

# Expert Report to the Infected Blood Inquiry: Psychosocial Issues (Supplementary)

September 2020





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## INTRODUCTION

This supplementary report has been written by a psychosocial expert group, which was appointed by the Infected Blood Inquiry. In addition to the seven members of the group, who produced the first report in January 2020, two additional members were appointed to provide expertise for responding to specific questions in the supplemental letter of instruction. The names of all nine group members and their areas of expertise are shown at the end of this report. As with the first report from this group, we have tried to capture the range of experiences and impacts of infected and affected individuals who provided witness statements to the Inquiry, and to link this with what is more generally known from published research. In that report, we also emphasised that there is no such thing as a typical pattern of responses since these will depend on many factors such as the life-stage, social support and coping patterns of the individual, their social and cultural background and the healthcare settings, in which diagnosis, treatment and on-going care took place.

**13. When answering question 13.1 in the initial letter of instruction\* please also consider the psychological impact on a parent or carer who:**

**13.1. actually administered the treatment (such as factor VIII) to a child or other family member who was infected in consequence of that treatment; and/or**

**13.2. took decisions (such as agreeing to home treatment with factor VIII) about their child's treatment, where the child was then infected in consequence of that treatment.**

**How could this impact on their relationship?**

The psychological impact on a parent of deciding on or administering a treatment, which subsequently caused harm to a child has to be understood in the broader context of parenting a child with a major health problem. In general terms, being a parent involves a number of demands that contribute to the sense of having been a successful parent. These include ensuring their child's safety and well-being and helping them develop and progress ultimately to independent living. More specifically, the diagnosis of a long-term health condition in a child can create a sense of parental grief and loss that can last for years. For example, mothers of children diagnosed with diabetes have described symptoms similar to PTSD many months after the initial diagnosis. They also report 'lower self-development, restrictions on their well-being and emotional stability and lower levels of daily functioning' (Goldbeck, 2006).

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Parents often feel guilty about conditions, such as haemophilia, where there is a genetic component feeling that they are the 'cause' of their child's condition. Children can feel resentment and anger towards their parents for having 'caused' them to become unwell and subsequently require treatment that has unpleasant side effects and/or is burdensome. 'Normal' adolescent/parental conflict where teenagers push back against parental control can be significantly exacerbated by parents having had, or continuing, to administer treatment. Adolescents feel frustrated when their desired autonomy and future hopes and dreams are impacted on by medical interventions that they perceive are being imposed upon them by their parents (Ivey et al., 2009).

Parents' long-term satisfaction with treatment decisions or their involvement in the decision-making process is under researched, however it is known that the way that parents are involved in making decisions about treatment can have a significant impact on their well-being and other aspects of their experience (Aarthun et al., 2019). A lack of knowledge as a parent and insufficient information about the condition, the side effects of the treatment and prognosis makes involvement in treatment decision-making demanding and stressful. Parents can also struggle to understand what is being said when they are trying to process information when they are also dealing with the shock of the condition and medical uncertainty about the child's prognosis, as was outlined in some detail in the main Psychosocial Report to the Inquiry.

It is assumed that parents make decisions in the best interest of the child and should therefore choose treatments which offer 'the greatest proportion of benefit in comparison to harm'. Parents who were responsible for giving consent for treatment and participated in decision making in relation to administering factor VIII were incredibly vulnerable given, as reported by many witnesses, they received incomplete, incomprehensible or inconsistent information about their child's health condition, needs and health care from clinicians. It is essential that substantial information is provided in order for parents to feel confident about their decisions and subsequently live with the decision that was made. A paternalistic culture and asymmetry in physician/parent relationships when the decisions were being made about treatment resulted in parents feeling powerless and uncertain with heightened stress, both of which impacted on their ability to cope. Parents are not happy with decisions they are asked to make when they do not feel they have made an informed choice or received adequate support (McKenna et al., 2010). Not being offered a chance to review options or evaluate risks takes away a sense of control over the health of their child.

When blood products, which turned out to be infected, were first offered, these negative effects were not yet known. Nevertheless, witnesses have described many examples of bad communication where physicians did not provide adequate consultation time, used medical jargon, where there was a lack of agreement within the team, where the physician had limited knowledge about the available treatments or suggestions that there were cost implications for different treatment choices. All of these factors compromised the degree to which parents felt competent about the decision being made and subsequently having to live with that decision and its negative consequences. A consequence of this poor communication is that parents became confused, frustrated and insecure, not knowing which of the professionals they should listen to. This makes it difficult to achieve an understanding of their child's condition and needs, and creates significant stress when required to take an active role delivering treatment. This leads to powerlessness, insecurity and lack of self-confidence which feeds into longer term emotional difficulties

There are significant emotional difficulties described in the literature (Golics et al., 2013) and reflected in many witness statements. These include helplessness, lack of control, guilt, anger, worry, upset, frustration, embarrassment, despair, loss, effect on sleep, concern about

medical treatment, limited freedom, and worrying about the death of the child or infected family member. There are also negative effects on family relationships between relatives and the affected child or family members and different members of the family including arguments, tension and a lack of understanding of feelings.

One of the most cited feelings by parents is of 'feeling guilty'. Not only was this reported by parents but it was also noticed by their children who were on the receiving end of the treatment. For example, one witness reported that "*My dad feels massive guilt for being persuaded to let me be treated with Factor 8.*" (Baumeister et al., 1994) pointed out that guilt causes negative self-evaluation that usually follows a specific act or behaviour. It is therefore not surprising that making a decision to agree to the administration of factor VIII or actually administering the treatment to a child or other family member who was infected as a consequence of that treatment has an impact on a parent's 'moral experience' and subsequent feelings of guilt (Carnevale et al., 2007). Moral experience is what parents see as morally significant which includes the dilemma of doing right or wrong, seeing themselves as good or bad, experiencing remorse or guilt, and self-identifying as a good or bad parent. It also includes gratification derived from doing the right thing, having a sense of responsibility and justice leading to a distressed or fulfilled conscience. Guilt is not only a psychological construct but is also societal and institutional. Guilt is driven by beliefs about how good parents should act, comparing yourself to others and the lived experience in the immediate and wider family. These create beliefs about what it is to be a 'good parent' therefore placing parents who have inadvertently caused their child or another loved one to become infected at a significant risk of developing guilt (Sutherland, 2010). Guilt is exacerbated by feelings of inferiority, exhaustion, confusion, fearfulness and anger (Douglas & Michaels, 2004) whilst persistent guilt can result in a sense of ineffectiveness that impacts physical well-being, mental health and the ability to be productive (Harper & Arias, 2004). There is also a significant link between depression and levels of guilt (O'Connor et al., 2002).

**14. When answering question 13.1 in the initial letter of instruction\* please explore and discuss the psychological impact on those infected of:**

**14.1. Living with the fear and uncertainty as to whether they have infected or may infect partners/family members and children (including unborn children).**

**14.2. living with the knowledge that they have (unwittingly) put others at risk of infection, even where no infection has been passed on.**

**14.3. living with the realisation that they have infected someone else.**

(Please note when considering and answering this question and/or question 13.4.8 that some witnesses have stated that they were not given adequate advice or information about safe sex or how to prevent transmission of infection by other means).

In the main Psychosocial Report to the Inquiry, the response about psychological impacts of infection on people infected and affected (section 13.1) provided an overview of the different ways in which HIV and HCV infection from contaminated blood and blood products and their treatment affected people's day-to-day social and emotional lives. Witnesses provided vivid descriptions of the many negative changes in social, interpersonal and emotional relations with spouses, family members, and the community (Sandelowski & Barroso, 2003). Here we focus on some very specific issues arising from fears of and responses to possible or actual transmission of HIV and HCV to others. The Inquiry heard from witnesses who described negative psychosocial impacts of being infected with HIV and HCV for themselves as well as living with anxiety and fears about passing on infections to their partners, children and family members. In one poignant example, one infected witness reported how he and his partner made the decision to terminate a pregnancy following his HIV and HCV diagnoses, which subsequently led to a breakdown in their marriage.

The fear and concern about infecting a family member is a major and consistent source of stress impacting on relationships during a time when HIV and HCV were considered to be highly stigmatising infections, being predominantly assumed to be transmitted through sexual contact and drug use. The Inquiry heard from infected individuals who highlighted fear of infecting partners as a huge barrier to forming lasting and meaningful relationships. Some 'unattached' witnesses underlined this fact by stating that they had not had any or many

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meaningful or long-lasting close relationships primarily because of the fear of transmitting the infection to a partner. Here we focus on two key areas of impact, namely intimate relationships and family functioning.

A number of witnesses described ways in which being infected had very significant impacts on either their current sexual relationship with a spouse/partner or a potential new partner. In terms of current sexual relations, it was clear from a number of witnesses that the fear of possible transmission was a major source of anxiety for them. Research has shown that anxiety linked with sexual intercourse is a significant barrier, and diminishes both desire and pleasure. For example, Florence et al., (2004) found that HIV positive women reported significantly lower levels of sexual desire post diagnosis, whilst Siegel et al., (2006) found that, regardless of age or ethnicity, HIV positive women reported that they had experienced less pleasurable or satisfying sexual intercourse since their diagnosis. This was largely attributable to the anxiety experienced during sexual encounters and to the fear of transmitting the virus to partners or becoming re-infected. There is also evidence that a diagnosis of HIV/AIDS may result in a subsequent loss of libido and cessation or reduction of sexual activity, all of which can give rise to the development of depression, irritability, anxiety, and lower life satisfaction (Florence et al., 2004; Goggin et al., 1998; Siegel & Schrimshaw, 2003). A small number of studies have also documented an increased prevalence of celibacy or sexual abstinence following diagnosis with HIV/AIDS. (Bova & Durante, 2003; Siegel & Schrimshaw, 2003).

In addition, the planning and preparation required to practise safer sex was seen as a further complicating barrier and served to remove the spontaneity that is so much part of the inherent enjoyment of sexual activity (Siegal et al., 2006). In this way, HIV and HCV infections can transform people's views of their intimate sexual lives from a positive, pleasurable process to a tedious chore and or a frightening and risky activity. The infection can also have a negative impact on self-perception and self-esteem, and a loss of one's sense of self as being desirable and sexually attractive. In addition, the pleasure derived from even protected sex may be diminished greatly by anxiety related to the possibility of infecting others. When such changes occur, the pleasure of sexual intimacy is likely to be reduced and as a result, there may also be a substantial decline in one's interest in sex (Yang et al., 2016).

Pleasure and a sense of meaning is often achieved through having children and developing good relationships with them. In a study from the UK, 81% of the HIV-positive heterosexual male participants agreed that their children gave meaning to their lives (Sherr & Barry, 2004), and another study of HIV infected women reported that their children were strong motivators in their desire to continue living (Yang et al., 2015). Anxiety and fears of transmission can however, interfere with significant relationships such as that between parent and child, and there is research evidence supporting this. While the likelihood of vertical transmission of HIV from mother to infant has significantly reduced as a result of antiretroviral treatment (ART), in addition to good prenatal care (Cibulka, 2006; Cooper et al., 2002), some HIV-infected parents continue to worry about transmitting HIV to their children via casual contact (Corona et al., 2006; Cowgill et al., 2008) even though such fears may often be unfounded (Courville et al., 1998). These fears can be detrimental as they may affect the ongoing development of the parent-child relationship by limiting the quantity and quality of their daily interactions, which may adversely affect their children's development (Bowlby, 1969; Coates & Lewis, 1984).

The research evidence on HIV related fears and transmission does suggest that there is a small amount of evidence supporting the notion that the quality and quantity of child parent interaction maybe affected. For example, Schuster et al., (2005) found that that although HIV infected parents rarely withheld routine physical affection, approaching one third avoided at least one type of physical interaction a lot of the time with their children because they feared

transmitting HIV or catching an opportunistic infection. Other evidence has identified specific areas of fears related to blood contact, bathroom items, kissing/hugging, and food as key areas of potential HIV transmission (Cowgill et al., 2008). Family members were concerned about HIV transmission through contact with the infected parents' blood. In some instances, the parents' fears about blood contact affected how the children felt and reacted when the parents were bleeding. Family members also mentioned fears about transmission in the bathroom that involved possible contact with blood or saliva. Fears of transmission through contact with saliva are considered to also occur when sharing food or drink and hugging and kissing. Within the Inquiry, many witnesses were concerned about possible transmission to their children especially with regard to contact with blood. In Cowgill et al.'s (2008) study, education was a key tool utilised by parents to reduce fears in children and, whilst some parents and caregivers were successful in dispelling myths about HIV transmission, others were less successful, as exemplified by the report of a 13-year-old daughter of an HIV-infected mother who would purge herself after eating the food her mother had prepared.

The significant delays that some witnesses experienced in receiving information about their HIV and Hepatitis infections meant that precautions were not taken, putting partners and children at risk and, in some cases, they became infected. With respect to concerns about putting their children at risk, witnesses described the wait for children's test results, years later, as agonising, fearing that they may have become infected during the undiagnosed period. Other witnesses made clear statements that living with HIV contributed to the development of marital problems or exacerbating on-going difficulties. Existing research evidence suggests that living with the realisation of infecting one's partner is distressing causing worthless and remorseful feelings in HIV-positive men who had infected their wives (Thapa & Yang, 2018; Yang et al., 2016). Similar very negative experiences were also reported by some Inquiry witnesses. For example, one witness, reflecting on the fact that when his wife became HIV positive, stated that it *"destroyed our lives, and if it wasn't for HIV infection we would still be together."* Another witness, who in commenting on the challenges that were posed by her husband's HCV status, stated that *"Hep C was like a third person in our marriage."*

These findings indicate the need for psychosocial intervention programs targeting the sero-concordant or sero-discordant couples, in order to provide comprehensive care to both partners. The emotional costs of being infected with HIV/HCV have been huge with many regrets of lost opportunities to have children and relationships ending prematurely. In the response to question 19 below, there is a very detailed outline of the many negative psychological effects of not having children or deciding not to have children because of HIV or HCV infection.

The Inquiry heard that very few infected or affected individuals were offered any counselling or psychological support. Yet the evidence reviewed suggests that many HIV/HCV infected people would benefit from psychological support /counselling around their intimate lives and sexuality. While a certain amount of anxiety concerning infecting others or becoming re-infected can be adaptive if it motivates safer sexual behaviour, too much anxiety may be maladaptive if it results in a fear of physical closeness and any kind of sexual intimacy, even acts that carry no risk of HIV transmission. Given the recognized association between aspects of emotional distress and low sexual desire among both HIV-positive and HIV-negative samples (e.g. Goggin et al., 1998; Laumann et al., 1999), psychological support in relation to relationship and sexuality problems is an important adjunct in enhancing the mental health and well-being of HIV and HCV infected individuals.



## 15. When answering question 13.1 in the initial letter of instruction\* please explore and discuss the psychological impact on those affected of living with the fear and uncertainty as to whether they have been, or may be, infected.

A number of affected witnesses described their concerns about being infected as the result of living in close proximity with someone who had been infected by a contaminated blood product. Just as patients who have been infected with HCV following blood transfusions or the use of blood products have major concerns about infecting family members and developing serious and potentially stigmatising illnesses (Minuk et al., 2005), their partners and other family members are very likely to have similar fears and worries. These fears are very real for the affected individual even though the actual probability may not be as great as the perceived risk (Kushner et al., 2019; Schneiderman & Kaplan, 1992). The psychological impacts of such fears might be manifested in a number of ways. The continuing worry about becoming infected could result in avoidance or decreased levels of contact with the infected individual. Affected individuals are also likely to become more vigilant and health anxious, monitoring for possible signs of infection, and misattributing benign or transient symptoms as possible indications of having been infected (e.g. Rollman, 2009).

In studies of transmission-related fears in families, where there is an HIV-infected parent, psychological impacts have been found in children and partners. Not only do parents have fears about contact when they have bleeding episodes but this was also mentioned by other family members, particularly in certain contexts such as the bathroom (Cowgill et al., 2008). Similar fears were also expressed about possible transmission by saliva when sharing a bathroom, hugging or kissing, and sharing food or utensils. Since they were unsure about hugging or kissing the infected person, some individuals then reported changing or reducing ways of expressing affection. Even though families try to address their children's fears by providing information about the nature of HIV transmission and by taking precautions to minimise risk, the fears sometimes persisted and there have been reports of children who were frightened of eating food cooked by an infected parent (Cowgill et al., 2008).

Other studies have shown that children of an infected parent worry about experiencing stigma and decide not to tell friends about their parent's condition to avoid this. This, in turn, may have led to loneliness and lack of potential support from peers (Bogart et al., 2008). Some family members and caregivers did still experience stigma due to the association with an HIV infected person and lost friends as a result. Not surprisingly, elevated levels of distress have been found in affected partners (Cherayi & Jose 2015; Remien et al., 2003), and challenges around intimacy were also reported. For example, in couples the perceived risk of HIV infection has been found to have a negative impact on their sexual relationship, resulting in feelings of discomfort and reduced levels of intimacy (Vandevanter et al., 1999).

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Although undergoing a test for HIV or HCV could have reduced anxiety about having been infected, research has shown that any reassuring effects may not be long lasting and that there were continuing worries about undergoing testing and revealing the presence of a serious stigmatising condition (Evangelini & Wroe, 2017).

## **16. When answering question 13.1 in the initial letter of instruction\* please address the psychological impacts of facing a shortened lifespan as a result of having been infected.**

The impact upon any individual facing a shortened life span is influenced by a number of psychological and social factors. Ill health causing a shortened life expectancy often presents with painful and debilitating physical symptoms which impact on a person's psychological and social well-being. But facing a shortened life expectancy has a more profound and complex impact than the physical aspects of ill health and imminent death. Chronic illness challenges a person's sense of themselves, from a previously healthy identity to an illness identity which requires major adjustment (Helgeson & Zajdel, 2017). Such adjustment is determined by a number of factors including personality variables such as individual resilience and vulnerability, and social and environmental variables including social support and social interactions. Facing a shortened life span requires enormous personal readjustment for the individual and, depending on their age, for those close to them such as parents, partners, children and siblings. Such readjustment is more successful and results in fewer mental health challenges if the individual is well-supported by healthcare professionals and by family, friends and colleagues.

A range of interrelated and additional psychological problems can arise when the shortened life span is caused by a publicly stigmatised condition. Research with people infected with HCV examine the profound negative impact of the diagnosis, concluding that the perception of severity and fear of death may not correlate with actual clinical deterioration and likelihood of death, but there exists an emotional burden which affects quality of life even in the absence of liver disease. The research highlights the importance of ongoing communication and the crucial role of the specialist in providing information for patients to better cope with their condition (Castera et al., 2006). When HCV infection was acquired via medical treatment, the psychological support and information required from health professionals appears to be severely compromised. Many witness statements describe an evasiveness from health professionals to engage. Witnesses describe being left making significant adjustments to their lives, living with the fear of an early death, with limited support or information. One woman, infected after receiving infected blood transfusions recalls the similar fears of many others *"I worried about if I was going to infect my children, how I was going to even – would I live to see them growing up, would I see the next month, the next year?"*

AIDS involves multiple co-morbidities because it is not one disease but a series of relentless conditions and treatment side effects. Witnesses describe dealing with or supporting those with debilitating illnesses and the terrible side effects of treatments. For those with HCV,

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often alongside HIV, experienced harsh treatment regimes, intolerable side effects and minimal success rates. Treatments undertaken with the constant fear that without them, the alternative was possible death associated with liver cirrhosis and liver cancer.

A shortened life expectancy usually comes with ill health but many witnesses who were given an HIV diagnosis, a poor prognosis and inevitable death reported *“a lot of mental anguish, but initially not much physical.”* Readjusting to the information was confusing, *“I recollect being told that I had – my life expectancy was going to be two to three years, I think, at that stage and it was unexpected piece of news and also slightly – I think there was slight disbelief in as much as I had no ill symptoms at that time. I was still playing five-a-side football even though I probably shouldn’t have been. I was still quite young, doing crazy stuff, and full of life.”*

Many people who were diagnosed with HIV and HCV infection in the early days had been infected for a number of years and that was certainly true of those who were infected via contaminated blood products. The diagnosis of HIV and HCV infection was often delivered without the clear information of the implications of that infection, likely prognosis, treatment options, or infection control measures. Where health professionals had no prior experience of the condition or expertise, the diagnosis was rarely followed up with what would today be considered essential professional psychological counselling and support. Witnesses often obtained information from television and other media. In 1986 the UK government launched the AIDS health campaign to warn and educate the public about avoiding infection. A hard-hitting campaign based on fear tactics including posters, television advertisements and leaflet distribution. For those already infected and facing a shortened life span the approach and information of this campaign increased the distress of the issues they were already facing. The opening words of the health information televised at prime time warn ‘there is a danger that has become a threat to us all. There is a deadly disease with no known cure’. The psychosocial impact for those facing a shortened life expectancy from infection with HIV was heightened fear, isolation and avoidance. As explained by one witness *“I closed the door and that was it. We shut the world out. We didn’t buy newspapers, we didn’t watch the news, because it was just terrifying, absolutely terrifying, and then I go out with my friends and it is reinforced that that attitude is there, so ....”*

Facing a shortened life expectancy requires adjustment to numerous social and psychological issues. When facing a shortened life expectancy because of HIV and HCV, those issues are likely to be intensified and complicated by the reaction of a fearful, intolerant and misinformed public. Witnesses recall how their diagnosis of HIV was accompanied by a warning to tell no-one because of the stigmatisation of the illness, but alternative sources of support were not provided. *“I was told I had about a year to live and I was told not to tell anybody, including my family and my parents. When you’re 23, you have life, you are generally fit, apart from bleeds, but then you are told you have 12 months to live. It’s very hard to comprehend that.”*

Those who did share information about their diagnosis of HIV and HCV often tell painful accounts of family members, friends, social groups and work colleagues who did not provide the empathy and support they needed. Many therefore chose not to disclose that they were infected or facing a life-threatening illness. Disclosure is required for support to be accessed, and there is a heavy psychological cost of not disclosing a condition where life expectancy is shortened. Coping alone, with non-disclosure and avoidance, increases and complicates long-term illness and negatively affects mental health, distress, depression, anxiety and isolation (Stanton et al., 2007). Commonly, people changed the diagnosis to one they felt would be more socially acceptable and result in more empathy and compassion. A wife, also infected, explains how she managed disclosure when her husband died, *“...and people all assumed he died of cancer because that’s what I told them he died of. So I had the sympathy*

*around cancer. I could never have told people that he died of AIDS and it's only in recent years that I'm beginning to do that. It was such a stigma... But I was hiding a truth. I was hiding, you know, my own health and my own issues and, you know, the mental anguish that goes along with having HIV in a world that's so hostile, because we're talking about hostility."*

The age and life stage when a person faces reduced life expectancy influences the management of the condition and its psychological consequences. An adult facing reduced life expectancy may adjust in a different way compared with a child or adolescent.

Children and adolescents with a life-threatening condition and reduced life span can suffer significant adverse impacts upon developing self-identity. Children and adolescents may find it more difficult to develop supportive intimate relationships with friends, parents and siblings which, in turn, adversely affects social adaptation, educational achievement and future opportunities for employment and relationships (Christie & Viner, 2009; Colegrove & Huntzinger, 1994).

For children diagnosed with HIV infection and facing a shortened life expectancy, school and education were often viewed as futile. HIV is a lonely condition to bear with thoughts of disease and fear and death, but especially when surrounded by other active, healthy children working towards careers and exciting social and sexual futures. At precisely the time that life should be presenting a child with independence, HIV infection demands increasing dependence on parents and on health interventions (Jones, 1991). One witness, diagnosed at 12 years-old, personally reflects the research on childhood development *"The most formative years of my life had been spent in a hospital... It was the time when you turned from being a child to an adult. It was the time where you stop being at school, go to university or get a job, and you're supposed to do that alongside all of your peers. You are supposed to get your life experience at that point. It's where you leave the apron strings of your parents and go and find your place in the world alongside everybody else and that I hadn't done. Everybody else that I'd grown up with had done that. They'd moved on but I was left as almost a 20-year old 16-year old, if you like. I was still back at that stage but with nobody then to experience those years with."*

Many were diagnosed in late teenage years prior to starting a working life or attending further studies. One witness explains the isolation when hearing of his diagnosis and imminent death, as he began university, *"'I've just got three months to live?', he goes, 'Yeah, I'm afraid so'. I mean there wasn't any other way to feel because at university I was away from the family, I was just creating friends and it wasn't something that you could share... You couldn't share this with the ones that you have just initiated a friendship with, you know, and that's the first wave of isolation. I thought, well, I can't tell that and I kept myself to myself and made sure that whatever I did, I did in kind of isolation or kept it as minimum as possible because I didn't want my friends finding out and also I thought, well, I can't really do anything. I wasn't sure how to carry on with the first year of university. I thought shall I carry on?"*

Children at schools with specialised haemophilia units received the same factor concentrates within the school system, became infected and then faced the news of their reduced life expectancy together. One witness having discovered he and a number of school mates were infected with HIV, returned to school the same afternoon, *"What were we going to learn after that? What was the point in studies? I did get GCSEs and so on, but what was the point in studies. You're going to die in two to three years. So teenage of course, the teenage world is different to adult of course. But it became a 'what's the point, what's the point?'"*

Children, adolescents and young adults facing reduced life expectancy, and their family members and carers, need emotional support tailored to their specific emotional, social, cultural and age-dependent needs. There should be ongoing assessment by skilled

professionals and appropriate intervention for the emotional and psychological well-being of young people. Although some witnesses recall significant support received from self-help groups, others acknowledge limitations, *“There was a Saturday afternoon support group, other haemophiliacs who were infected and their spouses, partners, friends, would get together – self-support group. It was good to know ... You weren’t alone. Somebody would say something and I had been feeling that same thing and you thought you were the only one who had those feelings. But over time it unfortunately changed. People started to get ill; people started to die, and, when you were going up for the next, you would be wondering who would be turning up, who’s looking worse than they were last time, so I’m afraid it didn’t end as well as it started.”*

Facing a shortened life expectancy is rarely faced alone, and the psychological impact is complicated by the distress and challenges faced by others. Chronic disease and the imminent death of a person has major effects on the quality of life for other family members. The impact on family members is often neglected in healthcare but there is a need for health professionals to provide support for those family members as well as the patient. Partners are often carers, but that role becomes particularly crucial when trust in health professionals has been compromised. Caring for someone ill and dying requires expertise and skill and, without professional support, family members face more pressure (Golics et al., 2013).

Family members can experience a range of negative emotions, including worry, sadness, frustration, anger and guilt. Chronic illness is also very likely to affect a family’s finances with multiple healthcare appointments, treatments, mobility aids but more so when partners or parents are required to take time away from work to care. Alternatively, family members may be required to work more arduous hours to make up for a loss of family income. Educational studies, social life, and relationships with other people can be severely disrupted and compromised by chronic ill health in a family. Family relationships can suffer from resentment, stress and tension and emotional and sexual relationships often deteriorate. All of these factors and additional challenges are presented by witnesses who are partners, children, parents and siblings of someone with HIV/AIDS and facing a shortened life span. A number of witnesses recount relationship breakdowns inflamed specifically by their partner’s HCV treatment side effects, causing distressing and unmanageable personality changes. Witnesses who were the children of a parent with HIV, recount feelings of distress, fear, anger embarrassment and resentment in having to face a parent’s constant ill-health and imminent death. When children are unable to share that distress because of the stigma of an AIDS death, the distress is magnified.

There were a number of witnesses who were infected sexually, both partners then faced a shortened life expectancy and all the complex psychosocial factors that arose. A partner, infected sexually, whose husband died, recalls *“It devastated him. It really devastated him. It was the day – well, I saw a change in him from that day on. He felt guilty. He felt awful.”* A reduced life expectancy causes many readjustments in ideas and expectations for the future. Decisions about having children together may be re-considered, particularly in the light of potential infection through sexual contact *“Once we sort of the made our mind up we couldn’t cope with our illness and we couldn’t cope with having the extra pressure of looking after somebody and if anything happened we wouldn’t have been able to forgive ourselves, so we chose to abort the baby and I think the doctors were ever so pleased. That’s how we felt. I’m not sure. I’m speaking on their behalf and it’s not my position to do that, but I think it was a relief for them.”*

Many witnesses attest that, as parents, they may be the person who is most affected when a small child is diagnosed with a life-threatening condition, whereas the child may remain unaware of the infection or its seriousness. Parents of children facing a reduced life expectancy do not usually keep such information a secret, but when the cause of a child's reduced life expectancy is HIV, parents face additional challenges and decisions, such as whether or not to divulge the HIV status of the child at playgroups and school, or with relatives and friends. It is difficult to know who to tell and who to trust in a society that stigmatises HIV and AIDS. A witness, diagnosed at 12-years old, but unaware, talks of his parents, *"My parents were really good parents and I think they very much tried to shield me from the turmoil that must have been going on in their mind, but from what they've told me they were absolutely beside themselves. They didn't know what to do, they didn't know what my prognosis was. All they knew was that they had to try and give me the best life I possibly could before I inevitably died in quite short order, really."* That witness was informed at the age of 13 of his diagnosis but for some this information is delayed. Parental avoidance of disclosure to infected children, with the wish to protect them from harm in light of society's reaction, resulted in ill-timed and inappropriate disclosure which can generate resentment, anger and family conflict.

Effective communication and support from health professionals to assist patients facing life threatening conditions requires appropriate experience and expertise developed through specific training for working with children (Himmelstein et al., 2004; Kim, 2020) and adults (Quill & Abernethy, 2013). Many witness statements suggest that their regular healthcare professional/s did not have the expertise to support them as they faced the psychological issues related to a shortened life span, and that few were referred to more appropriate health practitioners, *"I was left to my own devices to go home and absorb the information that I would die young. I would suffer and die a horrible and painful death. The outlook was bleak and terminal. I mean, it's like I suspect for many people here, either for those people that have suffered, are suffering and for those people who have cared or looked on as other people have suffered. It is a very stark and bleak prognosis and there's nowhere to go. There is nowhere to go with those kind of feelings, so yeah."* Witness statements differ about the information they were given in relation to their life expectancy; no information, inadequate information or alarmist information is recalled. It appears that clear, concise information relating to prognosis, treatment and research, and about ongoing expert psychological support for an individual facing a shortened life span, was often lacking.

When effective antiretroviral therapy became available in late 1997, people with HIV who had not died of AIDS experienced a new sense of hope and no longer focused on inevitable death. However, 15 years of living with HIV-related illnesses and treatments and expecting to die, had left many with compromised health, low educational attainments, poor work and career progression, poor finances and psychological and mental health issues – all of which had to be reviewed in light of a future living rather than dying. Many struggled with this adjustment to an unexpected and unplanned future. One witness who learnt of his HIV diagnosis as a young teenager said *"I had no idea. I had no idea. I had expected to die. Simple as that. I hadn't expected to be there or at least I hadn't expected to get better. There was no plan for the future and there I was, at home with the prospect of a future and I'd never had it before and I had not a clue what to do with it."*

**17. When answering question 13.5 in the initial letter of instruction\* please also consider and discuss the psychosocial impact of also being dependent on state benefits and all that entails in terms of the application and assessment and re-assessment processes required to claim and retain welfare benefits. In particular, please consider how the effects of infection and illness might impact on a person's ability to engage with this process.**

The severe financial difficulties experienced by many infected persons and their families is briefly described in the main Psychosocial Report to the Inquiry (section 13.3). This section focuses on experiences of applying for financial benefits to meet ongoing needs. This sometimes involved claims for the Disability Living Allowance and later Personal Independence Payment which is a general state benefit administered by the Department of Work and Pensions (DWP). Such claims were described as involving both practical demands and what witnesses described as the feeling of being '*looked down on by others*', reflecting the feelings of stigma often associated with receipt of state welfare benefits (Geiger, 2016). More commonly witnesses focused on applying for payments through schemes specifically set up to provide financial support to people infected by NHS supplied blood or blood products. These were run by three registered charities: The Macfarlane Trust (set up 1988), the Eileen Trust (1993) and the Caxton Foundation (2011), and two private companies: the Skipton Fund (2004), and MFET (Macfarlane and Eileen ) Ltd (2010). These five organisations received NHS funding, with some increase in funding following The Archer Inquiry (2009). However the schemes evolved in an ad hoc and incremental manner and differed in the disease group supported (HIV, HCV or both), the types of support provided (lump sum payment or grants and means tested ongoing payments), the criteria employed to determine levels of payment awarded (disease stage and level of 'need'), and whether the scheme extended to uninfected family members, including the bereaved (Department of Health, 2016).

The form and level of payments received through the specialist schemes varied widely. Some witnesses reported receiving an ex gratia lump sum payment of around £20,000 from one of the charities, and occasionally a further payment following a more advanced stage of disease. These payments were described as very important in avoiding overwhelming financial problems but did not compensate for the way in which their financial situation had been adversely affected by having to give up work or sell a business due to their health. Accessing such support was also often very difficult and demanding. For example, some people described difficulties in proving when their blood transfusions occurred in order to make a claim for a lump sum payment as letters and reports were not always found with their medical notes. One witness also stated that her application was rejected on the basis that the likely date of her infection by the NHS fell after the September 1991 cut-off date, which the NHS argues represents the point at which all transfusions were screened for HCV. However, she described the effects on her health and lifestyle as no different from those experienced by other infected individuals who were eligible, and observed, "*I spent over 10 years unsuccessfully attempting to receive compensation and the stress and wasted time*

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\* Question 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.

*involved only compounded the negative effects of my infection.*" In another case, a witness and her husband were only offered a lump sum payment if the charity bought equity in their home and then reclaim a percentage of the current value when the house was sold. The couple were forced to accept this as the husband was dying of AIDS and had only 18 months to live and they had very little money coming in, although receipt of the finance took what was described as *"nine harrowing months"* after the initial approach for financial support due to arguments regarding the value of the house and general slow processing. A condition of receiving lump sum funds was also sometimes the requirement to agree never to bring any other type of claim or further action. A witness described this as *"almost like a gagging order, in a sense."* However, he signed, explaining that *"what I wanted to do was live...we don't get much time."*

Other awards were in the form of grants for specific purposes. These included payments for specific medical needs, such as for a private ambulance to attend hospital when bedbound or mobility scheme deposits but more commonly were for more general social needs, such as grants for storage heaters, white goods, and children's clothes. Applications to meet these needs arising from severe financial difficulties were described as particularly complicated with unnecessary bureaucracy and *"too many hurdles and hoops for sick people."* This often led to a great deal of stress, especially as people were generally *"already immersed in and dealing with a nightmarish situation"* in terms of their own health and/or their partner's health. For example, a witness with HCV explained how in order to receive a clothing grant for her children she had to get two quotes even for socks and *"if I felt poorly it was difficult to go out and shop"*. Similarly, if she had been awarded a grant for repairs she could not pay the tradesmen on the day but had to wait for a cheque once given an invoice, and was also concerned that the cheque had Caxton Foundation on it, *"so it's not hard to find out what is wrong with me."* She concluded, *"So the whole system is/was horrendous, you know, and I believe that many people just didn't apply because of it and that's how it became for me in the end."* Another witness also described how they claimed for a new bed to replace one that smelt of pus caused by her husband's cancer and the springs hurt her fractured spine. However, they were asked to get supporting letters from the nurse who visited them, and it was suggested they also needed occupational therapy backing. As the witness commented, *"this started to make the whole thing a major undertaking."* More generally, the application process for small grants was described as unnecessarily lengthy with *'unbelievable red tape'* and little recognition that they were dealing with desperate and dying or bereaved people. This included the situation for bereaved spouses as their money stopped after their husband/wife died. The widow then had to wait to obtain the death certificate from the coroner, fill in forms and then wait up to 30 days for their submitted claim to be assessed with no money coming in.

Criticism of the process of applying for support reflected not only the demands and complexity of the process but also because witnesses often perceived an attitude of contempt and lack of sensitivity to their circumstances rather than being treated with the dignity, respect and professionalism they felt was deserved as a victim of medical errors. For example, a widow described being upset by how her dead partner was talked about by one of the schemes and described being asked in relation to a funeral grant how the money would be used and what the benefits would be. She stated that *"their attitude, their use of words, made me cry and I haven't been a great one for crying in public."* There was also the view that claiming benefits whether through the DWP or specialist organisations had a major psychosocial impact in that it meant that you *"... lost control of your life, which seemed to become a parade of people turning up deciding what is best for you. Nothing was private or 'ours' anymore. It was as though our lives had become available for inspection."*



Some people may have had positive experiences of the specialist schemes, especially if they received assistance in making applications from a local haemophilia society or other groups. However, the problems described by witnesses arising from complex processes of application, varying criteria and differing interpretations across schemes, together with what was perceived as a lack of understanding of the haemophilia community and insensitive questions and approaches, accords with evidence collected by previous investigations including The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood in January 2015 and earlier Archer Inquiry (2009). In response these schemes were replaced during 2017/19 by a new integrated system of support with a single body in each of the four countries of the UK (Department of Health, 2016). The new organisations have received an increased level of funding but continue to focus on support rather than compensation, with their stated aim to provide a simple and equitable system of financial support that is responsive to individuals' circumstances (Department of Health, 2016). However, separate implementation by England, Wales, Scotland and Northern Ireland which each have their own financial support system has resulted in significant disparities between schemes in their criteria and benefits which relates to both infected individuals and support for a bereaved spouse. These disparities have led to a recognised need to address the issue of parity across the UK. Some moves have been made towards this with increased funding in lower financing countries and changes so that more bereaved spouses are eligible for additional support in England. However, it is recognised that the system is evolving and that disparities continue to exist (Department of Health & Social Care, 2019).

## **18. When answering question 13.6 in the initial letter of instruction\* please consider:**

### **18.1. The psychological impact arising from the fact that many of those infected and affected have died (and that deaths continue to occur) while waiting [for explanations, apologies, investigations and/or answers as to what happened and why].**

In the main Psychosocial Report to the Inquiry (section 13.6), it was noted that many witnesses experienced inadequate and flawed communication. This included having to wait for explanations, apologies and answers, which left them feeling a range of negative emotions including frustration, helplessness and rejection, all of which made it even more difficult to cope with the situation. The fact that many of those infected and affected have died while people were still waiting for information can only have added to the psychological impact on those who were bereaved. Providing explanations and apologies for medical complications and errors requires a number of key elements if it is to be helpful to those who have been harmed and their families (Lazare, 2006). An apology, when provided in a timely, sensitive and patient/family centric way can be a key part of the healing process for those who have been left behind. It can help to validate and acknowledge the pain of the individual as well as begin to repair the relationship and trust with the healthcare system.

To be still waiting for explanations and apologies after one's family member has died adds an additional negative element into the grieving process. As was outlined in section 13.4.9 of the main Psychosocial Report to the Inquiry, grief can become much more intense and

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\* Question 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.

prolonged when the bereaved person finds it difficult to accept the death, feels unable to trust others, and continues to feel anger or even guilt (Shear, 2015), particularly in parents who lose a child (Meert et al., 2011). Thus, having experienced unsatisfactory communication, including insufficient explanation or apology, is very likely to complicate the grief process (Miyajima et al., 2014; Sanders et al., 2018). All grieving takes time (Stroebe et al., 2007) but the experience will very likely be made more difficult if the bereaved person is left with unanswered questions and still feels resentment for the way in which they and their loved ones were treated. When patients die, those who are left behind will reflect on the quality of care which their loved one received and on the quality of communication which they received. Since poor quality end of life care and communication has been shown to increase levels of anxiety, depression and regret in the bereaved (Krug et al., 2016; Miyajima et al., 2014), it is most likely that there were similar impacts on those whose infected relatives had died before satisfactory explanations or apologies had been provided.

## **18.2. The psychological and social impact of actively campaigning for answers and an investigation, over many years (and for some, for their whole lives).**

A number of infected and affected witnesses described how they had become involved in groups or campaigns, often over long periods of time, in attempts to getting answers and an investigation either for their own peace of mind or for purposes of compensation for the losses which were incurred directly or indirectly from the effects of treatment with infected blood. Having to wait for information and explanations, as well as an investigation, was a consistently stressful issue reported by witnesses and was discussed in the main Psychosocial Report to the Inquiry (section 13.6). Long waiting times are a strong predictor of patient dissatisfaction in healthcare, particularly if the quality of communication with the healthcare provider has been poor (Lee et al., 2020). For witnesses to the Inquiry, these long waiting times resulted in considerable dissatisfaction and distrust with healthcare providers and systems, and was clearly a major source of stress. People respond to these sorts of stressors in a range of ways (Lazarus & Folkman, 1984) but, in this context, many people developed a sense of helplessness and felt rejected and abandoned by the healthcare system. In contrast to this, a smaller number of witnesses reported that they had actively tried to cope with these stressors in an active way by initiating or joining campaign groups in an attempt to obtain information, improve access to compensation schemes and more generally to provide support and share experiences.

Although it was not possible to find published evidence on the psychological impacts of engaging in this type of campaigning in healthcare settings, some insights can be drawn from other related research on stress and coping (Chesney et al., 1996). This evidence demonstrates that people who use problem-focused ways of coping, such as trying to obtain information and dealing directly with the stressor, are more likely to experience better mood and well-being if the stressor is controllable or changeable. However, if people try to cope in this problem-focused way with stressors which cannot be changed or controlled, then the outcomes are much more likely to be negative, resulting in even greater feelings of distress.

Applying these findings from the broader stress and coping literature into the context of this question, two possible implications emerge. First for those who became actively involved in campaigning and managed to obtain some or all of the information or other outcomes they were seeking, this may have had some positive psychological effects. Also by actively engaging with others, they will have likely provided and received social support, which again may have generated positive psychological impacts. Unfortunately, the potentially positive effects do not seem to have occurred to any significant degree, since witnesses described

having spent considerable time and effort campaigning for proper explanations or better access to compensation schemes but ultimately without achieving these. While this did not seem to deter a few very determined individuals, it appears that others became ground down by the process. The long-term psychological consequences of experiencing this would then probably progress from initial frustration and anger to longer term distress, dejection and hopelessness.

**19. Question 13.3 of the initial letter of instruction\* asked you to consider, as part of your discussion of the social impacts of infection, matters such as deciding not to have or being unable to have children. Please also consider the psychological impacts of such matters, including making a decision not to have children in consequence of infection; making a decision to terminate a pregnancy in consequence of infection; being unable to have children in consequence of the infection or the side effects of treatment; having to undergo additional procedures (e.g. sperm washing) in an attempt to have children.**

### **Deciding about having children or not in consequence of infection**

Witnesses with and without long-term bleeding disorders (and their partners) felt their decisions about having children were very much affected by being infected with contaminated blood or blood products, and the advice they received about having children. As a result, many changed their fertility plans, with some decisions having long term negative consequences.

Witnesses also described that the context for decision-making about having children was poor and lacking in many aspects considered important to making good decisions. The main Psychosocial Report to the Inquiry already discusses at length the optimal way to communicate information to patients. Additionally, decision theory and decision support research show that unbiased information and deliberation components are critical for decision quality (e.g. decision satisfaction and avoidance of decision conflict and regret; Elwyn et al., 2011). Provision of information refers to information relevant to the decision (e.g. why decision is required, options considered reasonable/available, harms and benefits of options, and timescale for short, intermediate and long-term outcomes). Deliberation refers to active strategies to clarify values and preferences relevant to the decision, and match to available options. Decision-aids based on such components improve decision quality in healthcare (Scalia et al., 2019) and reproductive health (e.g. prenatal screening, terminations, fertility treatment, see Poprzeczny et al., 2020 for systematic review). Witnesses reported shortfalls in information-provision and deliberation opportunities which resulted in poor decision quality

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\* Question 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 6 employment; limited employment or career opportunities; detrimental impact on education; and financial hardship.

as evidenced by reports of distress, regret, feelings of not having real choice, and undesirable long-term consequences. Some of the decision issues encountered for parenthood were similar to those witnesses reported for other major healthcare decisions (see the main Psychosocial Report to the Inquiry sections 13.4, 13.6).

Deciding whether, when and how many children to have is for many a positive decision process that evolves over time and is nested in other personally and socially valued life plans (Boivin et al., 2018). For some people, family building is more complex. People with genetic disorders such as haemophilia and people living with HIV face challenges of transmitting conditions to children, parenting with a precarious health status or (for some) a shorter life expectancy and social stigma about having children in this context (Bravo et al., 2010; Miller, 1999). This complexity is reflected in lower intended and realised parenthood rates among people with bleeding disorders (Francis & Kasper, 1983) and HIV (Bongain et al., 2002; Heard et al., 2007) compared to the general population, but similar to people with other life limiting conditions (Clarke & McKay, 2014). In people with a child with and aware of their genetic condition the percentage having children within three years of predictive genetic testing was 39% in carriers compared to 69% in non-carriers (European Collaboration, 1993-1998 reported in Evers-Kiebooms et al., 2002). The parenthood rate in the general population is more than 80% (Office of National Statistics, 2018). One study reported that from 26 couples who wished to have children and where men were HIV positive haemophiliac, 14 (54%) decided not to have them (Goldman et al., 1992). The difference in parenthood rates could be due to having no children or fewer children than desired (Tedgard et al., 1999). The introduction of reproductive technologies to avoid transmission of genetic conditions has decreased inequality in parenthood rates (e.g. PGD, NHS England, 2014) as did the introduction of HIV antiretroviral therapy (e.g. Sharma et al., 2007).

Witnesses described a challenging context for decision-making about having children. They reported that due to being infected (or affected) the decision to have children (or more children) became very fraught, *“a terrible time”*, causing significant upset, worry and decisional conflict. The health advice to prevent transmission was incompatible with their desire to become a parent. Therefore, people had to make the difficult choice between having children or staying healthy (*“...despite our mutual fears [we decided] to have unprotected sex on specific dates to tie in with her cycle...”*) or risk trying to conceive but potentially compromising the health of the baby (*“I was very fearful of [being infected]; not so much for me but for any baby that we may have produced”; “[doctor suggested] delaying [HCV] treatment whilst I tried to conceive with no mention of any risks of HCV to a baby.”*). Witnesses also felt pressured into making particular fertility decisions, especially *“being told to not have children”*. Witnesses reported that while a choice was presented, it often felt as if only one outcome was expected (i.e., to not have children). The sense of pressure could come about because of direct criticism (*“I was even told by one of the doctors that people like me should be sterilised”*) or speed at which decisions were made (*“[my husband] was encouraged to have a vasectomy very quickly at age 26 and the doctors were a bit too willing to arrange this...”*). The perception of not having real choice was especially evident in descriptions of pregnancy termination: *“... it was not really a choice as they encouraged us to abort our child...that was a very difficult decision...”*; *“... I was made to feel like I had no other option than to terminate my pregnancy.”* These decisions could be repeated throughout the reproductive years, with multiple terminations reported. One witness felt that the true decision context was misrepresented in her medical notes: *“It says in my medical notes that I ‘asked’ to have a termination. This is a very bold choice of of words...”*

Infection changed fertility decisions which was distressing and resulted in different fertility outcomes than those originally desired or planned. As a result of being infected (or affected) witnesses described excluding themselves entirely from becoming parents (“*we would never have children*”, “*family was not an expectation*”), and made family-related decisions based on those expectations: “*I made the decision for us to separate so that hopefully she could go off and have children....*” Among witnesses that were already parents, or had started trying, some decided to be sterilised: “*We made the very difficult decision for [husband] to have a vasectomy*”, to stop trying naturally: “*we abandoned further attempts*” or (if infertile) to abandon fertility treatment: “*we decided not to go for any more IVF attempts*” (in vitro fertilisation, IVF). Others decided to pursue reproductive options that avoided risks related to infection (e.g. adoption, fostering, use of fertility treatment) and which implied not being genetically related to their offspring. However, access to these options was limited due to policies in adoption agencies (“*as I was likely to die in the short term, we were no longer considered suitable candidates. At the time, this felt devastating ...*”) or fertility clinics (see section 13.3.3.). These decisions had significant impact on well-being, and longer-term adjustment (see section 13.3.2.).

People also changed their plans when pregnant, with some having terminations as a consequence of advice from doctors. Meta-ethnographic research shows that the decision to terminate a desired pregnancy due to (risk of) foetal anomaly causes intense physical and emotional pain and feelings of powerlessness at the time of decision making because, as mentioned previously, the choice to terminate is often not perceived as a real choice (Lafarge et al., 2014). Witness reports were consistent with these conclusions of trauma, illustrated in this witness report: “*[termination at 7 months of pregnancy] There were plastic sheets all over the room and the nurses came in wearing space suits. I was made to feel like I was a murderer by them, and that is how I continue to feel to this day....*”

Even when people decided to have children, severe reactions to HIV/HCV infection or treatment could have unknowingly reduced their fertility and ability to reach their parenthood goal. Due to infection people delayed family-building, starting at an older age. Fertility is time-sensitive, with a marked decrease in chance of live birth after female age 35 years (Broekmans et al., 2007). Older male age also reduces sperm quality (Johnson et al., 2015). Reproductive technologies cannot compensate for this decline (Leridon, 2004). Delay could be caused due to infection making people delay having a relationship (“*put me off relationships for a decade ...*”) or treatment for infection delaying efforts to conceive: “*... I was 39 when I received the all clear, one year after treatment had ended, and had lost over three years of trying to conceive from diagnosis at 36.*” Contracting HCV through contaminated blood or blood products triggered severe reactions in some people which could then have compromised their fertility (e.g. coping with discovery through excess drinking) (Ricci et al., 2017). It should be noted that some witnesses reported improving health behaviours in response to infection “*immediately cut down my intake [alcohol]*”. Finally, severe psychological reactions to HIV/HCV diagnosis could also have compromised accessibility of some fertility options (e.g. adoption): “*The adoption process has now been put on hold after 18 months of training, etc., as social services remain concerned about my mental state....*” While it could be tempting to blame witnesses for such decreases in fertility, witnesses clearly felt that the cause of severe reactions was the manner in which healthcare was provided to them.

Witnesses recalled little support for making parenthood decisions with counselling “*never an offer.*” The support and information available were poorly timed (“*all came too late*”) or ambiguous (“*they just told us ‘this is not a good idea, but we will monitor you’*”). This meant that witnesses obtained information through their own efforts, or haphazardly (“*[based on] advice from a study in Switzerland... we therefore tried for another child...*”). Due to perceived

poor quality of information people did not understand the links between their disease and their fertility, and often revisited information: *“It always nagged at the back of my mind that the Hepatitis C would not just be linked to issues with my liver but also with my fertility.”* Importantly, lack of timely information denied people the opportunity to preserve their fertility, with some only discovering that HCV treatment could have rendered them infertile *“after many failed attempts to conceive.”* Direct information about impact of treatment could have led to cryopreservation of sperm before HCV treatment, which was possible at the time of contamination of blood products (Witherington et al., 1977) and could have helped with future fertility. However, cryopreservation of oocytes was not available.

Witnesses reported that, in hindsight, appropriate counselling about parenthood decision-making would have been *“extremely helpful”*, especially to process fertility decisions (e.g. vasectomy) made *“based on limited information”*. When received, counselling was perceived to have clarified fertility decision-making (*“It was through this counselling that I realised I wanted to have a family”*) and promoted adjustment to losses that resulted from parenthood decisions made because of infection: *“During the adoption process... I found a private counsellor... the counselling has saved my life.”* Though that was not the case for all, as described by this witness: *“I have since seen many counsellors and try to meditate to forgive myself. I have nowhere to go to mourn for my baby [pregnancy terminated due to infection].”*

### Being unable to have (more) children in consequence of the infection or the side-effects of treatment

Multiple witnesses referred to not being able to have (more) children as a major negative consequence of being infected (or affected) which led to intense suffering, regret with long-lasting repercussions on well-being, social relationships and satisfaction with life.

The psychological literature consistently shows that people who are unable to have the children they desire, either because they are unable to have children or as many children as desired, experience poor mental-health and well-being. Common aspects to this experience are a sense of profound loss, grief and pain that tends to alleviate with time but does not disappear, re-experiences of the loss as people progress in their lives without being able to meet normative milestones (e.g. grandparenthood), significant social isolation, either by self-exclusion (e.g. avoiding situations with children) or due to losing affinities with peers who become parents, and a negative impact on some partnerships (Gameiro & Finnigan, 2017). The longing for children eases with time but 10 and 17 years after the initial confrontation with the parenthood loss between 6% (Gameiro et al., 2014) and 23% of women (Wischmann et al., 2012) still hold a child wish. A meta-synthesis of qualitative research suggests that most people come to terms with their situation and that this translates in better adjustment, a renewed sense of equilibrium and hope towards the future (Gameiro & Finnigan, 2017).

Witnesses described being impacted in this way. First, it was clear that they felt they were being *“robbed of the chance of having a family”* and that this was a major loss that deprived them of a meaningful and happy future: *“We both found it very difficult that we could not have children. I had always wanted a family... and to devote myself to caring for them and for my husband.”* Second, in many instances this sense of loss remained with them throughout their adult life (*“I was, and still remain, deeply saddened that I was never able to have a baby”*) and some felt guilty towards their parents *“for denying them grandchildren and ... the opportunity of seeing me have a family.”* One couple stated feeling upset when their child told them that she was *“sad”* and *“lonely”* and *“felt isolated at school being an only child.”* As per parenthood literature, the loss was manifest in a range of reactions, such as sadness, self-blame or low self-esteem. Third, the inability to have children put additional strain on the partnership and in

some cases led to break ups (*"I made the decision for us to separate so that hopefully she could go off and have children, which thankfully she did and she seems happy. After this I went into a downward spiral"*). Fourth, there were reports of a profound impact on social relationships. Witnesses experienced social isolation due to not having children (*"...our friends all went on to have children and social occasions became centred around children which excluded us"*) and to avoid painful family situations and the re-experience of loss from witnessing peers as parents. The literature emphasises that the social burden of childlessness varies according to social characteristics (e.g. gender, BAME) (Culley & Hudson, 2009), as noted in the main Psychosocial Report to the Inquiry (section 13.3).

As described, for some witnesses the unfulfilled child wish resulted from a decision to terminate a desired pregnancy because of infection. A meta-ethnographic review shows that the grief of termination is enduring, that women yearn for their child long after termination and that this pain can subside but never totally disappears (Lafarge et al., 2014).

For some witnesses the unmet parenthood goal meant having no children at all. The evidence indicates that, compared to people with children, childless individuals are more negatively impacted by an unfulfilled child wish (Gameiro et al., 2014) and report lower access to companionship and support in older age (Dykstra, 2006). One witness stated that *"the prospect of growing old is bleak... [with] no kids to fall back on. We don't have that cushion as its been taken away from us"*. The lack of support in older age could be more problematic for witnesses due to financial problems also associated with being infected documented in the main Psychosocial Report to the Inquiry: *"However we are now at the point where [husband] has no pension and I only have the small teacher's pension that I accrued."*

Examples of resilience were observed despite unmet parenthood goals, for example, being able to find positives in their situation (*"I suppose if I was married and had kids I would want more assistance, but I feel that I am in a lucky position of not having this financial burden"*) or pursuing alternative paths (e.g. adoption, fostering) to have (more) children. While evidence suggests people can adjust, witnesses also made reference to multiple factors known to hinder positive adjustment. Specifically, lack of control over reproductive decision-making (as extensively described in the previous section), the inability to pursue alternative meaningful life goals (e.g. limited employment and career opportunities due to infection; see section 13.3 of the main Psychosocial Report to the Inquiry) and lack of psychosocial support (*"I have never been offered any support, nothing"*). Particularly difficult is knowing now that different decisions could have been made with better information (*"[the decision to have vasectomy] was partially driven by a lack of information on the subject, which years later is extremely distressing thinking back, thinking that we could have had more children"*). In some instances, adequate support could have enabled people to pursue other avenues for parenthood, as reported by one witness (*"The counselling has enabled me to talk about what has happened to me without crying, which was a concern for social services in the adoption process"*). Nonetheless, there are mixed reports regarding ability to access support, its fit to specific needs (*"Yes. Psychological support. He was sent to an old person's group in [name of location] which was for people with old age and dementia. It was just not appropriate"*) and personal preferences (*"[...] he was offered psychological support in the form of sessions with an Art Therapist, but he felt that it was nonsense and did not feel that it was of any help to him"*), as well as perceived usefulness. Testimonies make it clear that from a certain moment in time (which we could not ascertain) the government started funding psychosocial support for contaminated blood victims, but this may have come too late as one witness stated: *"I would have benefited the most from the government funding sessions if it had been made available sooner."*

A related issue mentioned by witnesses was that HIV settlement awarded lower amounts to childless people than to those with children. This was perceived as “*an insult and unfair discrimination*” because the lack of children was due to the infection and the scheme did not acknowledge the profound negative impact of childlessness (“*In that letter, he implied that I was ungrateful and that I ought to think of others; that I do not have children... He might as well have stuck a knife in my stomach*”). It is worthwhile bearing in mind that the main correlate of poor adjustment is not parental status per se but the unfulfilled desire for (more) children (Gameiro et al., 2014), so people who had children but were unable to have more may experience grief (“*despite all our efforts nothing was able to fill the void we felt about not being able to have a larger family*”) and feel this was not recognized in that settlement, even if it accounted for them having children.

### Having to undergo additional procedures (e.g. sperm washing) in an attempt to have children

Witnesses required Medically Assisted Reproduction (MAR) to avoid transmission of infection and to address infertility caused by HIV/HCV or its treatment. Several challenges were reported in accessing and using these treatments. The types of treatments required depended on the scenarios that applied to people. Witnesses described two types of treatments in their testimonies, intrauterine insemination (IUI) or In Vitro Fertilization (IVF) with processed (‘sperm washing’) or donated sperm, which applied depended on multiple factors (see HIV/HCV Reports to the Inquiry). In IUI sperm is collected and transferred to the uterus and fertilisation left to happen naturally. In IVF the woman injects fertility hormones to stimulate the ovaries to produce several eggs, which are then collected and mixed with sperm in a laboratory for fertilisation. If fertilisation is successful and viable embryos develop, some are transferred back into the womb and the remaining are frozen for future attempts.

Different issues impacted access to MAR. Some clinics were not willing to provide treatment due to risk of contamination (e.g. “*hospital would not take/store sperm*”; “*would not freeze their embryos*”) meaning witnesses had to access specialist centres or use overseas fertility care (“*I then read about a sperm-washing treatment programme which was available in Italy*”), which implied additional financial costs and disruption to personal and professional life (“*[MAR] was on the NHS but as the clinic was in [location] I had to travel every other day for scans and tests*”). MAR is costly (current NHS estimates for IUI and IVF are up to £1,600 and £5,000, respectively) especially for many witnesses that experienced difficulty in securing regular income due to the impact of disease and its treatment (see section 13.3 of the main Psychosocial Report to the Inquiry). One witness stated they were able to apply for a one-off grant to cover costs of donor insemination, but another reported having a funding application to pursue IVF rejected by the Macfarlane Trust. Witnesses reported they self-funded treatment and one witness reflected that “*perhaps that should have been funded by the NHS given the circumstances.*” The testimony of one witness revealed that, to avoid being contaminated by her HIV-positive husband, she underwent artificial insemination with live sperm, a treatment that put her at risk for the precise contamination she was seeking to avoid (i.e., HIV, as well as other infectious diseases). This technique has since been banned.

MAR is a challenging and protracted process that affects patients physically, emotionally and financially. Patients most often start by undergoing physically intrusive examinations to ascertain the cause of infertility and inform treatment options. Treatment can offer cumulative live birth rates approaching 60%, but because chances per cycle do not exceed 25% on average, patients are advised to undergo multiple cycles to maximise their chances of conceiving (McLernon et al., 2016). The burden of each cycle is multifaceted and includes disruption to personal and professional life – e.g. on average patients miss 23 hours of



work per IVF cycle resulting in a productivity loss of about €845 (Bouwman et al., 2008); side-effects of hormonal stimulation (e.g. pain, fatigue, depressed mood); painful medical procedures (e.g. oocyte pick-up); peaks of anxiety when patients are anticipating results, in particular during the 2-week waiting period to learn the outcome of the treatment cycle (Boivin & Lancaster, 2010); and high emotional distress when the cycle is unsuccessful, with 1 to 2 in 10 women experiencing clinically significant levels of depressive symptoms (Verhaak et al., 2007). All these challenges, but in particular the emotional burden of treatment, contribute to treatment discontinuation (Gameiro et al., 2012) with 1 in 5 patients discontinuing before they achieve pregnancy (Gameiro et al., 2013).

Witnesses did not comment extensively on their experiences of MAR, but they did refer to it as a prolonged *“physical and highly emotional journey”*, in which they *“kept trying ... regularly taking pregnancy tests and being disappointed each time”*. Failed cycles were described as a *“heart-breaking experience ... devastating to both of us”*; *“We were both really devastated.”* A systematic review shows that pre-existing psychological vulnerabilities, as was probably the case with many witnesses due to accumulated infection-related adversities, exacerbates hardship of fertility treatment (Verhaak et al., 2007). One witness talked about cumulative hardships stating *“I believe this and all the fertility treatment caused my severe reactive depression.”* Testimonies also demonstrate that undergoing treatment was harder at the time than it is now. For instance, one witness referred to not being allowed to cryopreserve sperm or eggs due to infection, which implied drug stimulation and oocyte retrieval at each cycle. Today cryopreservation of embryos for later transfer would be possible even with infection, avoiding repeat ovarian stimulation. This high burden of treatment could have contributed to treatment discontinuation, despite witnesses' strong desire for children (*“By the time sperm washing was available it was too late for us, as I was 40 and we decided not to keep on trying”*). The literature also identifies insensitive care as a motive for treatment discontinuation and some witnesses could recall upsetting comments from their fertility team about their treatment options (e.g. of sperm washing *“wouldn't touch it with a barge pole”*) or during medical procedures (e.g. in response to tension at unexpected internal vaginal exam for treatment, *“why are you like this? It doesn't hurt”*, causing extreme upset). Impact of insensitive care has been addressed extensively in the main Psychosocial Report to the Inquiry (see section 13.4).

Some men who became infertile as a result of the infection or associated treatment used donor insemination to conceive. For this treatment, the couple uses the donated sperm of a known or unknown donor to conceive, and the social father is not biologically related to the child. Most people who use donor insemination are pleased with having made this decision and have good and stable relationships with their offspring (Brewaey, 1996), who present a healthy development (Golombok et al., 2002). Nonetheless, prospective parents still have to decide who will be the donor, if and how to disclose donation to their child and other significant people, and what role the donor will have in the child's life. Many patients report concerns about the social stigma of donation, over disclosing donation to their child and fear of being rejected (Daniels, 2007). Today, disclosure is encouraged and the possibility of having an anonymous donor has been removed in UK law, this was not the case in the '80s and '90s where parents were often encouraged not to disclose this information to children. Although small in number, those witnesses who have not disclosed donation face the risk of their child(ren) inadvertently finding out that they are not genetically related to their father. Today this is a greater risk, of potential immense psychological impact, because donor-conceived offspring can independently discover their origins from direct-to-consumer DNA-testing sites (Crawshaw, 2018) and from the UK regulatory body (Human Fertilisation & Embryology Authority, HFEA, depending on date of birth). Witnesses did not make reference to the issue of disclosure in their reports, but that would have been difficult to do if they had wanted to

preserve secrecy from children and significant others. Nevertheless, disclosure could be an issue of considerable worry to families and secrecy would have created significant challenges for these families as it has for other families using donated gametes (Frith et al., 2018).

## Summary & reasons for caution

The review of testimony and relevant literature suggest that HIV/HCV infections negatively and profoundly affected decisions about having children (i.e. whether, when, how many, and how). This seems contrary to HIV-only studies of the time that concluded HIV status per se did not impact reproductive decision-making (e.g. to terminate or not, e.g. Kline et al., 1995). However, participants in those early HIV and parenthood studies acquired HIV through sex work, intravenous drug use or being partnered with a user (e.g. Kline et al., 1995) characteristics which were not descriptive of witnesses considered here. The conclusions of a more recent HIV review with heterogeneous samples were aligned to the decision-making difficulties witnesses reported here (Bravo et al., 2010).

The witness testimonies suggest that it was the traumatic HIV/HCV discovery, significant side effects of treatment on health, poor knowledge of HIV/HCV at the time and significant uncertainty about HIV/HCV effects on pregnancy, birth and developmental outcomes that made their fertility decision-making more difficult and not the prior genetic condition (or fertility problems). Furthermore, people with genetic conditions would have grown up knowing that parenthood might be complex which would have prepared them (Miller, 1999) but the benefit of that foreknowledge was undoubtedly undermined by unexpected and traumatic discovery of infection.

Witnesses also described that decisions were not fully informed and took place without benefit of counselling to deliberate their preferences about having children and adjusting to unmet parenthood needs. The offer of implications counselling for MAR has always been mandatory by law (HFEA). However, this offer was not consistently made at the time. Best practice today would be to offer implications counselling early after diagnosis of conditions and again when needed at critical moments in the life course. Implications counselling refers to types of counselling (e.g. genetic, fertility, family planning) that allow the exploration of personal, family and social implications of health conditions (e.g. inherited conditions, infertility, HIV, HCV), their features (e.g. health effects, recurrence of risk, transmission) or treatment (e.g. side effects) on parenthood needs and considerations (e.g. need to use assisted reproductive technologies, and donated gametes) (Blyth, 2012; Miller, 1999). Timing of such counselling is important because it should provide people sufficient reflection time to consider options before making irrevocable decision, for example, deciding to not have children (Blyth, 2012). In the case of witnesses, and at the time, the fertility options that could have been discussed were the possibility of having an affected child, having no (more) children, considering alternatives to biological parenthood (e.g. donor insemination, adoption) or using prenatal diagnosis and termination (Miller, 1999). Today people with genetic conditions would additionally have been given access to preimplantation genetic diagnosis (PGD). PGD involves in vitro fertilisation, biopsy and genetic testing of embryos with only unaffected embryos transferred for implantation. PGD has been available since early 1990s and has its own challenges (e.g. disposition of affected and supernumerary embryos, Harper & Handyside, 1994). It should be noted that implications counselling is separate from other forms of psychosocial counselling that could also have benefited witnesses in resolving other personal and psychological traumas secondary to infection (Blyth, 2012) for example death of partner before having children, grieving never-born children or dealing with accumulated adversity in pursuit of parenthood. Psychosocial support specific to parenthood needs (often infertility counselling) has been demonstrated to be beneficial for people with an unmet

desire for children (Frederiksen et al., 2015). Non-specific counselling or psychotherapy is also known to facilitate adjustment to loss (see the main Psychosocial Report to the Inquiry section, 13.9).

### Implications for clinical practice

Based on witness statements and known long-term impacts of unmet parenthood goals (Gameiro & Finnigan, 2017; Gameiro et al., 2014) people should have the opportunity to receive implications counselling about parenthood at the time of diagnosis and as needed. Counselling should be delivered by professional counsellors knowledgeable about medically assisted reproductive technologies, fertility problems and the reproductive options possible for people with genetic conditions or HIV/HCV (or both). Also required would be psychosocial support for impacts of fertility decisions arising at different times in the life course. In the UK, it is mandatory to offer psychosocial support and counselling prior to, during and after fertility treatment.

People should be given the opportunity to have fertility treatments to reduce risks of transmitting their condition, infection or both, and to prevent loss of fertility. People should be referred to fertility specialists to receive appropriate information (also mentioned in HIV Report to the Inquiry, p. 62). People should be referred only to centres able to manage treatment despite HIV/HCV infection. Fertility treatment for genetic conditions (i.e., PGD) is funded through the NHS (NHS England, 2014) and provision could be extended to people without genetic conditions.

Witnesses should be alerted to the fact that evolutions in direct-to-consumer genetic testing and the law governing access to information about donor conception puts families having used donated sperm at risk for unintended discovery of its use. Families should be informed that help is available to support decisions about disclosure through the regulator, the Human Fertilisation and Embryology Authority (HFEA).

Compensation schemes should take account of the significant and life changing impact of infection on fertility decision-making and outcomes, and adjustment to these in the longterm. Schemes should not discriminate infected (affected) people with genetically related children from others for whom infection led to different fertility decisions (i.e., childlessness, non-genetic parenthood, fewer children).

## **20. Please explore and discuss the psychological impact of undergoing treatment to clear an infectious disease and of the treatment then failing. Does the impact change if there is more than one failed round of treatment? If so, why? Does the impact change if the person experienced negative symptoms during the failed treatment?**

When considering possible psychological reactions to treatment failure in the context of this report, it is important to remember that it was the severe problems caused by the contaminated blood and blood products which resulted in the need for treatments to clear the consequent infectious diseases. At the time when they were first developed, it was anticipated that the new blood products would bring about many improvements in the management of haemophilia and other blood disorders, and they will have generated positive expectations in both patients and clinicians at the outset. However, when the problems due to contaminated blood products became apparent, not only were these early expectations unrealised but

also patients were then faced with having to cope with the medical complications, such as HIV and HCV, and the treatments for these. Since the devastating psychological and social effects of contaminated blood and blood products and the ensuing treatments were described in the main Psychosocial Report to the Inquiry, this section will focus on the impacts of the treatment failures of the ensuing treatments for HIV and HCV.

The treatments for HIV and HCV have changed markedly over the years, and are now not only much more effective but also produce considerably fewer unpleasant side effects. In contrast, the early treatment experiences described by the witnesses were from a time when the treatments were both very harsh and often ineffective. There were a number of reasons why these treatments failed, particularly during the period prior to the emergence of the newer, more successful treatments. Some failed because they did not bring about any discernible clinical improvement and were stopped. Moreover, as all the early treatments produced a range of extremely unpleasant side effects, which were described in detail by many witnesses, this then resulted in the decision to stop treatment by the patients and/or the clinician.

The decision by a patient to discontinue adherence to a treatment, either partially or completely, is quite common across treatments for all long-term conditions (Khan & Socha-Dietrich, 2018) and is exacerbated when treatments cause unpleasant side effects and do not seem to produce any obvious clinical improvement. The decision not to adhere to treatment can be caused by many other factors, including depression, negative treatment beliefs, forgetting and lack of support from healthcare providers and others (Kardas et al., 2013). There is also evidence that stigma can have a negative impact on the willingness to take treatment, arising from both the negative impacts of the stigma as well as concerns about inadvertently disclosing one's HIV/HCV status (Sweeney & Vanable, 2016).

Since there are many reasons why treatments fail, it is not always easy to specify the ensuing psychological impacts, particularly as these may also be possible causes of treatment failure or cessation in the first place. From witness statements and published research (Frost et al., 2000) the psychological impacts of failed treatment include anger, disappointment, depression and hopelessness. As one witness commented: *"I would become uncontrollably angry to the point of rage and then go into utter exhaustion and deep depression. The treatment left me in a very dark place and to find out that it hadn't worked was horrendous"*. Similarly, another witness stated that *"after my first treatment failed, I got very angry that I still had the virus and felt overwhelmed"*. The profoundly negative reaction to the failure of treatment was also felt by carers. One carer described it as *"such a kick in the teeth... we had put our life on hold for a year while he was injecting himself, it was all for nothing."* These effects clearly lasted for some time and created an apprehension about any possible future treatments. For example, one witness reported that *"each time a treatment failed, it would take me at least a year to recover both physically and emotionally. After each failed treatment, I felt as if I was being infected again."* Any early expectations of improvement or recovery will have been dashed and replaced with increases in negative outcome beliefs and fearfulness, including the anticipation of never recovering and possible death.

It is most likely that the experience of treatment failures reported by witnesses would result in a lowering of expectations for any subsequent treatments, particularly if these followed on quite quickly. In reality, there were often long gaps between treatments as the newer treatments were developed and, in this case, some of the emotional responses may have dissipated over time. Patients' expectations can play an important role in influencing treatment acceptance, adherence and outcome (Petrie & Rief, 2019). When a treatment for a condition has failed, there is a greater likelihood that future treatments will be viewed with

more negative expectations, which could become even more negative after further treatment failures. Negative treatment expectations are also more likely to result in two further problems, namely increases in nocebo effects and decreases in treatment adherence, both of which increase the likelihood of subsequent treatment failure. This apprehension and scepticism is likely to become more marked following further failures of treatment, and this was seen in a number of witness statements. For example, one witness stated that *“I have taken so many treatments over my lifetime, I was sceptical and convinced it wouldn’t work. In fact, I almost didn’t want to believe it would work as I was scared of facing disappointment again.”*

Some of these problems will undoubtedly have been worsened by the lack of support and poor communication from healthcare professionals, which were described in detail in the main Psychosocial Report to the Inquiry. Recommended good practice for any new, demanding treatment should include full preparation prior to initiation and good support during treatment, especially for helping patients to cope with harsh side effects as well as any obvious discernible improvement (Larrey et al., 2014). However, the witness statements indicated that this was often lacking as they felt that were left to cope on their own. These problems experienced by patients in healthcare communication and the inadequate support have been described in research findings (Zickmund et al., 2004).

## **21. Please consider the psychological impact on a person who has been told that they have, or may have, been exposed to a potentially fatal disease (such as vCJD) and is then told shortly afterwards that they most probably have not.**

Some witnesses reported being told that they may have been exposed to vCJD but were then told that they most probably had not. This clearly created initial anxiety and concern after the experience of previously being infected with viruses. There is little if any evidence in the literature regarding the emotional impact of a person being misinformed that they have or may have been exposed to a potentially fatal and untreatable condition such as vCJD.

There is some evidence on the emotional impact of a person being misdiagnosed with HIV, a serious condition for which some treatment is available. There is more evidence on the emotional impact of a person being informed of an increased risk of having or developing a serious disease such as cancer, a risk that is subsequently shown to be lower upon further testing. This evidence comes from studies of those undergoing screening, as opposed to diagnostic testing, for a range of conditions including various cancers and cardiovascular disease.

Evidence from two systematic literature reviews regarding the emotional impact of undergoing screening for a range of conditions suggests that those receiving test-positive results show raised anxiety or depression in the first few weeks but after four weeks this is no longer evident (Collins et al., 2011; Shaw et al., 1999). In a systematic review of the psychological impact of false-positive screening on mammography, there was no evidence of generalised anxiety. There was however evidence for breast cancer-specific psychological distress that could endure for up to three years, and reduce the likelihood that women returned for their next round of mammography screening. They were also more likely to have cancer diagnosed when they next returned for screening (Bond et al., 2013). In a study of women participating in an ovarian cancer screening trial there was also no evidence that general levels of anxiety were increased (Barrett et al., 2014). Amongst women with a predisposition to anxiety, receipt of false positive test results increased their levels of anxiety and the likelihood that they withdrew from the screening programme (Jenkins et al., 2015). Amongst men who received

a raised PSA test on screening for prostate cancer and underwent prostatic biopsies that revealed no cancer, nevertheless experienced many negative psychological and socio-behavioural consequences up to a year later (Fowler et al., 2006). Similar findings have been seen in studies of women undergoing biopsies for ovarian and breast cancer (Barrett et al., 2014; Brett & Austoker, 2001).

There are few reports in the literature of the psychological impact of a false diagnosis for conditions that are similar to vCJD. There is one report of a case series of four patients who received false positive HIV test results (Bhattacharya et al., 2008). Importantly, such misdiagnoses are very rare, estimated to occur with a frequency between 0.0004% and 0.0007% (Bhattacharya et al., 2008). The descriptions are taken from the medico-legal records for each patient. Initial responses included shock followed by elation for a few weeks then a chronic phase of anger and resentment about the wasted time and opportunities whilst thinking they were HIV positive. Readjustment was characterised by chronic stress, depression, anxiety and panic attacks. All these patients had been tested before protocols were instigated in 1996 requiring any diagnosis of HIV to be confirmed three months later with further testing. We do not know how representative those involved in legal action might be of others receiving false diagnoses. This does not of course diminish the experiences of those included in these case studies but heralds caution in over-generalising from them.

## **22. Please explore and discuss the psychological impacts of a patient being given experimental treatments by way of clinical trials. Is this impact different to a patient receiving ordinary treatment, and if so how and why?**

All patients, especially in the context of life-threatening disease, crave certainty about their treatment but medicine is not the exact science that they might wish it to be. Patients being given standard or most usual treatment have the psychological comfort of knowing that it is probably the best, safest available option even if the outcomes are not especially good. Being invited to join a trial of experimental treatment can increase uncertainty and anxiety.

A Phase 3 randomised trial compares a novel therapy with 'standard', currently available best treatment to discover which treatment works better, gain information about side effects and how the treatment affects people's quality of life. The new trial may compare standard treatment against a completely new treatment, the same treatment at a different dose or different frequency of dosing. A randomised placebo-controlled trial, although methodologically speaking the purest form of evaluating new treatments – 'something versus nothing' – provokes unease in many patients and are often very difficult to recruit patients to. Randomisation assures that patients or health professionals do not choose who receives the new treatment, and who receives no treatment/the placebo. All patients receive 'a treatment' but it may be 'placebo' and contain no active drug. 'Blinding' the trial ensures neither patients nor health professionals involved are aware which 'arm' – treatment or placebo – of the trial they are allocated to. Placebo trials are not used if a patient would be put at risk, for example in the study of serious diseases, by being denied available effective treatment. Potential participants are told if placebos will be used in the trial before they agree to participate.

Early Phase 1 and 2 trials that are not randomised have their own problems. The trial is to ascertain the best dose and/or the safety of the drug or procedure and this may not benefit the patient personally at all.

The participants of the Inquiry often refer to experimental treatments and trials for the treatment of HIV and HCV. There were many experimental trials in the mid-1980s and early 1990s, when thousands of people were dying of AIDS, and when initially no 'ordinary treatment' was available. Understanding the development of such trials provides insight into what issues many patients were facing. The first randomised placebo-controlled trials commenced with Zidovudine (AZT) in 1987. After only 16-weeks, evidence showed that among those on the study drug there was clear evidence of decrease in the number of participants dying and an improvement in morbidity (Fischl et al., 1987). In response to the early results, pressure was exerted, the trial was controversially discontinued and the drug licensed in 1987 for widespread use for those dying with AIDS. Numerous clinical drug trials followed throughout Europe and the US, to assess drug doses, dose frequency and associated side effects. The British and French Corcorde Trial randomised asymptomatic patients to receive either AZT early or defer AZT treatment until symptoms developed; a bold intervention to give a toxic drug to people who were still healthy, with limited knowledge of the natural progression of the condition. The results of the trial in 1993 were disappointing, showing there was no evidence of benefit of AZT in terms of survival or progression to AIDS (Cohen, 1993). It became clear that although AZT was beneficial in the short-term, toxic side effects were considerable and viral resistance occurred after 12 months. Although limited in the use of preventing disease progression, trials of AZT undertaken with HIV infected pregnant women were ground-breaking and considered one of the greatest public health successes in the last 30 years. These reduced the rate of infection from mother to child from 25-42% with no intervention, to less than 1% with interventions and AZT treatment for mother and baby (Connor et al., 1994).

Further clinical trials with similar drugs to AZT were commenced in the mid-1990s and it became clear that reduced doses would reduce severe side effects, specifically of peripheral neuropathy and pancreatitis, but retain the effectiveness. The Delta Trial, a double-blind trial comparing AZT monotherapy with AZT in combination with many new agents, resulted in a new realisation of the improved effectiveness of combination therapies. Further trials across the world combining new classes of drugs led to the breakthrough of highly active anti-retroviral therapy (HAART) in 1996, which forms the basis of current treatment options for people with HIV infection (Delaney, 2006). There is now extensive availability of effective treatment, but many clinical trials continue; to reduce long-term side effects, discover a vaccine, initiate long-acting treatments and to discover a permanent cure for HIV infection.

Knowledge that one has been infected and that there is no effective treatment other than an experimental therapy that could produce harmful side effects can be extremely disquieting as seen in the following quote from a patient *"I spoke up expressing anger that we had been infected and all they could offer was a trial of unlicensed, highly toxic medicine. Prof... 's reply is one I won't ever forget. She said 'think yourself lucky you don't live in America, you get free treatment here in the UK which you wouldn't get there'."*

Participation in a clinical trial has advantages and disadvantages. How individuals view these issues will impact on willingness to participate and the psychological impact during participation. Advantages may include access to a new treatment, otherwise unavailable, or a more effective treatment which might be of personal benefit or general benefit to others. More frequent visits to the clinical trials setting will be required, usually involving contact with experienced, specialist healthcare workers offering intensive monitoring of health, additional attention, support and updated information. However, such intensive, invasive and frequent healthcare intervention may be experienced as a psychological burden for some patients and their families, alongside the fear and uncertainty of what treatment is being taken, the trial

outcome and the unknown and unpredictable side effects. Many may be unable to cope with the restrictions and demands that are imposed by the clinical trial requirements and the need to move to a new healthcare setting to gain access to a trial.

This question posed here is to 'explore and discuss the psychological impacts of a patient being given experimental treatments by way of clinical trials', consideration should also be given to the psychosocial impact on patients who were denied experimental treatment and access to treatment trials because of strict inclusion/exclusion criteria; pregnant women, children and people with haemophilia were often excluded. Also excluded from some more recent HCV treatment trials were those who had previously received some form of earlier treatment. A significant and distressing barrier for treatment access has been related to issues of NHS funding. Many witnesses' express anger at being denied treatment by the NHS, for a condition they acquired from the NHS.

Good Clinical Practice (ICG-GCP) is the international ethical, scientific and practical standard to which all clinical research is conducted. Compliance with this standard provides public assurance that the rights, safety and well-being of trial subjects are protected and consistent with the principles of the 1964 Declaration of Helsinki, and that the clinical trial data is credible (Bhatt, 2010; Vijayanathan & Nawawi, 2008). Any treatment, be that a test, procedure, examination or administration of blood, requires consent from the patient. The principle of consent is a fundamental requirement in medical ethics and in international human rights law. To be valid this consent must be given voluntarily, it should be educated or informed and the person giving it (or their proxy) should have capacity to make a decision. Consent to some procedures could be verbal such as the person saying 'I am willing to have my blood taken.' It could be tacit consent namely the person holding out their arm voluntarily for the blood to be taken when requested to do so. In the situation of an experimental treatment trial, the consent must be written and the patient aware of the voluntary nature, the right to refuse or withdraw at any time, the known risks of participation, the fact that there may be unknown harms, the possibility that the individual may not benefit themselves. However, some witnesses did not recall having ever given either verbal or written informed consent: *"I have realised since that my doctors were doing research on their patients including myself, and this makes me feel worse that I was tested without informed consent and not told for some time. Writing this now brings back dark memories."*

Due to the fact that most effective clinical treatment is assumed to be determined through rigorous clinical and behavioural studies, there has been a great deal of interest and research undertaken to determine how clinical trials impact on people and how they feel, in order to better understand willingness to participate and how to best attract, recruit and retain patients. There have been numerous extensive studies to assess the motivation, satisfaction and barriers to participation in clinical trials among patients with HIV infection. The barriers to participation include fear of drug side effects, distrust of researchers, poor availability of information and interference in life, particularly travel and day-to-day routine. (Mills et al., 2006). One motivation for clinical trial participation in randomised Phase 3 trials of cancer treatment is altruism and the psychological benefit of knowing that one is potentially helping others. (Jenkins et al., 2013). A potent disincentive to participate is lack of trust in the doctor.

An early study with patients with HIV infection (Ross et al., 1994) emphasised that the major influence to enter a clinical trial was the relationship with the doctor, the benefit to self was rated as the least important factor and the major reason for participation was the benefit to medical science. The data suggest that participation in this specific clinical trial was based



on altruistic, rather than personal reasons. Further studies (Sengupta et al., 2000; Volkmann et al., 2009) reiterate the same sentiment, that trust and the relationship with the doctor and institution determines participation in clinical trials.

There is little research considering the psychosocial impact of clinical trials specifically for those who were infected through blood and blood products. The Royal Free Hospital in London reviewed HIV-related clinical trial participation of 2,703 patients over a 12 year period (Madge et al., 2000). Recruitment was high among all patients, which may be explained by a dedicated research unit staffed by specialist research nurses, but trial participation was from predominantly white, homosexual men, and also women. Participation was lowest among heterosexual men and IV drug users. There is no information considering whether the low participation of heterosexual men were those infected through blood and blood products. With regard to patients with haemophilia, a Belgian study of patients' willingness to participate in clinical trials (Henrard et al., 2015), claimed 'to the best of our knowledge, this is the first study that has evaluated the factors influencing the willingness of people with haemophilia to participate in clinical research.' The study concluded that the majority of people with haemophilia questioned, felt they were unaware or had poor knowledge about clinical trials, which impacted on their willingness to participate.

There is an effect of trial type on willingness to consent, in early phase studies, patients with metastatic disease often express hope and expectations of benefit, despite being told explicitly that the likelihood of personal treatment benefit is small. In an interview study involving 40 Phase I trial patients, only one said that wanting to help others was the primary reason for taking part (Catt et al., 2011) whereas the four main reasons for trial involvement were: expectation of medical benefit (21%); trial was the best available option (21%); to maintain hope (15%); and to help with research (13%).

It appears from the research, and from anecdotal experience of one member of the psychosocial group working as a nurse with HIV patients, including 12 years specifically co-ordinating HIV clinical research, that willingness to participate in clinical trials and a positive experience is strongly determined by doctor-patient relationship. Conversely, lack of trust or a compromised relationship with medical staff and/or with the medical institution, as many testimonies in the Inquiry refer to, hinders willingness to participate in clinical trials (Sengupta et al., 2000). If, as was the case in the early 1980s, there are limited treatment options available, and a clinical trial is the only option to access treatment, it is likely that ongoing detrimental psychosocial issues would be enhanced.

### **23. Please explore the psychological impact of a person discovering that they were or may have been identified as a previously untreated patient and were then given treatment and became infected.**

In order to answer this question, we requested clarification about which treatment was being referred to, and were informed that it was treatment involving factor concentrates. This clarification was necessary as there is a range of treatments to address bleeding episodes. These treatments address the level of individual clotting deficiency and the likelihood of severe bleeding and long-term detrimental issues. Since there is individual variation, for some, despite having haemophilia, very little treatment, if any, may be required. Thus, in the context of this question, the phrase 'previously untreated patient' refers to someone with haemophilia who because of their young age, or sufficient levels of factor VIII or IX

had not experienced bleeding episodes which required treatment with factor concentrates. Management of bleeding episodes for this group of patients may have previously been with desmopressin (DDAVP) or cryoprecipitate or the requirement of no treatment.

For most patients with mild and moderate haemophilia, treatment with factor VIII or IX concentrates is not required. Bleeding episodes which are unlikely to cause long-term damage or are not life threatening, can be managed 'conservatively' or with infrequent infusions with DDAVP or cryoprecipitate. With increased concern relating to the possibility of infection, in 1984 guidelines were produced by the UK Haemophilia Centre Directors Organisation (UKHMDO, 1984) stating that, for patients with haemophilia, bleeding is the commonest cause of disability and death, so concentrates should be continued but alternatives to be used for patients previously untreated: 'Virgin patients those not previously exposed to concentrates and children use cryo or heated NHS factor VIII (if available)'.

In the Infected Blood Inquiry, there are accounts where people state that they became infected with HIV and/or HCV through the use of factor concentrated treatment, where previously they had been untreated. They believe that HIV/HCV infection could have been avoided. A small number suggest the treatment was not required for any medical reason, but that factor concentrates were administered for the first time as part of treatment trials. Such realisation resulted in a number of negative psychological impacts on both infected and affected individuals. For example, two witnesses (a mother and her son with mild haemophilia) describe the impact of being an untreated patient, subsequently receiving treatment and becoming infected with HCV: *"I had never heard of a virgin haemophiliac until I saw [his] notes, it had never ever been mentioned or I'd never heard the expression before". On the issue of consent, she explains "I would never ever have allowed my child to be part of a trial – never... With an innocent child of three and a half, I would not have considered such action. It was never discussed with me. If it had been, I would have been very categorically clear: he was not going to be part of a trial, no. No, no way."*

Her son, who was three and half at the time of receiving infected blood product, describes the discovery when he was a teenager *"I'm starting to understand that as a child, I've gone into a hospital with a non-life-threatening bleed in my mouth and I have come out with a life threatening disease"*. The long-term impact, after living with HCV and undergoing treatment, he explains as *"Somehow, somewhere down the line somebody has seen me as being so irrelevant that they can do that to me... When you are treated with that much disrespect by the NHS, by doctors, you feel like you are worthless, because of course you are worthless, you are."* The psychological impact of that worthlessness is then described in terms of negative behaviour as a teenager which continues *"...the anger that I still feel and the frustration I still feel and the depression that is constantly just on my shoulder, I battle it every day, every day, to make sure that it doesn't ever disrupt what I have built in my life because how dare it. How dare it?"*

Considerable anger was expressed by both infected and affected individuals for the prescription of what is perceived as unnecessary treatment, which resulted in devastating consequences. One account from a widow whose husband died in 1998 states that *"so for no good reason they've exposed my husband to four separate risk levels, knowing full well that he hadn't previously been exposed – knowing full well that the factor was potentially contaminated, knowing that he didn't have a life-threatening bleed and he wasn't about to die imminently."* She continues *"I mean is this the very epicentre of incompetence that we've got here or is there something more sinister going on? What is happening here that this was allowed to be carried on like this?"*

International bodies for haemophilia management in the early 1980s presented guidelines in relation to those patients with mild and moderate haemophilia and for young children with severe haemophilia who had not previously received imported concentrates, and whose risk of having been infected with hepatitis and the then unknown pathogen resulting in AIDS, was minimal. The World Federation of Haemophilia recommended that *“Cryoprecipitate to be used to treat patients in the following groups except when there is an overriding medical condition: new born infants and children under four; newly identified patients never treated with factor VIII concentrates; and patients with clinically mild haemophilia who require infrequent treatment”*. Despite these recommendations, two witnesses explains how their son was identified as being previously untreated, but subsequently at 12 months old, received both British blood products and commercial factor products with no discussion of the risks involved. His parents believe he was part of a trial. The child become infected with HIV and died of AIDS when he was seven years old. His father explains the deep psychological impact that he continues to live with: *“I could cope with death but not with the death of my son. I still have trouble today the fact that he’s in a grave on his own and the guilt will never go away.”*

From these witness statements, it becomes clear that there were very negative psychological impacts arising from the discovery that the factor concentrate treatment administered was not only unnecessary and avoidable but also resulted in adverse consequences. A dominant response was anger at the error, which was exacerbated by poor quality communication, particularly associated with both the lack of information about possible risks and the fact that treatment was being offered as part of a trial, for which no obvious consent or joint decision making had occurred. Anger and high levels of related distress have also been found in patients in other healthcare settings, such as surgery, following the occurrence of major errors or accidents. For example, Vincent et al. (1993) found that patients who had experienced surgical accidents had even higher levels of distress than those who had suffered serious accidents or bereavements, and that their psychosocial adjustment was considerably worse than those with serious illnesses. These psychological impacts were particularly negative when no explanation, or a poor explanation, was provided. This also seems to have been the experience of a number of witnesses to the Inquiry, as described in the main Psychosocial Report to the Inquiry. Similarly, other studies of medical errors and their effects on patients or loved ones have also indicated how poor quality communication, such as lack of disclosure and explanations, can make outcomes even more distressing. A survey of patients’ attitudes showed they believe the way error was disclosed to them directly affected their subsequent emotional experience, and many said they would be less upset if the physician disclosed the error honestly, compassionately and apologised. Patients surveyed thought that explanations of the error that were incomplete or evasive would increase their distress, and recommended a patient advocate or psychologist to assist patients in coping with errors (Gallagher et al., 2002). From the witness statements to the Inquiry, there is little evidence that professional psychological support was offered to the family members or patients, who experienced short and/or long-term distress after receiving factor concentrate for the first time and became infected.

Parents of children who received factor concentrate, which then resulted in serious infection, also reported guilt and regret at not being able to prevent this occurring. For example, the mother referred to earlier, stated that *“...I was the mother and I was hoodwinked. I was lied to. I didn’t stand up for my child when I should have done but I didn’t because I didn’t know what it was I needed to stand up for and there is a guilt there that you cannot get away from. It’s a reality and the one thing you want to do as a mother is to protect your child and I didn’t.”* In the first section of this supplementary report, we describe the extent to which guilt occurred with witnesses who were parents of an infected child, and how this can have very corrosive long-term effects on self-esteem and mood, with the strong likelihood of depression. In the

main Psychosocial Report to the Inquiry, we describe the huge loss of trust which ensues when healthcare communication is poor in the context of a serious medical problem, which arose as the result of a treatment complication and failure, as occurred here. When a patient, or their partner or parent, believes unnecessary treatment was undertaken, not because of clinical need but to evaluate a new treatment, and in the absence of consent or explanation, it is highly likely there will be considerable feelings of anger, betrayal and major long-term psychological distress.

#### **14. Please explore the psychological impacts on wider family members and through further generations.**

Those most greatly affected by a family member receiving infected blood are the immediate nuclear family of their partner and children (or parents and siblings for a child) who experience 'spillover' effects in terms of a high psychological burden and the need to manage new demands and disruptions to daily life as well as often severe financial difficulties (Wittenberg et al., 2013). The notion of 'spillover' effects is also applicable to wider relatives with witnesses sometimes describing relatives' fears of clinical risks in terms of beliefs about 'catching' the condition together with concerns about becoming labelled with an associative stigma and responded to negatively by others. Witnesses therefore described their wider relatives as often cutting off contact in response to these perceived risks thus reducing a potential source of interaction and support.

Whereas the effects of the chronic and disabling effects of the illness of a family member have mainly been considered in terms of the immediate effects on everyday lives and psychological functioning, these effects may often be much longer term and involve generational impacts. This is a particular issue for children when suffers from a debilitating chronic illness. In this situation, children and adolescents have been shown to have increased risks of poor physical and/or psychological functioning, with higher rates of anxiety and depression as well as risks of diminished self-esteem and deficits in social competence (e.g. Phillips, 2014; Shaffer et al., 2001; Sharpe and Rossiter, 2002). These impacts reflect the need to cope with a variety of stressors including the suffering and threat of the loss of a parent or sibling, decreased parental availability, increased household responsibilities that may include a caring role, and possibly limited social and financial resources (Korneluk & Lee, 1998).

While some individuals, who have been carers for their infected parents, report positive long-term effects including a greater sense of responsibility and enhanced life skills, the long-term effects are generally more negative. In particular, most studies point to a negative relationship between the chronic illness of a close family member and young people's educational outcomes This may occur through the strain caused by the parents' illness and by caring responsibilities causing reduced engagement at school and disruption to the child's education (Bortes et al, 2020; Chen, 2017).

The overall picture of the future lives of the generation of young carers indicates that they are more likely to report adverse effects on mental health and physical well-being together with a more limited view of their future selves and lower expectations of adult life (Robison et al., 2020). These early risk factors may then influence educational outcomes and interact to reduce life chances and adult well-being. However, there is known to be considerable variation in the extent and level of longer term social and emotional impacts experienced by children with a chronically ill parent. This is thought to be influenced by the interplay of characteristics of the illness including its course anticipated outcome, level of predictability and treatment status (Chen, 2017), the individual's characteristics including age, gender

and personal resilience, and family variables including communication styles and cohesion among family members (Rolland, 1987) as well as the type of caring role which they engaged in (Pakenham & Cox, 2012).

There is little longitudinal research examining these childhood effects of the ill health of a parent or sibling through adulthood and for the next generation. However, traumatic adverse experiences more generally (involving household challenges, abuse and neglect) have been shown to influence risks of adverse long-term outcomes related to disease, disability, social integration and as much as 20 years lower life expectancy, and led to recognition of the importance of responding to adversity in childhood (NHS Highland, 2018).

**At the end of the hearings, Sir Brian Langstaff requested that the Psychosocial Expert group provide their response to two further questions. The questions and the group response to each are shown below.**

### **1. What are the most significant psychosocial recommendations which the group would suggest in order to support patients and minimise further harm in case of healthcare error (further supplementary question 6)?**

To reduce the likelihood of the multifaceted failures that contributed to the negative psychosocial experiences of the infected and affected, the group recommends the following:

- (1) Any healthcare professional involved in any error causing harm should immediately follow the published guidelines about open disclosure and the duty of candour.
- (2) To adequately fund access to relevant and appropriately qualified psychological support.
- (3) Duty of candour, effective and sensitive communication and the policies and practice to ensure no harm should be included in the training of all healthcare workers and other associated groups such as NHS managers and national level policy makers. Staff need to feel part of a non-punitive working environment with a culture of openness. Case studies from the Inquiry could be utilised as examples within such training.
- (4) As a core part of healthcare training and continuing professional development, there should be full recognition and acknowledgement of the ways in which implicit and explicit biases affect interactions with patients and families. Training could include case studies drawn from the Inquiry, professionally developed and evaluated to establish efficacy.
- (5) The Infected blood Inquiry should provide an example of a case study that is included in all training of (a) healthcare professions – to draw out principles of duty of candour, effective and sensitive communication and (b) other groups including NHS managers and national level policy-makers – to draw out the principles of policies and practice to ensure no harm, and that staff feel part of a non-punitive working environment with a culture of openness. The case study should be professionally made and comprise multiple materials including footage of the infected and the affected giving evidence to the Inquiry.
- (6) In challenging new healthcare situations, where expertise, experience and knowledge is not yet developed, healthcare professionals should look to the evolving dedicated, specialist multidisciplinary teams for patient management care and treatment as well as

acknowledge, respect and involve the expertise of both infected and affected individuals, and work in partnership with them.

## **2. The Inquiry has heard evidence of the stigma those infected with HIV and Hepatitis can experience in a healthcare setting. How can this stigma be addressed? In particular what role does education of the healthcare workforce play (further supplementary question 5)?**

As a core part of their training and continuing professional development, the education of all healthcare professionals needs to ensure that there is full recognition and acknowledgement of the ways in which their implicit and explicit biases affect all their interactions with patients and their families. This training, which could include case studies drawn from the Inquiry, will need to be professionally developed and properly evaluated to establish its efficacy.

Key requirements of this training are to increase awareness of the nature of stigma and its impacts on both patients and families/carers; reduce fear of contact with patients due to incomplete knowledge; assurance regarding necessary precautions and provision to facilitate this; challenging assumed links with negatively valued behaviours. This requires a multi-strategy approach to increasing knowledge, changing attitudes and translating this into behaviour change.

More generally, there needs to be a focus on the general population's beliefs and enacted stigma, much of which was linked with how public campaigns were interpreted and the effects of media scare stories at the time. It is therefore important that national policies take account of the Inquiry experience and include use of the mass media to mitigate prejudicial beliefs and fears in order to reduce stigmatising attitudes and behaviours among the general population. This also has implications for health professionals who are themselves influenced by the beliefs and fears prevalent in the community.

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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.

## Authors

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Jacky Boivin is Professor of Health Psychology and Practitioner Health Psychologist (School of Psychology, Cardiff University). She has played a major role in psychosocial research and clinical developments in the fields of fertility, infertility and reproductive technologies. She has led many international projects, published extensively and produced many tools to support the care of people with fertility problems and barriers to family building. She is currently on the endometriosis advisory group for Welsh government, the executive committee of the British Fertility Society and expert advisor for the World Health Organisation Guidelines for Infertility Development Group. Her current research is focused on fertility awareness among young people, planning fertility futures and global fertility health.

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## **Professor Myfanwy Morgan**

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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.

### **Acknowledgements**

The group is very grateful to Sophia Quirke McFarlane for all her invaluable work in searching for published research across a range of topics, and for checking and organising the references for the whole report.

## Appendix

**The following questions, answered in this Supplementary Report and the main Psychosocial Report to the Inquiry, 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 nonprivate 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 Letter of Instruction: part one (answered in the main Psychosocial Report to the Inquiry)**

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).

### **Supplemental Letter of Instruction: part two (answered in this report)**

13. When answering question 13.1 please also consider the psychological impact on a parent or carer who:
  - 13.1. actually administered the treatment (such as factor VIII) to a child or other family member who was infected in consequence of that treatment; and/or
  - 13.2. took decisions (such as agreeing to home treatment with factor VIII) about their child's treatment, where the child was then infected in consequence of that treatment.

How could this impact on their relationship?

14. When answering question 13.1 please explore and discuss the psychological impact on those infected of:



- 14.1. Living with the fear and uncertainty as to whether they have infected or may infect partners/family members and children (including unborn children).
- 14.2. Living with the knowledge that they have (unwittingly) put others at risk of infection, even where no infection has been passed on.
- 14.3. Living with the realisation that they have infected someone else.

(Please note when considering and answering this question and/or question 13.4.8 that some witnesses have stated that they were not given adequate advice or information about safe sex or how to prevent transmission of infection by other means).

15. When answering question 13.1 please explore and discuss the psychological impact on those affected of living with the fear and uncertainty as to whether they have been, or may be, infected.
16. When answering question 13.1 please address the psychological impacts of facing a shortened lifespan as a result of having been infected.
17. When answering question 13.5 please also consider and discuss the psychosocial impact of also being dependent on state benefits and all that entails in terms of the application and assessment and re-assessment processes required to claim and retain welfare benefits. In particular please consider how the effects of infection and illness might impact on a person's ability to engage with this process.
18. When answering question 13.6 please consider:
  - 18.1. The psychological impact arising from the fact that many of those infected and affected have died (and that deaths continue to occur) while waiting.
  - 18.2. The psychological and social impact of actively campaigning for answers and an investigation, over many years (and for some, for their whole lives).
19. Question 13.3 of the initial letter of instruction asked you to consider, as part of your discussion of the social impacts of infection, matters such as deciding not to have or being unable to have children. Please also consider the psychological impacts of such matters, including making a decision not to have children in consequence of infection; making a decision to terminate a pregnancy in consequence of infection; being unable to have children in consequence of the infection or the side-effects of treatment; having to undergo additional procedures (e.g. sperm washing) in an attempt to have children.
20. Please explore and discuss the psychological impact of undergoing treatment to clear an infectious disease and of the treatment then failing. Does the impact change if there is more than one failed round of treatment? If so, why? Does the impact change if the person experienced negative symptoms during the failed treatment?
21. Please consider the psychological impact on a person who has been told that they have, or may have, been exposed to a potentially fatal disease (such as vCJD) and is then told shortly afterwards that they most probably have not.
22. Please explore and discuss the psychological impacts of a patient being given experimental treatments by way of clinical trials. Is this impact different to a patient receiving ordinary treatment, and if so how and why?

23. Please explore the psychological impact of a person discovering that they were or may have been identified as a previously untreated patient and were then given treatment and became infected.
24. Please explore the psychological impacts on wider family members and through further generations.

### **Further Supplemental Letter of Instruction**

5. The Inquiry has heard evidence of the stigma those infected with HIV and Hepatitis can experience in a healthcare setting. How can this stigma be addressed? In particular what role does education of the healthcare workforce play?
6. What are the most significant psychosocial recommendations which the group would suggest in order to support patients and minimise further harm in case of healthcare error?

