularly at times of crisis, will result in initial frustration and anger, followed by resignation and helplessness, all of which only serve to increase the psychological burden on infected and affected individuals.

In the following sections we outline the type of psychological care and support which should have been offered to infected and affected individuals to help them cope with the many physical, social and psychological challenges which they experienced and which were outlined in earlier sections. The lack of access to this more supportive aspect of healthcare will have only served to exacerbate the negative moods and feelings of abandonment by the healthcare system which were described by many witnesses.

### **13.9. Care and support: What sort of psychosocial care and support should be available for a person diagnosed with a life-threatening disease on first being diagnosed and as the disease progresses?**

As was outlined in earlier sections of this report, there are major psychological and social impacts arising from any life-threatening disease. Coming to terms with the shock of the diagnosis and the ongoing demands and uncertainties of the illness will often require psychological support and treatment. Furthermore, when a condition starts early in life, it can interfere with normal adjustment to developmental challenges and achievement of personal goals (Riva et al, 2010). These impacts were highlighted in many witness statements, in which there were vivid accounts of the disruption on young people's physical and emotional functioning as they navigate school, college, and adult roles. These challenges become magnified when people are also diagnosed with HIV and/or hepatitis C, since these additional iatrogenic illnesses have durable effects on infected and affected individuals.

These challenges to the psychological well-being of the individual with haemophilia are recognised within the UK Quality Standards for the Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders (2018) and for Haemoglobin Disorders (2018). These Standards state that psychosocial/psychological care is an essential aspect of haemophilia care and should be organised in an integrated manner as one element to provide multidisciplinary comprehensive care to patients. Both the Haemophilia and Haemoglobin Disorders Care Quality Standards make specific recommendations that are particularly relevant and important to the planning and development of a specialist psychology service for people with haemophilia. The Standards recommend that psychological care should be provided as a routine part of haemophilia care in both paediatric and adult settings, and consideration must be given to the developmental/life stage of the person and the family context, and should ensure that psychological treatments are tailored according to each patient's needs.

The Haemophilia Care Quality Standards provide clear guidance that psychological assessments and interventions should be offered as an integral part of care in the management of haemophilia, HIV and hepatitis C, adjunctive to medical treatment and nursing care, and the recommendations would apply equally to people infected with HIV or hepatitis C through blood

transfusion. The overall goal is to help people build resilience, enhance coping strategies, develop ways to cope with treatment regimes, manage symptoms such as anxiety, depression and anger, be able to engage in valued activity and roles, and improve their quality of life. A group of applied psychologists working in multidisciplinary teams in haemoglobinopathies and haemophilia have developed the following four standards on specialist psychology provision (as found in the Haemoglobin Disorders Care Quality Standards):

- (1) Psychological assessments should be carried out when indicated or annually, to evaluate emotional well-being and pain experience; physical and social function; coping strategies and sources of support; and neuropsychological/cognitive functioning.
- (2) Psychological therapies, including cognitive behavioural therapy (CBT), should be offered as required, and could be offered in individual or group sessions.
- (3) Where serious mental health difficulties or psychiatric problems are identified, referral to a secondary mental health service should be considered and, if possible, discussed with the team psychologist in a timely fashion.
- (4) Group psychological support should be offered to patients, and carer support groups.

The current expectation would be that all infected individuals, who had received infected blood or blood products, as well as their affected family members, would have received some form of counselling or psychological support, particularly in the context of additional diagnoses of HIV and hepatitis C infection. However, the evidence emerging from the witness statements is that counselling and psychological support was rarely offered, and many witnesses describe being offered no counselling or support. One witness describes how her deceased husband had not been offered counselling because the consultant did not want to raise more fears for the patient. Moreover, neither his daughter nor his wife were offered counselling, both of whom were severely affected by the patient's infection and its treatment. Another witness describes how her son was offered counselling 21 years after the diagnosis of hepatitis C, during which time he had experienced serious emotional consequences.

Some witnesses describe not only an absence of support from healthcare professionals, but also hostile communication. Two witnesses describe consultants dismissing their concerns about infection in a threatening manner. For example, one witness who refused a blood transfusion because of a fear of HIV recounted that the consultant had raised his voice and accused her of bed blocking by refusing the transfusion. Another witness, concerned her son was infected with HIV, was ordered off the hospital premises by the doctors who she accused of lying when they attempted to reassure her (falsely as it turned out) that her son was not infected by HIV. This same witness describes how her child was examined by his GP on the doorstep, raising concerns for this witness about an undisclosed infection.

Children, young people and adults with HIV and/or hepatitis C infection have a greater risk of developing emotional, behavioural and relationship difficulties. Witnesses describe developing depression, anxiety and feelings of intense anger, which impacted on current and future educational choices, future life aspirations and work choices, and the development of relationship issues with siblings, children, parents, partners and the wider family system. Children, adolescents, young adults and their family members or carers should be offered emotional support after diagnosis, which should be tailored to their emotional, social, cultural and age-dependent needs. Medical teams should assess the emotional and psychological well-being of young people with HIV and/or hepatitis C infection on a regular basis, after diagnosis and during specific treatment regimens.

A lack of adequate psychosocial support has a negative effect on various psychological outcomes, including adherence to treatment regimens. This was an ongoing theme in witness statements regardless of the age when diagnosis was received. Medical teams should provide screening for a range of psychological problems that can impact on the management of a patient's medical condition and well-being (anxiety, depression, behavioural and conduct disorders, and family conflict). Medical teams should have access to appropriate mental health professionals to assist in psychological assessment and the delivery of psychosocial support. Children, adolescents and emerging adults and their family members or carers should be offered timely and ongoing access to mental health professionals with an understanding of chronic and life-threatening conditions. They are most often located within paediatric psychology services and health psychology services in adult departments.

A number of witnesses describe 'going off the rails' following being told of the infection. Young people and family members or carers who are trying to manage behavioural or emotional disorders should have access to an appropriate mental health professional who can offer evidence-based treatment. If there are difficulties with illness-related family conflict, family-based interventions, such as systemic family therapy should be offered. Where there are concerns about psychological well-being, medical teams should work with paediatric psychology services to develop a programme of therapy that should include support and improvement of health-related quality of life. These should include counselling, cognitive behavioural therapy (CBT) or solution-focused and narrative approaches to build a positive attitude to living with challenges, and help build self-esteem and preferred identities that are not overwhelmed by illness. Medical teams should also offer psychological support for adherence to treatment – for example, motivational interviewing or multi-systemic therapy. Teams also need to be aware that children, adolescents and emerging adults may develop psychological problems (such as anxiety and/or depression) as they move through different life stages. Many witnesses describe how psychological problems developed some years after they had been told of the infection, and the expectation would be that all infected individuals and their affected family members would have received some form of counselling or psychosocial support, particularly in the context of additional diagnoses of HIV and hepatitis C. However, the evidence emerging from the Inquiry's witness statements is that counselling and psychological support was offered in very few cases.

In a life-long condition, an important aspect of any clinical service needs to focus on adolescent transition, which is aimed at a planned and smooth transition from paediatric to adult-oriented health services. From the witness statements, it is clear that many children and adolescents experienced a range of negative psychological effects as a consequence of being given infected blood products or blood. In the transition from adolescence, there is a need to address a number of adaptations, ranging from greater demands for self-management of their healthcare, and the impact of their illness on their emerging sexuality and independence, together with the move from familiar paediatric healthcare settings to unfamiliar adult providers. Key communications about healthcare needs and planned treatment should take place at such clinics, with all the relevant members of the care team, the adolescent and his/her parent/guardian or appropriate adult representative. There is considerable evidence from the witness statements that some adolescents were informed about their HIV and hepatitis C diagnoses without their key adult representative being present. Good practice guidance as well as guidance from both the Haemophilia and Haemoglobin Disorders Care Quality Standards is that imparting such significant health news to minors (under 16 years of age) must be done according to the recognised protocol of mandatory inclusion of a parent or person who will act in the name of parent. In addition, psychological support would be offered and a named psychologist would be responsible for providing ongoing support to the adolescent and their parents.

Non-disclosure as a protective coping strategy is a common theme within the witness statements, where people kept their diagnosis secret within the family. Little or no support was offered at these times, resulting in feelings of isolation and loneliness amongst those with HIV and/or hepatitis C infection and others affected. As noted in earlier sections of this report, there are serious psychological costs associated with undisclosed issues and concerns.

Another support need arises at the time when disclosure becomes significant. Many of the witnesses identify concerns in relation to sexual transmission and safer sex, which impacted on family planning. They received little or no support around these sensitive and challenging concerns. Psychology staff within a specialist service for haemophilia should offer support for such disclosure concerns, including support for parents to disclose their diagnosis to their children. Support for disclosure within the family is based on individual preferences, privacy needs and treatment needs. There are additional challenges in providing support for facilitating disclosure to wider social circles and the workplace.

Witness statements reveal that large numbers of individuals and their families were unsupported as they struggled to come to terms with the diagnosis of HIV and hepatitis C infection. Wives and partners had not been involved when significant and devastating health information was being imparted. The Haemophilia and Haemoglobin Disorders Care Quality Standards recommend a specialist psychology team should support patients and families around receiving significant and difficult health news, when making complex treatment decisions, and that healthcare professionals should invite “a significant other” (as nominated by the patient) to attend when major health news is to be imparted.

Many witnesses indicate that a considerable period of time elapsed between test results being available to the healthcare team and when diagnosis was actually received. This raised concerns about whether such delays compromised appropriate and timely treatment. In terms of current psychological care provision, a specialist psychologist would be involved in support of people giving consent for testing, ongoing support at diagnosis, and for the varying stages of ongoing adjustment and accommodation (see also question 13.4 for a discussion of related communication issues).

Many witnesses mention being so overwhelmed by receiving a diagnosis of hepatitis C, additionally to HIV, that they focused on and communicated about only the HIV diagnosis. The psychosocial burden of being diagnosed with the co-infections of HIV and hepatitis C is enormous and, as very few people received any formal counselling or psychological support to adjust to this situation, many found their own ways of coping. The NICE Guidelines (2018) on post-traumatic stress disorder (PTSD) include dealing with a life-threatening illness, and the requirement to attend frequent hospital appointments as an important area of assessment and management of PTSD. This is clearly another area where specialist psychological services should have a key role.

Currently, the accepted good practice based on specific recommendations from the Haemoglobin Disorders Care Quality Standards is that a dedicated psychology team would provide support to the infected person to enable them and/or their close family members to make informed decisions around treatment. Adherence to complex treatment regimens for the management of HIV and hepatitis C infection is important for effective management and improved immune functioning. A best practice service would play a key role in supporting people on complex treatments. Despite the challenges and complexity of treatment, the support described by many was inadequate or non-existent. The Haemophilia and Haemoglobin Disorders Care Quality Standards recommend support should be offered for individuals and their partners in considering treatment options. However, many wives and partners mention in their witness statements that they had not been involved in treatment decisions. Supporting

and developing interventions to enhance treatment adherence and facilitate lifestyle changes is also important, but the evidence from witness statements suggests that there had been little or no psychology or counselling support offered for this at any stage along the way for infected or affected people.

Embedding psychology services within the Multidisciplinary Team (MDT) enables people with these long-term conditions to access psychological care across all of the healthcare pathways (Haemoglobin Disorders Care Quality Standards, 2018). This approach ensures that psychological distress, coping difficulties and life style concerns can be identified and supported in a timely manner. Locating the psychology service within the MDT ensures that psychological care and support would be available in the main treatment centre, and available to both infected and affected individuals. Locating psychological support services within the team should ensure that both individual and family needs can be anticipated, assessed and addressed in a timely manner.

### **13.9.1. What sort of psychosocial care and support should be available for a person who has been informed that they might be at risk of having been exposed to vCJD (there being no diagnostic test to determine if a living person is so infected)?**

The primary aim of vCJD risk notification is to minimise the risk of transmission within the healthcare setting. Individuals are informed of their status if deemed to be at greater than 1% risk. A significant number of witnesses, the majority of whom had haemophilia, reported receiving letters informing them of their potential risk of developing vCJD, and reported that they were advised that they should inform all healthcare professionals of their risk of vCJD. The request to follow advice in order to minimise the risk of transmission includes not donating blood, tissue or organs; informing family; and informing healthcare professionals prior to any invasive procedures. The expectation is that the specialist psychologist within haemophilia centres would undertake assessment of emotional concerns linked to vCJD. If assessments reveal significant issues, such as anxiety or depression, then appropriate evidence-based treatment, such as CBT, would be utilised to support and empower individuals.

The only existing study of vCJD notifications to our knowledge is a qualitative study, based on interviews with 11 people notified of being at risk for vCJD (Elam et al, 2011). Between 2002 and 2004, 60 people were notified in person after undergoing a surgical procedure involving instruments previously used on those with, or at increased risk of, vCJD, and 110 people were notified in writing after donating blood that was transfused to one of the three patients who subsequently developed vCJD. There was no formal evaluation of the impact of these risk notifications.

The interviews took place between six months and five years after risk notification, and included six notified following surgery and five notified following their donation of blood. Mindful of the limited conclusions that can be taken from such a study, the results suggested that although initially shocking, notification left no lasting emotional impact, with those informed correctly judging that their risk of being affected was extremely low. While those notified were clear that they should not donate blood, tissue or organs, there was more variability in sharing their risk status with healthcare professionals. This, in part, reflected an assumption that there were systems within healthcare that meant this information was already known. These findings, particularly those relating to emotional impact, reflect those from larger salient literatures, which document the short-term nature of the emotional impact of risk information (Shaw,



Abrams, Marteau, 1999). Pre-existing emotional resources, including pre-notification levels of depression, are important modifiers of responses to risk notification (Broadstock, Michie and Marteau, 2000).

By contrast, many of the witnesses in this Inquiry who received notifications, having had the experience of previously being infected with viruses, reported that this additional risk information caused significant anxiety and concern of yet another infection that could have devastating health consequences. For example, one witness within the Inquiry, who required regular endoscopy and sigmoidoscopy procedures was given his own camera, which reflects good practice of individualised care; however, when that camera “went missing” the staff told him that the camera had been transferred to another hospital. On another occasion he was told that a camera had been destroyed because staff were not confident of lack of cross infection. These incidents are reported as examples of highly stigmatising repeated hospital treatment processes that added to the burden of living with difficult long-term conditions.

There are no quality standards of care for vCJD currently available, but descriptions of care and counselling are available from the National Prion Clinic (<http://www.prion.ucl.ac.uk/clinic-services/counselling-and-support/>), which provides important exemplar templates for developing specialist psychological support services in the future. The National Prion Clinic (NPC) is an internationally-recognised NHS service for the specialist diagnosis and care of patients with prion disease. The clinic sits with the National Hospital for Neurology and Neurosurgery, Queen Square division of UCLH NHS Foundation Trust, and is led by consultant neurologists who have extensive experience in the management of neurodegenerative and other neurological diseases. The Clinic currently offers a range of physical and psychological care, focusing on the management of symptoms and issues which can present in this disease, including psychiatric and behavioural disturbances; disorders of movement; sleep; communication, bladder and bowel; eating and drinking; as well as advising on infection minimisation; pain management; activities of daily living; end of life care and carer support. There is also a very helpful guideline on vCJD, which is available for social workers (Manthorpe & Simcock 2018).

The National Prion Clinic national centre is a tertiary service and currently sees people from across the entire United Kingdom. Whilst providing emotional and practical support to patients and their families/carers, the clinic also signposts patients to psychological support and palliative care services in their locality. This centre also provides bereavement support for grieving family members. People affected by vCJD can also access support from the CJD Support Network – a national charity offering a 24 hour helpline (<https://www.cjdsupport.net/>).

### **13.9.2. What sort of psychosocial care and support should be available for an affected individual (e.g. partners, children, parents, families, carers and others close to those infected) both during an infected person’s illness and during bereavement?**

Witnesses with HIV and/or hepatitis C infection identified their parents, spouses, partners, children and other close family members to be vital in providing ongoing care and support. The affected family members endorsed these statements and highlighted the fact that while many continue this source of support, this is a role for which they were largely unprepared and for which they received little if any counselling or psychological support. For those who start medical treatment at a very young age, they and their families often develop lifelong relationships with healthcare professionals. Through such interpersonal interactions trust

should be developed and this is perceived to be very important in healthcare relationships. Research evidence has shown strong support for the influence of trust on health via disclosure of relevant information, treatment adherence and continuity with healthcare providers (Calnan and Rowe, 2006). However, it is clear from witness statements that both infected and affected individuals have felt let down and had their trust violated by healthcare professionals, and some have moved their healthcare as a consequence of these negative experiences. Strong family support can impact positively on the coping resources of infected individuals, whilst life stresses and challenges within the family can reduce this important source of support (Helgeson and Zajdel, 2017). These stressors are diverse and include school problems, divorce, and death in the family, job worries and financial problems. The evidence arising from witness statements suggests that significant numbers of families have experienced the multiple life events of divorce, deaths in the family and loss of job roles, resulting in significant and ongoing financial concerns.

For families affected by haemophilia, von Willebrand disease (vWD) and other genetic haematological disorders, the psychosocial stress inherent in caring for someone with these disorders is well recognised (Buckner, Witkop, Gulcher et al, 2016; 2018; Akin and Ahmad, 2000). Strong negative work-related consequences have been found and linked with higher rates of depression (Buckner et al, 2019). Where partners and children had significant caring duties without adequate support, many of the witnesses describe feelings of isolation. Concealment of these diagnoses was a key coping strategy, because of the stigma linked to HIV and hepatitis C infection and the negative public response. As HIV progressed to AIDS, the increasing signs of ill health forced disclosure, or some type of explanation. There were reports among the witness statements of being the target of abusive and judgemental language, which added enormously to daily stress. People who had previously been so dependent on and trusting of hospital staff in haemophilia centres, soon developed anger at the growing recognition that they had been let down, and in some cases told untruths and misinformation. However, as their infected loved one's need for healthcare is ongoing, they are rendered powerless, as they must continue interacting because of the healthcare requirements. In some cases, evident from witnesses' transcripts, some families made decisions to transfer their care to other NHS trusts as a result of a breakdown in trust. As demonstrated in witness statements, there were significant bereavements to contend with, and in some families, parents lost several children, children lost fathers and uncles, partners lost their life partner and brothers-in-law, and siblings were left bereaved. It appears that the 'grief work' was predominantly managed within the individual families, who supported one another.

A dedicated psychology service (described above) within the haemophilia centre, as recommended by the haemophilia quality care standards, is ideally placed to offer support for affected individuals. A group of UK psychologists with special interests in haemophilia have emphasised that caring for 'the affected' is within their job roles and responsibilities. Ideally, the psychosocial care and support available to affected individuals should begin with assessments of emotional/psychological well-being, bereavement/grief issues, and coping strategies and sources of support. Following assessment, the guidance from the haemophilia care quality standards that informs the current practice guidelines, is for the provision of evidence-based psychosocial care and support to be available to the affected individuals (such as partners, children, parents, families) according to their needs (NICE, 2009).

While these care standards have been outlined in the context of haemophilia, the recommendations are equally applicable to affected individuals, whose relatives had died from HIV or hepatitis C, which was the result of being treated with infected blood or blood products. The bereavement support should include:

- (1) Psychological therapies, including cognitive behavioural therapy (CBT) offered in individual or group sessions
- (2) Where serious mental health difficulties or psychiatric problems are identified, referral to a secondary mental health service should be considered and, if possible, discussed with the team psychologist in a timely fashion
- (3) Group psychological support for carer support groups

When a loved one dies, psychological assessment of the affected is concerned with bereavement needs, focusing on type and quality of experiences such as shock, panic and behavioural responses. It is also possible that anxiety/fear, depression, anger/resentment, work-related concerns, guilt and sleep disorders may be presenting features within bereavement support. As was outlined in question 13.4.9, as there is a greater likelihood of more intense or prolonged grief in people who have been caring for someone who has been infected with HIV and/or hepatitis C, the need for bereavement support is particularly important. The main goals of this support are to enable people to express thoughts and feelings, make sense of what has happened, come to terms with loss, and to recognise the possibility of building a new life without the deceased. CBT is an effective psychological therapy for the bereaved, because it provides a framework to understand their own experiences, identify the barriers that they might be facing and develop strategies to increase their perception of personal control. CBT can be delivered as an individualised short-term intervention or within a group. People who are close to but not related to the infected individual, may also need psychological support, but the provision of psychological support to non-relative groups is less likely due to resource problems. The expectation for this group is that they would be 'sign-posted' for bereavement counselling services, to organisations such as the Samaritans, Cruse Bereavement Care or Improving Access to Psychological Therapies services and other NHS counselling, via GP referrals.

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## Verifying Statements

Each contributing group member confirms that he or she understands his or her duty to provide independent evidence and has complied with that duty.

All contributing group members confirm that in respect of those parts of the report to which they have contributed:

- (i) They have made clear which facts and matters referred to in this report are within their knowledge and which are not.
- (ii) Those that are within their knowledge they confirm to be true.
- (iii) The opinions they have expressed represent their true and complete professional opinions on the matters to which they refer.

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Deborah Christie is Professor of paediatric and adolescent psychology and lead Consultant Clinical Psychologist for paediatric and adolescent psychological services at University College London Hospitals NHS Foundation Trust. Professor Christie was awarded a PhD in neurobiology from UCL, was an MRC research fellow at the University of Oxford, and Leukaemia Research Fellow at Great Ormond Street Hospital. She has won a number of awards including a Fulbright travel fellowship, the Outstanding Scientific Achievement in Clinical Health Psychology in 2004, and the Quality in Care Best Initiative for young people with diabetes. She was also awarded an honorary fellowship by the Royal College of Paediatrics and Child Health in 2017 and served last year as president of the Society of Adolescent Health and Medicine (2018/19). Her current research interests include the development of effective systemic clinical interventions for children and families living with chronic illness. She is an internationally recognised presenter and trainer. Professor Christie is Editor in Chief of Clinical Child Psychology and Psychiatry and has published over 100 peer reviewed papers and book chapters and edited a bestselling book on psychosocial aspects of diabetes for children and families.

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Sian Edwards has worked as a nurse in HIV care for 32 years. Her experience includes both HIV clinical nursing and educational roles in HIV units in the UK, Australia and Zambia. She initially worked as an HIV community nurse in Sydney, Australia in 1986, a specialist lecturer in HIV and AIDS at St. Thomas' Hospital London and as a nurse lecturer at Chelsea and Westminster Hospital. Following two years working in Ndola, Zambia, in a Home-Based Care Program she returned to the UK as a community clinical nurse specialist in the Guy's and St Thomas' Haemophilia Reference Centre. Sian managed two research projects while a senior lecturer in HIV and Sexual Health at Brighton University, focusing on recording the life histories of people with haemophilia and HIV and their families. She has written on the topic of HIV care in nursing and management of AIDS, including a set of guidelines for healthcare workers in 1994. She is currently employed as an HIV Research Nurse Coordinator at Northside Clinic in Melbourne, and has just completed the life history project 'The AIDS Era: an oral history of UK healthcare workers.'

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Dame Theresa Marteau is Director of the Behaviour and Health Research Unit at the University of Cambridge, and a Fellow and Director of Studies for Psychological and Behavioural Sciences at Christ's College, Cambridge. In 1986 she began lecturing in health psychology at the Royal Free Hospital School of Medicine, followed by a senior lectureship in 1993 and then a professorship at King's College, London, where she stayed until 2010 when she moved to Cambridge. Her research focuses on the development and evaluation of interventions to change behaviour – principally food, tobacco and alcohol consumption – to improve population health and reduce inequalities, with a particular focus on targeting non-conscious processes. It also includes research on risk perception and communication. She is a Fellow of the Academy of Medical Sciences, and the Academy of Social Sciences. Her research is funded by Wellcome Trust, MRC and NIHR.

## **Professor Myfanwy Morgan**

Myfanwy Morgan is Professor Emeritus of Medical Sociology at King's College London. Her research has primarily focused on patients' experience and management of chronic health conditions and the acceptability and impact of interventions, with particular emphasis given to the influence of socio-economic circumstances, life stage and ethnicity. Her research contributed to the early application and development of qualitative methods in the health field including approaches to eliciting children's experiences of chronic illness, and has involved collaborations with a variety of clinical specialties and with universities in Europe and North America. She has been a member of grant awarding panels, editorial boards, government policy and advisory groups, and in 2013 gave oral evidence to the All Party Parliamentary Committee for Sickle Cell and Thalassaemia. She was awarded Fellow of the Faculty of Public Health for contributions to research and teaching and has been a speaker at a number of international conferences including the International Sociological Association Forum and the Annual Congress of European Society for Organ Transplantation.

## **Dr Veronica (Nicky) Thomas**

Dr Nicky Thomas is a Consultant Health Psychologist within the Departments of Haematology and Therapies at Guy's and St Thomas' Hospitals Foundation Trust (GSTT) and has recently retired as Head of Psychological Services at this trust and as Honorary Lecturer in health psychology at the Institute of Psychiatry at King's College, London. She started a specialist health psychology service for people with Sickle Cell Disease (SCD) in 1997, which has now been expanded to provide health psychological input for medical haematology and haemophilia patients. Dr Thomas has specialist experience in the use of Cognitive Behavioural Therapy in the management of pain in sickle cell disease. Her other clinical and research interest areas include; pain management; coping with haemophilia and other long-term conditions and cultural awareness training. She has been a speaker at international conferences for the British Psychological Society, British Society for Haematology and at the Sickle Cell Disease conference in the USA. In 2013, she received an Outstanding Contribution Award from the British Psychological Society for her contribution to the field of Health Psychology Practice.

## **Professor John Weinman**

Professor John Weinman is based at the School of Cancer and Pharmaceutical Sciences at King's College London, where he is a Professor of Psychology As Applied to Medicines and Co-Director of the KCL/KHP Centre for Adherence Research & Education. He is a Fellow of the British Psychological Society, the European Health Psychology Society, the Academy of Behavioural Medicine Research and the American Academy of Behavioural Medicine

Research. He has played a major role in the development of academic and professional health psychology within the UK and Europe and is the founding editor of the International Journal: Psychology & Health. The main focus of his research has been on the psychological impact of and behavioural adjustment to major physical health problems, and has increasingly been concerned with understanding the reasons underlying non-adherence to treatment, and in developing effective interventions for improving use of medicines and other treatment. In 2011, he was awarded an Honorary Fellowship of the British Psychological Society and in 2018 he was made a Distinguished International Affiliate of the APA Society for Health Psychology.

## APPENDIX

**The following specific questions, answered in this report, were listed in the Inquiry's Letters of Instruction to the Psychosocial Expert Group.**

### Letter of Instruction

As far as possible, your report should cover the following topics insofar as they are within your areas of expertise and it is possible to address them:

- 13.1. Psychological impacts of infection on people infected and affected: Please explore and discuss the psychological impacts of being infected with HIV, HCV, HBV and/or of being at risk of developing vCJD, by blood or blood products. Please also explore and discuss the psychological impacts on those affected by the infection of a person close to them. Please consider as part of this topic the psychological impacts and stresses of serious and/or constant ill health (often leading to multiple treatments with severe side effects). You are asked to note that the Inquiry has received evidence from witnesses describing a range of psychological reactions on the part of persons infected and persons affected to the fact of infection with hepatitis and/or HIV and/or to the risk of being infected with vCJD, including anger, depression, PTSD, shame, guilt, fear for oneself and of infecting another person, grief, survivor's guilt, risk taking behaviour, going off the rails, disbelief, shock, social isolation and/or helplessness.
- 13.2. The psychological impact, on people infected and affected, of having to continue to be treated by, or interact with, professionals or medical institutions whom they hold responsible for the original infection and/or the impact of a loss of trust more generally in the medical profession or the NHS. In addition, the impact on those who must continue to receive the same treatment that was itself the cause of their infection. (The Inquiry has, for example heard from witnesses who no longer feel able trust clinicians or NHS bodies but who continue to require treatment for lifelong conditions such as haemophilia or thalassaemia).
- 13.3. Social impacts of infection on people infected and affected: Please explore and discuss the social impacts of being infected with HIV, HCV, HBV and/or of being at risk of developing vCJD, by blood or blood products. Please also explore and discuss the social impacts on those affected by the infection of a person close to them. Please consider as part of this topic the social impacts and stresses of serious and/or constant ill health (often leading to multiple treatments with severe side effects). You are asked to note that the Inquiry has received evidence from witnesses describing a range of adverse social consequences of infection, including relationship or family breakdown; divorce; deciding not to have, or being unable to have, children; reduced ability to care for or interact with one's children; losing friends; social isolation; loss of employment; limited employment or career opportunities; detrimental impact on education; and financial hardship.
- 13.4. Psychosocial impact of poor, inadequate and/or insensitive communication of information about testing, diagnosis, infection and treatment: Please explore and discuss the psychosocial impacts of poor, inadequate and/or insensitive communication of information about testing, diagnosis, infection and treatment.

In particular please address the following issues:

- 13.4.1. What is the best way to inform a person that they are infected with a serious disease? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.
- 13.4.2. What is the best way to inform a person that they have been infected with a serious disease as a result of medical treatment they have received? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.
- 13.4.3. From a psychosocial perspective, has best practice in terms of communicating with patients changed over the years, and if so, how and why?
- 13.4.4. The Inquiry has received evidence from a range of witnesses who have described being told of their infection by letter, over the phone, casually or informally in a non-private setting or being told of their infection by someone who has little knowledge of the disease, or being told in an indifferent, unsympathetic or callous way. Could the way in which a person is told of their infection affect the psychological experience of that individual and if so, how and why?
- 13.4.5. The Inquiry has received evidence from a range of witnesses who have described not being told that the treatment which they were being given (whether with blood or blood products) might expose them to a risk of infection and/or who have stated that they did not give informed consent to such treatment. Could a failure to provide sufficient information about risks and/or a failure to obtain informed consent affect the psychological experience of the individual and if so, how and why?
- 13.4.6. The Inquiry has received evidence from a range of witnesses who have described not being told that they were being tested for HIV and/or HCV and/or HBV. Could finding out subsequently that such testing was carried out without their consent impact on the psychological experience of the individual and if so, how and why?
- 13.4.7. The Inquiry has received evidence from a range of witnesses who have described not being told of their infections for years after their infected status was known by clinicians. Could this withholding of information about their diagnosis impact on the psychological experience of the individual and if so, how and why?
- 13.4.8. The Inquiry has received information from a range of witnesses who have described being given little or no information about their infection, prognosis and/or treatment. Could this impact on the psychological experience of the individual and if so, how and why?
- 13.4.9. Please consider and discuss whether the circumstances in which a person is infected, and/or the circumstances in which a person or their family and loved ones learn about that infection, may impact on the grieving process in the event of the death of the person infected.
- 13.5. Psychosocial impact of financial hardship and dependence: Please consider and discuss the psychosocial impact of financial hardship and/or of dependence upon financial assistance from the trusts and schemes established by central government. You will note from the material that is being provided to you that the Inquiry has received evidence from a range of witnesses about their experiences in dealing with the trusts and schemes.

- 13.6. Please consider and discuss the psychosocial impact for people infected and affected by waiting for many years for explanations, apologies, investigations and/or answers as to what happened and why.
- 13.7. Stigma and discrimination: The Inquiry has received evidence from a range of witnesses who have described the stigma and discrimination of being diagnosed or having a person close to them diagnosed with HIV and/or HCV and/or HBV, particularly in the 1980s and 1990s. How does stigma and discrimination affect a person's psychological and social experiences? Please consider from the perspective of both a person infected and affected.
- 13.8. Access to treatment: The Inquiry has received evidence from a range of witnesses who have described difficulties in accessing treatment for the conditions with which they have been infected. Could this impact on the psychological experience of the individual and if so, how and why?
- 13.9. Care and support: What sort of psychosocial care and support should be available for a person diagnosed with a life-threatening disease on first being diagnosed and as the disease progresses?
  - 13.9.1. What sort of psychosocial care and support should be available for a person who has been informed that they might be at risk of having been exposed to vCJD (there being no diagnostic test to determine if a living person is so infected)?
  - 13.9.2. What sort of psychosocial care and support should be available for an affected individual (e.g. partners, children, parents, families, carers and others close to those infected) both during an infected person's illness and after bereavement?

### Supplemental Instructions: Part One

The following supplemental questions, which are described in the Supplemental Letter of Instruction as Part One, have been addressed in this report.

5. When answering the questions posed in paragraph 13 of the initial letter of instruction, please ensure that you consider whether the impact is any different for those who have been infected with more than one infectious disease, and if so, why.
6. When answering question 13.1 and 13.3 please address the psychological and social impacts of:
  - (i) Living with the possibility that a person might develop other associated illnesses or complications arising from their diagnosed infections.
  - (ii) Living with the knowledge that their condition could deteriorate in the future.
  - (iii) Living with uncertainty and fear about whether other (as yet unknown) latent illnesses or infections may yet be identified.
  - (iv) For those people who have cleared a virus, living with the fear that the virus may return.
7. Please consider, as part of your answers to question 13.1, 13.2 or 13.7, the psychological impact on those infected of the (erroneous) assumptions frequently made by medical staff, schools, employers and wider society as to the aetiology/cause of the infectious diseases contracted.



8. When answering question 13.4.6 please be aware that the Inquiry has heard evidence from witnesses who have described samples being taken from them for testing without their consent and later being used in medical studies or research. Could finding out subsequently that such testing was carried out without consent and that the results were used in medical studies or research impact on the psychological experience of the individual and if so, how and why?
9. When answering question 13.4.8 please ensure that you consider the impact of not being informed, or not being given adequate information, about the possible side effects of treatment and/or the after-effects of treatment.
10. When answering question 13.7 and/or 13.8 please be aware that the Inquiry has heard evidence from a number of witnesses who have described being treated differently as a result of their infection, or the infection of a relative, including: people being segregated during hospital stays (including for child birth), people routinely being put to the end of the day's treatment list and people being treated by clinicians in full protective clothing (for example, more than one witness has described being treated by staff dressed in 'space suits'). How might such experiences further impact upon trust in the medical profession and NHS (question 13.2)?
11. When answering question 13.7 (which asks about the impact of stigma and discrimination), please explore and discuss the psychological and social impact of those infected and affected of not telling their family (including their closest relatives, such as parents or siblings or children), friends, employers and colleagues about their infections; of having to keep their infection and its consequences secret; of (in the words of more than one witness) having to "live a lie". Please consider also when answering this question what the impact might be of a clinician advising their patient to keep the infection a secret.
12. Question 13.2 of the initial letter of instruction asks you to consider the impact of loss of trust in treating clinicians, the medical profession and the NHS. Please also explore and discuss the psychological and social impact on those infected and affected of a loss of trust, or lack of trust, in the state more generally, and in particular the psychological and social impact on a person who has experienced incidents which could suggest a cover up or lack of candour on the part of the state or an NHS body or other organisation (such as missing medical records or a failure to provide information as to what has happened).

