DRAFT RECOMMENDATIONS

Proposed by those represented by Milners Solicitors

1. Milners Solicitors and Sam Stein QC represent a distinct group of individuals whose lives have been completely devastated through the use of pooled plasma products. Amongst our client group are haemophiliacs, people with Von Willebrand's, misdiagnosed people, wives and partners who have been infected with HIV and wives and partners who have been affected by this tragedy; we also act on behalf of some of the most prominent and longstanding campaigners. This scandal has rightly been recognised as the worst medical disaster in the history of the NHS.

2. Without the work of the living and deceased campaigners we represent, this Inquiry would never have been established. Their lives have been completely diverted to exposing the truth, identifying those responsible and achieving justice.

3. Of our clients who were infected, they have had HIV and Hepititis driven into their veins by a government and health service who not only failed to protect them but actively exposed them to risk. Those who have survived, live under the unknown long-shadow cast by exposure to vCJD.

4. We represent many wives, partners and children of people infected by Blood Products who lived with and nursed those infected through every hour of their ill health and slow deaths. The wives, widows and partners fought and continue to fight against a system which has failed to protect their partners and offered nothing for themselves. Many wives and partners were advised not to have children, those who did become pregnant were ostracised and suffered severe discrimination and miscarriages due to stress whilst others endured severe anxiety and some people had to bear the cost of IVF and sperm-washing. The consequential damage to health and mental health for those who care for their partners has had a devastating and irrevocable effect on all parts of their lives.

5. In addition to their caring work, some wives and partners were infected with HIV and/or Hepititis via their haemophilia husbands/partners when the health service offered no protection (or even warning) for them and whilst they were fighting, daily, to support their directly infected partners. For this group of people knowing that they were not protected and should never have been infected though any form

of transfusion medicine administered to their partner, nothing can ever be done to restore their lost lives and lost health. They effectively went from healthy young women with no disability, no medical intervention to living with a life-threatening condition for which there is no cure and only treatment for the rest of their lives with added stigma and discrimination, impacting on their human right to have children.

6. All of the wives, widows and partners have been hidden and neglected victims of this disaster; where they have been remembered, it has all too often been with the use of pejorative labels which (whether by design or not) seek to minimise human suffering which lies behind such labels – "infected intimates" and "secondary beneficiaries" being but two examples..

7. We represent a number of misdiagnosed people who were negligently treated as though they had a bleeding disorder and infected by doctors who have consistently failed to accept responsibly or any blame. For this group of people, knowing that they should never have received any form of transfusion medicine is a particularly bitter pill.

8. There has been a consistent failure to recognise the breadth and depth of the disaster caused by contaminated blood products. Those infected and affected through the use of blood products have been re-abused over decades by the fact that the government has ignored its responsibility for so long and treated financial recompense as a 'hand out' and not compensation for its negligence. The campaigners who with indefatigable determination, are responsible for this Inquiry have experienced little regard for their lost lives, lost careers and lost time with their loved ones. The wives and partners have all too often been ignored and no attempt has ever been made to recognise the sheer scale of their efforts, what they have lost and their own suffering. For the infected partners little or no support is found within haemophilia care and they find themselves being treated in sexual health clinics, where they don't belong.

9. We respectfully ask the Inquiry to hold in its mind the depth of loss, the indignities and day to day hell that those we represent have endured over such a protracted period. It is important to remember, we suggest, when considering these suggested recommendations what has happened in the real world to those people who have died and those who have survived, just about, to bear witness.

Recommendations to improve the remainder of the lives of the infected and affected

Recommendation	Rationale and proposals as to possible evidence
Recommendation 1 **The Inquiry should make an interim recommendation at the earliest opportunity, that work should begin on the implementation of the recommendations of Sir Robert Francis QC.**	Sir Robert Francis QC's first recommendation[1] is that *"irrespective of the findings of the [Infected Blood] Inquiry, there is a strong moral case for a publicly funded scheme to compensate both infected and affected victims of infected blood and blood products infected with HCV or HIV, and that the infections eligible for compensation be reviewed on a regular basis."* By de-coupling his recommendations from any future findings or recommendations of the Inquiry, Sir Robert has empowered the Chair to make an interim recommendation that work be started on the implementation of the Francis recommendations because those recommendations are not contingent upon any finding of the Inquiry.

[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1081007/Compensation_and_Redress_for_the_Victims_of_Infected_Blood_-_Recommendations_for_a_Framework_-_Sir_Robert_Francis__Final_.pdf

	Whilst the fine detail of the resultant scheme remains unclear, Sir Robert makes clear that there is much preparatory work to undertake before the picture becomes clearer. There is no reason why this work should not commence as soon as possible, particularly given Matt Hancock's commitment on 21 May 2021 that "I will respect its [the Inquiry's] recommendations, and should the Inquiry's recommendations point to compensation, then of course we will pay compensation and Sir Robert Francis's Review on compensation is there in order that the Government will be able to respond quickly to that."[2] Mr Hancock made government's implementation of the Francis Review recommendations contingent upon a recommendation of the Inquiry; there is no reason for the Inquiry not to make an interim recommendation to this effect in order to avoid the delay that Mr Hancock, himself, sought to avoid. Finally, an added advantage of making an interim recommendation is that the Inquiry will be able to monitor the speed with and extent to which, government begins implementation.
Recommendation 2.	The Inquiry has heard a wealth of evidence from its HIV, Hepatitis and Bleeding Disorder Expert Groups that those infected will not see any improvement in their conditions.

[2] Transcript 21/05/2021, Page 151, Lines 4-9

That those in the infected and affected[3] community who are in receipt of disability benefits be excused from any/all future eligibility assessments and it be recognised that their conditions will not improve.	As to those affected, those who have suffered disability as a result of contaminated blood/products (whether that be through psychological injury such as PTSD or through the physical exertion of caring for an infected person) are unlikely to see improvements in their conditions and should be similarly excused. It is important to remember that PTSD brings with it physical manifestations impacting on the body[4]. The Inquiry heard evidence from many affected people about the impact which their experiences have had on them throughout the hearings which took place in 2019 (WITN1056009_0002-0006 & 0034 being important written evidence on the point in addition). **The Inquiry may wish to request from the relevant department any evidence or reason which might be put forward to oppose this recommendation.**

[3] Any reference to infected and affected must be taken to include haemophiliacs, sufferers of Von Willebrand's, the affected wives and partners of haemophiliacs, the infected wives and partners of haemophiliacs and those with von Willebrand's as well as those treated as though they had blood disorders (the misdiagnosed).

[4] Symptoms of PTSD – PTSD UK

Recommendation 3.	
Haemophilia centres should be transformed into centres of excellence for all people who have been infected or affected through contaminated blood products as well as younger generations of patients who suffer from bleeding disorders without the complication of infection(s).	Lack of funding and a movement away from specialist treatment has caused issues for the infected and affected community whose experience has been that medical care has become increasingly variable and lacking in knowledge of the issues confronted by all of those who have been infected and affected.
These centres of excellence should be inclusive clinics for all those infected and affected by contaminated blood products – whether infected with or affected by HIV or Hep C, whether diagnosed (or misdiagnosed) with haemophilia or not whilst still providing the highest quality of bleeding disorder care for sufferers outwith the tragedy of contaminated blood products.	Infected wives and the misdiagnosed don't have centres where their conditions are understood or, sometimes, recognised. They need to be brought within the specialist centres so that support from those with, at least, the best knowledge of their infected status can be brought into their treatment. Many people with
The centres should give a patient-centred approach and NOT disease focussed treatment which is what is needed to deliver the most appropriate yet dynamic care and treatment when indicated. They should follow the NICE guidelines and quality assurance already in place to support this type of model. Any financial support should be directed to this model not given to the current haemophilia centres which are disease focused.	There are no ongoing studies within the UK into long term survivors of HIV and/or HCV infection in men or women and the symptoms and co-morbid conditions and medical consequences of HIV and/or HCV infection albeit there are studies being commissioned in the USA.
Each person should have a named individual that coordinates their care and treatment using specialists who are fully informed of the infected blood product disaster and can be called upon to bring their own expertise to the table; Psychology teams, Haematologists, Endocrinologists, Pharmacists, HIV specialists, HCV specialists,	"The understanding of how HIV causes long-term infection continues to deepen, and in doing so provides new opportunities for potential cure. However, none of the above approaches has shown sufficient promise to be available for widespread clinical use in the next 10 years. A combination of approaches is likely to be needed to effect a cure. With over 80% of those infected with HIV living in sub-Saharan

Hepatology, Transplant Specialists, Radiographers, and many more would be required to deal with the complex care needs of all patients. The term "haemophilia centre" should be reconsidered in order to recognise those with other blood disorders who are treated there and also all people (such as infected partners) who do not have a blood disorder but who have been infected by contaminated blood products. In summary, there should be: 1. Recognition within the treatment centres of all those who have been infected and affected by contaminated blood products; 2. Increased funding; 3. 'One stop shops'; to allow for all treatments (including dentistry) to be dealt with under the new centre of excellence umbrella;	Africa, most healthcare systems will have insufficient resources to deliver a complex medical intervention at scale. Consideration needs to be given to prioritising therapies that can be delivered in resource-limited settings" HIV Expert Report to IBI [EXPG0000004_0069]. "The likelihood of long-term comorbidities alongside HIV[7] is increasing particularly as people with HIV grow older, some of which are the inevitable consequence of old age and others are directly related to HIV and its treatment. As life expectancy has increased the broader HIV care agenda that is emerging needs whole system approaches focusing on integration of care across teams, disciplines and organisations. HIV services are becoming less self-contained. Close working relationships between HIV specialist services and primary care is particularly important. However current commissioning arrangements for the HIV pathway are complex and split across multiple commissioning bodies which can risk fragmentation of care.16 NHS England has a national service specification that is used as the basis for the commissioning of HIV treatment and care. A working group exploring long-term condition management for HIV has been established by NHS England." HIV Expert report [EXPG0000004_0089]

[7] This also applies to HCV: see J Med Virol. 2017 Dec; 89(12): 2158–2164.
Published online 2017 Aug 30. doi: 10.1002/jmv.24848 PMCID: PMC5656818 PMID: 28480974 Comorbidities and medications of patients with chronic hepatitis C under specialist care in the UK Benjamin Hudson, Alex J. Walker, and William L. Irving

4. Specialist haematologists to coordinate treatments for the infected and affected and to be present during consultations with other medical professionals; 5. HIV/HCV specialists to be brought in when required to consult on treatments and medical options; 6. Specialists in HIV infected women need to be identified and made available through the specialist centres; 7. Collate information and learning regarding the aging population of HIV/HCV infected individuals within the UK; 8. That as recommended by the Psychosocial Report[5] a "dedicated psychology service [...] within the haemophilia centre" as recommended by the haemophilia quality standard" are established[6] in each haemophilia centre to offer support for affected and infected individuals. This should also apply to the thalassaemia and sickle cell centres. 9. That the card system set out below be used to determine eligibility and access to these treatment centres.	"Reporting of HIV-related data is undertaken by clinicians on a voluntary and consensual basis and is processed through the HIV and AIDS Reporting System (HARS). Information sent to PHE is `de-identified' and the NHS number is not part of the dataset so potential linkages to other conditions are not made in the way they could be if the number were available 19 National surveillance of HIV infection and vertical HIV exposure is carried out by the National Surveillance of HIV in Pregnancy & Childhood (NSHPC) and covers all infants born to HIV positive women in the UK and Ireland, as well as all children diagnosed with HIV (regardless of country of birth) before the age of 16.20 There are several comprehensive research data sets that investigate secondary health conditions and complications. Public Health England has recently completed a nationally representative survey of patients attending HIV specialist care in England and Wales, Positive Voices. This has given rich data on secondary health conditions and complications as well as quality of life, social needs, and treatments. Currently this is running as a research project." HIV Expert Report [EXPG0000004_0092] The long-term effect of treatment for HCV, the question of an increased incidence of cancers and variations in care across different geographical parts of the NHS all require careful study and report. There should be monitoring of those with HCV currently and those

[5] EXPG0000003_0034

[6] The Expert Psychosocial (Supplementary Report) recommends that adequate funds are made available to access relevant and appropriate psychological support (EXPG0000042_0037)

	who have achieved an SVR and have then been, in effect, discharged from care. The warning flags on medical records for infected haemophiliacs which refer to HIV/HCV/vCJD cause huge issues with medical professionals and dentists not understanding what they should do, how they should treat or whether they will treat people with this in their files. The misdiagnosed we represent report that warning flags consistently fail to appear on their files which means they have delays in treatment, they are concerned about how they might inadvertently infect others and they have to constantly repeat their case histories. Warning flags need to include everyone that has received infected blood. The services provided by the proposed centres of excellence should be assessable by those infected and affected by blood products irrespective of whether they themselves have a bleeding disorder this is because there must be recognition that whether as a result of being infected by a haemophilia suffering partner, widowed to a haemophiliac or misdiagnosed with haemophilia these are people have spent significant parts of their lives in haemophilia centres and feel more comfortable in that setting. This we suggest must be a matter of choice for the patient whether they wish to avail themselves of these services or not. If an individual does not wish to use the specialist centres that has to eb their right after so many years of

	stigma and discrimination, if so alternative treatment routes must be made available. For some people such as Infected wives, widows and partners attending a haemophilia centre is or can be uncomfortable and re-traumatising as for some people it has been decades since they attend a haemophilia centre. Provision for sperate support for those who have been ignored and repeatedly traumatised by a male orientated (because of the higher percentage of male haemophiliacs over women haemophiliacs) must be made. **The Inquiry may wish to request from the NHS and the NCHDO any evidence or reason which might be put forward to oppose these recommendations.**
Recommendation 4. An NHS card system be adopted for those infected and affected to explain that they have been infected or affected by this scandal and to explain to any treating clinician the possible range of consequential symptoms and their possible treatments with fast-track access to a specialist treatment team for those infected and affected. As above the card system would also serve as an access path to treatment at the specialist centres for those who have been infected and affected by contaminated blood products.	Infected and affected people confronted by a new symptom constantly have to repeat and explain their complex background medical history (when both ill and sleep deprived) to a new generation of the medical profession for whom the blood contamination scandal is believed to have been part of a previous medical profession's history. Fasttrack access to those who understand and have knowledge of the treatment and diagnosis of these complex and interacting infections and the consequential effects on those who

Sir Robert Francis QCs report published on the 7th of June 2022 states (at 2.87) "The scheme should have a support unit to provide or arrange for the provision of medical, psychological and social support to infected and affected persons. The Archer Inquiry recommendation of a card entitling beneficiaries to benefits not freely available on the NHS should be revisited to consider whether such a facility should be made available via the compensation scheme or otherwise". Within the Republic of Ireland those infected through contaminated blood products are entitled to a Health Amendment Act Card (HAA). "Persons who contracted Hepatitis C[8] through the administration within the State of contaminated blood and blood products and who therefore hold a Health Amendment Act (HAA) card are eligible for a range of primary care services and hospital based services including: GP Services •Prescribed drugs, medications, aids and appliances • Dental services • Aural services	have been infected and affected would improve treatment effectiveness and outcomes. Many people with blood disorders have had the same experience of being asked questions which demonstrate a profound lack of expertise or even basic knowledge of haemophilia/VWB; questions such as 'how did you get haemophilia' or 'are you on warfarin' are just two examples. For others the assumption is made that they have contracted HIV through drug use, or if a woman, because they are thought to be a sex worker. **The Inquiry should call for evidence as to the viability within the NHS of having a summarised treatment history for patients and fast-track advice. The Chief Executive of the Irish Haemophilia Society, Mr Brian O'Mahoney can provide evidence to the IBI as to the work and utility of this scheme.**

[8] In June 2006 the Minister for Health and Children agreed that any persons who had received an award from the Hepatitis C and HIV Compensation Tribunal Courts prior to 20th June 2006 would be entitled to access health services under the Health (Amendment) Act.

• Ophthalmic services • Home support • Home nursing • Counselling • Complementary therapies • Chiropody services • Physiotherapy" https://www.hse.ie/eng/national-hepatitis-c-treatment-programme/haa-information-guide.pdf	
Recommendation 5. A study of the question of whether there is bias within haematology which operates to discriminate against women, women (whether directly or indirectly) through blood products and/or any minority group, why it took to so long to recognise that women who bleed excessively were haemophiliacs (as opposed to symptomatic carriers) and whether support organisations discriminate against carers and the concerns they express.	The failure to recognise women's status as haemophiliacs, the failure to take account of the concerns expressed by women (or simply to ignore women) and the failure within support organisations to listen to women has been an issue across this inquiry. **The Inquiry may need further evidence to consider whether these failures may continue into medical treatment currently and if so why and what can be done to listen more to issues raised by women and carers.**

Recommendation 6. An assessment of the past and present insurance, life assurance, mortgage availability and employment management arrangements that have applied to those people infected and affected by contaminated blood. In the Republic of Ireland if an individual has received compensation or is the holder of a HAA card then they are entitled to access an insurance scheme. "The Hepatitis C Insurance Scheme was set up under the Hepatitis C Compensation Tribunal (Amendment) Act (No.22) of 2006. This Scheme enables all persons with State Acquired Hepatitis C and/or HIV to take out Life insurance as if they were not infected. The Scheme provides for three different types of Insurance Cover to be taken out; Life Assurance, Mortgage Protection Cover and Travel Insurance." https://www.hse.ie/eng/national-hepatitis-c-treatment-programme/haa-information-guide.pdf at page 24	The availability of insurance, life assurance and the effect of infection on mortgages and employment have prevented infected and affected people from eligibility for life assurance, engagement in some career paths, taking holidays and breaks and buying properties. The criterion used for assessing, as an example, a previously HCV infected (but self-cleared) individual is currently a barrier to obtaining life assurance. **The inquiry should consider fresh evidence from the insurance and financial sector as to the appropriateness of their systems in assessing haemophiliacs and those who have been infected and affected and how far the financial industry's whether their systems correctly and fairly assess individuals who have been infected and affected within this scandal.** The IBI is requested to hear evidence from the following as regards the operation of the Insurance Scheme in the Republic of Ireland: Brian O'Mahoney, Chief Executive of the Irish Haemophilia Society Hepatitis C Insurance Scheme Mr. John Dwyer Administrator 2nd Floor, HSE Offices Mill Lane Palmerstown

	Dublin 20 Lo Call: GRO-C Website: www.hepcinsurance.ie Life Assurance & Mortgage Protection Zurich Insurance Ireland Ltd Eagle Star House Frascati Road Blackrock Co. Dublin LoCall: 1850 221 584 Travel Insurance Emerald Travel Insurance https://haemophilia.ie/hiv-hepatitis-c/insurance-scheme/life-mortgage-insurance/
Recommendation 7. In recognition of the fact that some with bleeding disorders are still compelled to use blood products which are manufactured with human plasma:- • That any application for a product licence for a recombinant product which could replace (in part or completely) the use of	Those suffering from Von Willebrand's Disease are still compelled to use human plasma sourced Von Willebrand Factor replacement therapies despite a recombinant alternative recently being approved in the USA. The approval of recombinant VW Factor in the UK ought to be expedited and, once approved, made available to VW sufferers universally and irrespective of their age, location or infection histories.

a product which would otherwise be sourced from human blood/plasma be expedited; • If/when approved, that any such product be offered universally to all those who could benefit from it in place of any product sourced from human blood/plasma **The Inquiry should request any evidence as to why these recommendations cannot be implemented.**	Delays in the rollout of recombinant FVIII led to the exposure of many to vCJD at a time when the medical profession and medicine regulators had a degree of overconfidence in the efficacy of heat treated, human sourced products. In recognition of the fact that blood/plasma transfusion carries inherent risk of infection despite viral inactivation processes, no person ought to be maintained on transfusions where a recombinant alternative exists.
Recommendation 8. The Inquiry has heard evidence about the failure to properly record (or record at all) the batch numbers of blood products used to treat or mistreat patients. The Inquiry should consider any necessary recommendations to improve record keeping, particularly in relation to transfusion therapies.	This Inquiry is best placed to recognise the importance of good record keeping and the consequences for those whose records were inadequate. The Inquiry has already heard evidence that historically, inadequate record keeping has hampered lookback exercises and impeded the ability of those infected to (i) understand the pathogens to which they have been exposed; and (ii) seek justice and/or recompense. **The Inquiry should request up to date information which sets out the current procedures for provision of relevant information about blood products from manufacturers and from the NHS as to the**

	system currently used to track the use of these products in the treatment of patients.
Recommendation 9. That the remainder of the residual MacFarlane Trust monies held by the Terence Higgins Trust be surrendered by the THT and be divided into four equal parts and transferred to the national Haemophilia Societies of the four Home Nations for the purposes of constructing a monument in each nation to those infected (whether directly or indirectly) with HIV through the use of contaminated blood products and their affected families. **The Inquiry should hear any evidence from the THT as to why these monies should not be:** **i. Surrendered** **ii. used as suggested within this recommendation.**	There are complex reasons why it is inappropriate for the Terence Higgins Trust to administer the residual monies which it received from the MFT but at its simplest, there is a profound and fundamental conflict of interest which stems from two basic facts: - 1. The victims of the contaminated blood disaster have historically (whether rightly or wrongly) been labelled as the 'innocent victims' of the AIDS pandemic. This implies that those infected through other routes of transmission (such as through sexual transmission) were not innocent. THT is a sexual health charity and historically, its core body of beneficiaries were infected with HIV through sexual contact. There is a natural tension between THT's core body of beneficiaries and those it has adopted following the closure of MFT. 2. Whilst not diminishing the stigma suffered by those infected through contaminated blood/products they are, if they so wish, able to give an explanation for their infection which elicits social sympathy in a way that those infected through sexual contact are perhaps less able to do. This means that the

	focus of THT's activities is heavily centred on continuing to break down the stigma associated with HIV infection through sexual modes of transmission; a point that is evident in their 'U=U' campaign which fundamentally tries to convey the message that by taking a daily pill, your infection is controlled, and you cannot pass the virus to any other person. Whilst no criticism is made of THT for such campaigns (and to the contrary, they are worthy of recognition) these campaigns advance a message which is completely different from that which many of those infected through contaminated blood/products wish to convey. Our clients want to see a push for research and treatments for the long-term effects of living with HIV and the co-morbidities associated with it; to argue that taking a pill everyday gives someone with HIV a completely normal life is simply at odds with our clients' lived experiences. We suggest that it be recommended that the money be divided amongst the four national haemophilia societies and used for the purposes of creating monuments (suitable for all faiths and none) because there is unlikely to be any other way of spending the money which would generate a broad consensus of opinion from the former registrants of the MFT and because monuments can have a very real purpose not only in commemorating those who have suffered but in acting as a reminder of mistakes which were made.

	It must also be recognised that the MFT was a malevolent presence in many people's lives, an uncaring organisation from which they were forced to beg for financial relief. MFT naturally came to be regarded as exerting a degree of control over the lives of those infected and affected and that control persists whilst ever its funds remain; many from the former MFT community have expressed outrage at THT's attempts to advocate on their behalf. The only way to end the re-abuse of the infected and affected perpetrated by the MFT, is for the last of its funds to be spent. In this regard, it is not so much the THT's administration of the fund which is objected to but the fact that any organisation should seek to continue the MFT's sad legacy.
Recommendation 10. That the UKHCDO be brought into public ownership. **The Inquiry should consider any evidence from the UKHCDO and NHS as to whether there are practical reasons why UKHCDO cannot be brought into public control and oversight.**	It is surprising that clinicians working under contracts with the NHS and treating NHS patients have been allowed to form a private organisation with the juridical personality of a private limited company, for the purposes of collecting information on NHS patients and pronouncing upon the preferred methods of such patients' treatment UKHCDO should be subject to the same control, accountability, and scrutiny as any part of the NHS and should not be able to operate in such a way as to create a separate organisation for the select group of physicians involved.

	Evidence may be required to consider whether patients understand that their medical records are being exported outside of the NHS into a private company, the extent to which records are retained and how this material is used. Evidence might also be sought from the UKHCDO and DHSS as to any reasons why UKHCDO ought not to be brought into public ownership.

Recommendations to avoid repetition of the tragedy

Recommendation	Rationale
Recommendation 11. After hearing all of the evidence setting out the causes and reasons for the Infection of all of those who have been treated with contaminated blood products, the Inquiry should, we suggest, review the current protection of the blood supply. The lack of haemo-vigilance is a matter of real significance to this Inquiry and a review of current haemo-vigilance should ensure that, as at the close of the Inquiry that current measures ensure that blood products are safe.	**The inquiry should take evidence on the current systems in place to detect and mitigate the risk from emerging and developing pathogens. If fault is found within those systems, then recommendations should be made that such faults be rectified.** For the avoidance of doubt, the evidence to be taken should include current donor screening and donation screening measures. The abstract referred to below identified 68 potential threats to the blood supply.

	"The Emerging infectious disease agents and their potential threat to transfusion safety": Susan L Stramer[1], F Blaine Hollinger, Louis M Katz, Steven Kleinman, Peyton S Metzel, Kay R Gregory, Roger Y Dodd. Transfusion; [2009] Aug;49 Suppl 2:1S-29S. doi: 10.1111/j.1537-2995.2009.02279.x. This is still very important to those with Thalassemia, Sickle Cell and of course bleeding disorders who do not have access to synthetic treatments or developing countries reliant on treatment donated.
Recommendation 12. The role of patient advocates be expanded across the NHS and be offered to anybody diagnosed with a life altering or chronic condition. **The NHS should be requested to outline the current provision of patient advocates and explain why this recommendation cannot be put into practice.**	As we understand matters, the current patient advocate system relies upon an application being made for an advocate to be appointed; such a system inevitably deprives those most at need of advocacy from the services of an advocate because the most vulnerable are also the least likely to make such an application. Upon diagnosis of any chronic condition with life altering consequences and prior to the recommendation of any course of treatment aimed at treating such condition, the role of a patient advocate should be explained to the patient and an appointment with an advocate offered.
Recommendation 13.	

That the NHS system of complaints should be reconsidered to make it independent and easier to access, with feedback provided and decision making made more transparent.	Infected haemophiliacs, infected wives and partners and those affected by this tragedy are effectively 'expert patients' who are used to dealing with complicated medical issues which the NHS appears all too often to fail to appreciate are difficult and whose treatments for one condition can have profound implications for another condition. Many haemophiliacs have to resort to the complaints system in order to either obtain better treatment or to inform the health service of a failing physician. The ombudsman system is commonly (and unsatisfactorily) employed in place of an effective independent complaints system. **The Inquiry should call for evidence to demonstrate the effectiveness of the complaints system and how often it is employed to obtain improved services.**
Recommendation 14. That the effectiveness of 'consenting' patients within the clinical field be reviewed and consideration be given to whether consent within the clinical setting is obtained with an understanding and acceptance of the risks involved. As well as an understanding of current 'consenting' practise there are two areas of current concern which require consideration given the evidence from survivors within the IBI:	The troubling subject of consent has been considered within the evidence of many of those who have been infected and affected by the Infected Blood Scandal. Many of those infected were denied essential information which if they had been properly informed may have led them to have refused consent to treatment or have asked for another treatment (cryoprecipitate for example). The Inquiry should **call for further evidence from clinicians** as to the current system of consent for treatment, how this operates and

i. "The duty to inform is not absolute. As we have seen patients may opt not to be informed of material risks and alternatives[9]" ii. The "therapeutic exception" sometimes referred to as therapeutic privilege "this applies in exceptional circumstances where clinicians consider disclosure pf material information to be detrimental to the health of the patient[10]" The IBI Ethics Group is asked to consider the use of Shared Decision Making (SDM) or Supported Decision Making (SUDM); see discussion: https://jme.bmj.com/content/47/1/47. As regards Medical Errors the literature appears to demonstrate that there is a reluctance of disclose medical errors to patients with the suggestion (May 2005[11]) that as low as 30% of medical errors are disclosed.	whether it operates to actually provide informed consent. The following questions require answer: i. Have we now reached the stage where people are over-consented (asked for multiple consents when under treatment negating understanding and effective consent[13])? ii. What should clinicians say when they are asked for their opinion? iii. How should minimal risks be explained and how should a risk be assessed on a range of minimal to high risk by the clinician? iv. How far should minimal risks be explained and can minimal risks ever be ignored and not set out?

[9] Ethics Expert report !NQY0000241_0029
[10] Ibid
[11] EXPG0000020_0001
[13] Note: The Medical Ethics Report considered the issue of multipurpose consent practices (INQY0000241_0036) but has not considered the issue of a patient who has to decide in adverse conditions of actual or potential hospitalisation and with limited time to consider his/her consent to a number of different connected treatments at one time.

The literature[12] suggests that there is a need to research the explanation and delivery of Life Threatening Conditions to Children: "Despite the potential benefits of effective communication, many children are not told about their diagnosis. The global prevalence of LTCs in children makes it an urgent priority to develop robust, child-focused communication guidelines and a research agenda to address the limitations and gaps in the literature. Limitations of the research literature include the wide age range of participants and stage of the illness. Some work has explored these issues by actively recruiting participants at specific points on their treatment journey.' The reviewed qualitative studies are dominated by interview accounts; analyses of recorded consultations are rare, but could advance our understanding. A proportion of studies do not have relevant control/comparison groups which makes evaluating the impact of communication difficult to determine. There is almost a complete lack of adequately powered, controlled evaluation studies, especially randomised controlled trials (including pragmatic trials), to evaluate interventions or best practice."	v. In what circumstances should relevant and material information ever be withheld from disclosure to a patient? vi. Do clinicians have sufficient training to implement SDM or SUDM where patients are frightened or fearful of 'knowing' or in circumstances where there are issues as to the mental health of the patient? vii. To what extent does the presence of a patient advocate (see above) assist and support a patients actual exercise of their consent? viii. How is the process of consent taught within medical qualifications and what can be improved?

[12] Communication with Children and Adolescents about the Diagnosis of their own Life-Threatening Condition [2019] (EXPG0000038_0016)

	ix. Has there been an improvement in the training[14] of health care professionals and reporting as regards medical errors[15] and what systems are in place to record, log and consider medical errors within in the clinical setting? x. The BMA and the specialist Royal Colleges should be requested to consider to what extent their training provides support for healthcare professionals in the delivery of information, consent to treatment and care as regards children with LFCs
Recommendation 15. That the concept and principle of clinical freedom be reviewed and qualified in order to prevent a situation where a body of those in the medical profession might act in an objectively inappropriate way but	At INQY0000241_0020, the Medical Ethics Expert Group succinctly set out the development of the jurisprudence concerning clinical negligence; they conclude with the 2015 Supreme Court Judgment in

[14] The following recommendations as regards training were made: Cognitive component: This would comprise some didactic presentation of evidence-based practice together with prepared annotated bibliographies of key readings about communication skills, perspectives of patients and relatives about preferences for disclosure as well as legal and ethical issues. Behavioural component: This would involve 1) review and group discussion about trigger videotapes of healthcare professionals discussing error with patients and relatives, 2) interactive, demonstration role-plays and 3) videotaped role-play of participants with simulated patients followed by review and constructive feedback. Affective component: Doctors would be encouraged to discuss errors that they have made or witnessed, how these were dealt with and how they affected the individuals concerned. Barriers to disclosure would be discussed as well as appropriate ways to overcome some of these: COMMUNICATION WITH PATIENTS IN THE CONTEXT OF MEDICAL ERROR [2003] (EXPG0000017_0044 and _0045)

[15] The Psychosocial Expert Report (Supplementary Report) recommended that "any healthcare profession involved in any error causing harm should immediately follow the published guidelines about open disclosure and the duty of candour" see p.35 (EXPG0000042_0037)

which, through the fact that their behaviour is co-ordinated, brings about a veneer of appropriateness which allows their actions to go unchallenged. The Inquiry should hear from the GMC and the BMA as to the current guidance and training provided as to clinical freedom and what work is being done at this time to consider whether medical practitioners are employing clinical freedom appropriately.	Montgomery v Lanarkshire Health Board which provided that doctors must take reasonable care to inform patients of material risks and reasonable alternatives to the proposed treatments. Whilst this is a welcome departure from the old Bolam/Bolitho test for negligence, the position remains unsatisfactory in two regards:- 1. The Montgomery Judgment does not account for the persuasive effect of the clinician's advocacy for one treatment course over another. A doctor is obliged to recommend a treatment course and a patient will naturally be more likely to adopt the doctor's recommendation without giving proper weight to the alternatives suggested by the bye. 2. The ability to seek redress through the courts for inappropriate treatment is no protection against the harm suffered in the first instance. A preventative approach should be taken which should incorporate the following factors:- i. Doctors should be compelled to set out all treatment options with their associated benefits and risks before making any recommendation to the patient. Where possible, a 'cooling-off' period should be given where a patient can research or seek counsel (from a patient advocate for example) before decisions on a treatment course are taken.

	ii. Statistical analysis should be used (to the extent that it is not already) to monitor the prescribing patterns of medications across the entire NHS and where anomalies are detected, investigations should be undertaken. iii. To the extent that it is not already the case, any doctor wishing to prescribe an unlicensed product on a named-patient basis should have ethics committee approval. iv. The Department of Health, acting upon the advice of or in consultation with the British Medical Association Medical Ethics Committee and other relevant bodies, should reserve the ability to interfere with a doctor's clinical freedom to prevent unacceptable risk to patients where it is objectively perceived. It is worthy of note that the Infected Blood Inquiry is not the only investigation to encounter tragedy arising from the misapplication of clinical freedom – the findings of the Gosport War Memorial Hospital (non-statutory) Inquiry also attribute blame to the freedom granted to clinicians.

Recommendation 16. The issue of disclosure of potential conflicts of interest by a clinician who has a "commercial relationship with, or any renumeration, support or assistance received from, suppliers of products or treatments[16]" has been addressed within the employment relationship and academic environment but there is still a need to address this issue from the public/patient perspective (IBI Ethics Report)	**The BMA and the GMC should be requested, as a matter of urgency, to bring the disclosure of potential conflicts of interest information up to date as regards patients and public notification. There seems to be no logical reason, other than the continuation of a patrician relationship, for the public and for patients to be excluded from such disclosure.**
Recommendation 17. The Psychological Expert Group (Supplementary Report) made a number of recommendations[17]; these need to be considered with the relevant training organisations who should be requested by the IBI to report back on what training is currently offered in these areas and what further improvements can be made.	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. 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

[16] INQY0000241_0112
[17] EXPG0000042_0037

	from the Inquiry, professionally developed and evaluated to establish efficacy. 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. 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. 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.
Recommendation 18. The duty to inform of risks has been discussed within the Inquiry's proceedings. It should be recommended that the GMC commission	The benefits of such a recommendation would be twofold:-

the creation of a module to be compulsorily taught on all undergraduate medical degrees which incorporates :- i. The history of the contaminated blood disaster including how the dangers of pooling plasma were recognised in the 1940s only to be forgotten with the advent of pooled plasma coagulation products in the 1960s; ii. The dangers of medical paternalism and the importance of patient freedom of choice, which can only be achieved through the frank exchange of information with patients; iii. The inherent danger of blood transfusion and the importance of its conservative use; iv. The findings and recommendations of the IBI final report. v. Captures the evidence of a number of those infected with Hepatitis (A, B, C etc), Hepatitis and HIV, HIV alone and those who are threatened with possible infection with VCJD. vi. Captures the evidence of wives/partners/carers - to understand the impact on their health both physical and	1. It would help to ensure that the mistakes of the past were not forgotten and that the lessons learnt through the work of the Infected Blood Inquiry will not be forgotten but will instead be instilled into the minds of all future doctors; and 2. It may reduce the instances of those surviving, infected haemophiliacs having to recount their life stories and mode of infection to every new clinician charged with their care. 3. It may reduce the instances of infected wives and partners having to preface any encounter with a medical professional with an explanation. It may reduce the assumptions that some is a drug user and misinterpret debilitating illness fro intoxication or side effects of drug use. **The GMC should be requested to provide evidence as to how it intends to react to and implement the Inquiry recommendations into its training programmes.**

mental - the consequences and impact of creating additional patients that had not previously existed vii. Captures the evidence of those who were mis-diagnosed and therefore mistreated and infected.	
Recommendation 19. That a programme be instigated for testing of recipients of blood and blood products for infection with Hepatitis, HIV and vCJD. We suggest that the Inquiry recommends a cohesive and comprehensive advertising campaign to inform the general public that anyone who has received a blood transfusion or blood products prior to 1992 needs to visit their GP for screening. On the 17th of May 2022 Professor Ironside gave evidence (p.145) as to testing which should be carried out within the community of those who have been exposed to CJD: "Q. I have asked you questions about the different blood tests and so on. Is it right to understand your evidence that you consider there should be a blood test available for those that have been exposed to risk of vCJD?	The evidence has revealed that whilst efforts have been made to assess the dates of 'risk from infection' some of those infected believe that their infection arose from a period after the accepted likely infection dates. IBI should recommend that the blood test described should be developed for use to test those who have been exposed to CJD followed by a prevalence study to consider the possible rate of growth of CJD infection within those who have been exposed. **A further statement may be required from Professor Ironside as to the steps that may be required to fund, develop and implement the proposed testing regime.**

A. Well, yes. That would be one use of it. I think the other use -- the other important use would be to do, if you like, a prevalence study using these tests to see if the results of the appendix study are actually reinforceable in that way, or, if there's something different, then, that might be good news or it might be worse actually, but it would be good to do that. I think in terms of individual testing, there would have to be some wider discussion about that because if it was just shortly after an exposure, a negative test might not be as reassuring as it would be some time further down the line. But there's no reason why that scenario couldn't be looked at and developed." There is a need to ensure that such a re-call test system is robust and inclusive of all. For example, the experience of misdiagnosed people is that they tend not to be included on recall lists.	
Recommendation 20. The Hepatitis Expert report referred[18] to the plans by both the English and Scottish government to eliminate hepatitis by 2024	**IBI should request from the PHE and the HPS Working group established in 2019 and the HPS working group (action plan 2019) an update as to progress and delivery of the plans to eliminate Hepatitis by 2024. In particular IBI should request an update as to progress on**

[18] EXPG0000001_0008

	the recommendations and issues set out below from the Hepatitis C in England 2022 "Working to eliminate hepatitis C as a public health problem", Full report (Data to end of December 2020)[19]: UKHSA in collaboration with the Office for Health Improvement and Disparities (OHID) and commissioners should scope how access to, and uptake of, NSP in all settings can be mapped and monitored to contribute to the evidence of NSP impact. UKHSA in collaboration with OHID and the National Institute for Health Research (NIHR) Health Protection Research Units (HPRU) should evaluate the impact of changes in NSP provision that took place during COVID-19 lockdowns and assess their impact on health inequalities. The National Health and Justice Team in UKHSA, working with national and regional leads in NHS England Health and Justice, should continue to work collaboratively to improve HCV prevention programmes (as well as HCV testing and access to treatment) for people in secure and detained settings through commissioning and delivery of evidence-based services supported by appropriate advice, guidance and resources for prisons and associated healthcare teams. This includes the provision of

[19] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf

	disinfectant or decontamination equipment for sharps and access to drug treatment services. Commissioners of services for people who use drugs and alcohol should encourage the provision of low dead-space injecting equipment through service specifications and commissioning standards. The National Strategic Group for Viral Hepatitis (NSGVH) should work with stakeholders to consider how to improve harm reduction and prevention activity among those who are less likely to access drug services, for example those who are homeless. Treatment and BBV prevention services, including drug and addiction services, should ensure that appropriate harm reduction support is provided to help guard against reinfection. UKHSA should support this by monitoring HCV reinfection rates and including this information in the HCV data dashboard. Commissioners of services for people who use drugs and alcohol should encourage the provision of low dead-space injecting equipment through service specifications and commissioning standards. The National Strategic Group for Viral Hepatitis (NSGVH) should work with stakeholders to consider how to improve harm reduction and

	prevention activity among those who are less likely to access drug services, for example those who are homeless. Treatment and BBV prevention services, including drug and addiction services, should ensure that appropriate harm reduction support is provided to help guard against reinfection. UKHSA should support this by monitoring HCV reinfection rates and including this information in the HCV data dashboard. **Increasing case-finding and the proportion diagnosed** All stakeholders should work to improve awareness of HCV and national guidance on testing for HCV among health care professionals, for example by encouraging participation in, and audit of, Royal College for General Practitioners (RCGP) e-learning (for example, Hepatitis B and C e-learning course) (12). All stakeholders should improve the offer and uptake of HCV testing to those at risk of HCV infection and reinfection following treatment by implementing NICE guidelines (13). Commissioners and providers of BBV prevention services should ensure that testing guidance is fully implemented, among those attending drug, and other, services (including pharmacy, outreach and web-based NSP providers) (14). The use of alternative

	approaches to sampling and testing, including capillary or fingerprick blood sampling and point of care testing, that facilitate testing in non-clinical settings or alleviate delays initiating treatment, should be considered, and evaluated. Commissioners and providers of drug services should consider implementing BBV opt-out testing upon initial assessment for all attendees, and ensure at least annual repeat testing for those at continued risk, including for reinfection after successful antiviral treatment, in line with NICE guidance (13, 14). UKHSA, national policy makers, and stakeholders should consider the evidence base for broader HCV testing strategies, to include opt-out, universal and targeted testing approaches, in broader healthcare settings such as emergency departments, antenatal care and primary care. UKHSA and NHS England Health and Justice commissioners should ensure that BBV opt-out testing for new receptions to English prisons continues to be monitored to improve testing offer and uptake. Testing data outside the 14-day period from reception should also be available for monitoring and evaluation. NHS England Health and Justice commissioners should maintain support for peer workers (for example, those provided by The Hepatitis C Trust) who facilitate BBV testing and HITT initiatives within the prison estate.

	Commissioners and providers of laboratory services should ensure, wherever possible, that reflex testing (RNA amplification testing on the same sample as the original antibody assay) is implemented to decrease the turnaround time for referral, benefit patient care and increase cost effectiveness (15, 16). All diagnostic laboratories should include recommendations for onward patient referral on the laboratory report, and implement direct reporting of new diagnoses to their operational delivery network (ODN), as well as to the individual requesting the test. <u>Increasing the numbers accessing and completing hepatitis C treatment</u> NHS England and other commissioners of HCV treatment and care services should continue to work with public health agencies, primary and secondary care clinicians, patient organisations and other stakeholders to simplify and strengthen referral pathways and continuity of care (especially on transition from prison to the community), to improve access and uptake of HCV treatments in primary and secondary care including mental health services, drug treatment services, prisons, homeless services, pharmacies and other settings. UKHSA and the NIHR HPRUs should evaluate the impact of the

	Hepatitis C re-engagement exercise (17) and consider what lessons can be learnt to improve the use of surveillance data for case-finding and engagement in care. Relevant stakeholders should consider scoping the feasibility and evidence for a national media campaign to encourage those with past risk factors but silent disease to come forward for testing. UKHSA in collaboration with OHID and the NIHR HPRU should evaluate the impact of changes in HCV antiviral treatment provision that took place during COVID-19 lockdowns and assess their impact on health inequalities. <u>Strengthening a person-centred, holistic approach to hepatitis, recognising the role of syndemics</u> UKHSA and NHS England, in collaboration with delivery partners, should support the evaluation of new models of testing and service delivery and assess their impact on health inequalities. All stakeholders should embed hepatitis C prevention, testing, diagnosis and care within a broader person-centred health and social care rights-based approach. All stakeholders should continue to support evidence-based

	innovative approaches to strengthen community and outreach service delivery. Making improvements and monitoring metrics UKHSA and the NSGVH should consider alternative approaches to monitor HCV incidence to support validation of elimination and evidence of harm reduction impact. UKHSA should continue to update modelled estimates of HCV prevalence and burden and refine as new data becomes available. UKHSA should further develop the HCV data dashboard to incorporate local prevalence and burden estimates and support partners in the development of data driven action plans to improve local care pathways. All stakeholders should support national and local initiatives to improve data quality to inform monitoring metrics, including more consistent reporting of full identifiers for data linkage with other health data sets to help identify where people fall out of the care pathway. Commissioners of services for people who use drugs and alcohol should specify, in contracts with providers, the legal requirement to report (as a notifiable disease) all HCV positive laboratory results with patient identifiers to UKHSA, including those from DBS and point of care testing.

	Public health professionals working with local authorities and NHS commissioners should consider including HCV diagnosis and treatment in health and wellbeing needs assessments and strategies, particularly services targeting marginalised populations at increased risk of HCV infection, like PWID and those experiencing homelessness. All stakeholders should endeavour to accelerate efforts to eliminate HCV in the context of the COVID-19 pandemic by working together to develop, refine and embed metrics and national indicators needed to monitor this, including the contribution of reinfection following treatment and how this impacts progress to elimination . NHS England should consider recording confirmation of HCV treatment completion as a proxy for successful HCV treatment when testing for SVR is not possible. UKHSA should consider establishing a national HCV sequence database to help monitor the potential threat of antiviral resistance in England.
Recommendation 21 That the Liver and Cardiac Advisory Groups of NHS Blood and Transplant give weighted consideration to those who have	The liver plays a central role in the clotting process, and acute and chronic liver diseases are invariably associated with coagulation

been infected and repeatedly infected with HCV (and Hep A, B, D etc) and/or HIV as to the increased likelihood of liver disease (and heart failure in the case of HIV) and the probability of need for such patients to have early inclusion on Transplant lists.	disorders due to multiple causes: decreased synthesis of clotting and inhibitor factors, decreased clearance of activated factors, quantitative and qualitative platelet defects. **The Inquiry is asked to request from the Liver and Cardiac Advisory Groups what policies they currently have in place which adequately take account of the infected blood scandal and also to question whether such groups have an understanding of:** **(i) the progression of liver damage and its impact on clotting factor leading to changes in clotting levels and more severe bleeds** **(ii) that whilst a liver transplant will mean that a person will non longer be classified as a haemophiliac the impact of the haemophilia leaves severe joint damage** **(iii) that a person who was a haemophilia loses their sense of identity as belonging as a haemophiliac**
Recommendation 22. The Expert Report: Palliative Care in Advanced Liver Disease has recognised that the provision of palliative care for patients with advanced liver disease "remains patchy across the UK, and is	**IBI should recommend to the BMA, BASL[22] and the BSG[23] that they jointly consider the promotion of these services to improve awareness of the palliative care services and request evidence from**

[22] British Association for the Study of the Liver
[23] British Society of Gastroenterology

contingent upon local interest, expertise and resources. The patient and carer experience of healthcare for advanced liver disease remains frequently poor[20]". The report also recommends that the profile of liver disease needs to be raised to "give clinicians the support needed to secure funding for services, as well as the confidence to initiate anticipatory care planning discussion and to consider referral of their patients to specialist palliative care services[21]"	**these bodies as to their work in this area, funding of these services and their availability to those suffering from advanced liver disease.**
Recommendation 23. That where parallel structures exist within the civil service, an administrative civil servant shall not have the authority to override or otherwise amend the advice of a specialty civil servant without the explicit knowledge and consent of the politician with overall responsibility for the department.	Diana Walford told the Inquiry that the DHSC civil service had two parallel structures, the administrative and the medical civil servants and that the administrators chose when to seek medical opinion and might change advice from medical civil servants before presenting it to ministers [WITN4461001_0027]. A prime example of this practice comes in the cross reading of [DHSC0002229_019] where the medical advice which becomes the 'no-conclusive-proof' line to take is qualified by adding "...but the evidence is suggestive that this is likely to be the case" and Diana Walford's memo of 20/07/1983 [DHSC0001109] where it is said that that whilst there is no conclusive proof, the assumption is that transmission of AIDS may be possible with Lord Glenarthur's response

[20] EXPG0000043_0019
[21] _0020

	to a question from Baroness Masham [WITN4461147] where the qualification to the line has been dropped. The removal of this qualification had devastating consequences in that it served to offer false reassurance to haemophiliacs about the treatments they were receiving and may have led many to continue with their treatment despite their reservations. Simply, there is no point in taking expert advice if such advice is amended by someone with no expertise to serve a political purpose. Expert advice should be delivered to politicians unamended and if they wish to deviate from that advice, they may do so but they are accountable for their decisions. The example cited above illustrates a situation where an administrative civil servant has amended advice before delivering it to the politician with responsibility thereby removing any accountability for the fact that the advice was not followed. **Chief Operating Officer for the Civil Service, Alex Chisholm be requested to provide a statement to IBI setting out the current guidance on the use of advice from a civil servant with special expertise.**
Recommendation 24. All briefing papers and advice given to a minister by the civil service or any other advisory body should be made available to their successors.	Lord Glenarthur and Lord Clarke both described the convention by which the advice received by a minister from (particularly) the civil

Chief Operating Officer for the Civil Service, Alex Chisholm be requested to provide a statement to IBI setting out the current guidance on the use of briefing papers and advice provided to a previous minister (whether from the same Political Party or not).	service is not available to that minister's successors. It is said that this convention exists to ensure that ministers and their civil servants are able to have full and frank discussions on issues before taking decisions without the fear that a future administration will make political capital from the deliberations. It might be said that whatever the purpose of the convention, the effect is that with each change of administration, the civil service is given a clean slate on the full range of activities undertaken by their department. There should be recommendation that whenever a new minister takes office (whether as a result of reshuffle or election) they be provided with a briefing paper dealing with the full range of policies being implemented by the department at the point at which the new minister takes office. All briefing papers which relate to policy decisions which directly impact upon the quality or longevity of the health of the public should be made available, complete and unredacted. It is worthy of note that Lord Owen's evidence to the Inquiry was that he formulated the policy of self-sufficiency based on a book review he authored of Richard Titmuss' The Gift Relationship [WITN0663001_0002]. Lord Glenarthur and Lord Clarke both failed to recall being aware of Lord Owen's commitment at the time they took office. On the other hand, [DHSC0003741_135] is a DoH memo which

	pre-dates Lord Owen's time in office and illustrates a move towards self-sufficiency as early as February 1973. Had politicians who were accountable for decision making been aware of the various reasons to aim for self-sufficiency (in blood products) from its first roots in the early 1970s, it is possible that with proper political will, self-sufficiency may have been attained in the timescales envisaged by Lord Owen and in any event, before Lords Glenarthur and Clarke took office.
Recommendation 25. That the IBI recommend the establishment of a Consultative Council in line with the Republic of Ireland: "The Consultative Council on Hepatitis C is a statutory body appointed by the Minister for Health to advise and make recommendations on all aspects of Hepatitis C in Ireland. For further information see the Consultative Council's website at www.consultativecouncilonhepc.ie The Consultative Council since its establishment in 1996 has made a significant impact on the provision of appropriate services for persons infected with Hepatitis C through contaminated blood and blood products. Additionally, the Consultative Council has participated in and overseen many developments in the areas of research, establishment of a national database of persons infected through blood and blood products, facilitation of annual information days and	**IBI is requested to consider the calling of evidence as to the effectiveness and work of the Consultative Council** from: Consultative Council on Hepatitis C The Current Chair is: Ms Ger Kane Stewarts Hospital 2nd Floor Health Service Executive Mill Lane Palmerstown Dublin 20 Tel: GRO-C Fax: GRO-C

international conferences, development of a suite of relevant publications for patients and the setting up of an insurance scheme specifically for persons infected with Hepatitis C and/or HIV through blood and blood products. The Consultative Council on Hepatitis C has an annual information day and all HAA cardholders are invited to this by the National HAA Card Office." https://www.hse.ie/eng/national-hepatitis-c-treatment-programme/haa-information-guide.pdf at page 25	E-mail: ger.kane GRO-C Website: www.consultativecouncilonhepc.ie
Recommendation 26 A UK wide national monument should be created to the memory of all those infected or affected by contaminated blood and blood products and should be situated in a place prominent to those responsible for the care of NHS patients, such as Christchurch Gardens, adjacent to the premises of the Department of Health.	The extent of the tragedy of the contaminated blood disaster must not be forgotten nor must the reasons why it came about. The monument should serve as a reminder of the lessons which will hopefully be learned as a result of the Infected Blood Inquiry. A monument will also serve as a focal point for those infected and affected who are still alive to remember the friends and family members they have lost to infection. **The DoH should be requested by IBI to respond to this proposed recommendation.**