The Scottish Response to the Terms of Reference Consultation

A joint response from Haemophilia Scotland, the Scottish Infected Blood Forum, and Scottish Campaigners to the Infected Blood Inquiry Consultation on Terms of Reference

April 2018

HAEMOPHILIA SCOTLAND

Scottish Infected Blood Forum

Terms of Reference Consultation Scottish Response

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Introduction

This response to the Infected Blood Inquiry Terms of Reference is made on behalf of the Scottish Infected Blood Forum (SC043464), Haemophilia Scotland (SC044298), and independent campaigners in Scotland.

It is informed by our members, specifically through consultation on our Joint Position Statement, issued in October, and a consultation meeting covering the questions in the Inquiry's consultation document. Members of our communities have also informed this response by contacting us directly, on email, by phone, and through social media. We do not claim to represent the views of every affected person in Scotland but are confident that this response reflects the majority view of our communities.

The views expressed in this response are consistent with the more detailed Joint Position Statement which has already been submitted to the Inquiry and is available online at https://haemophilia.scot/wp-content/uploads/2017/11/UK-Contaminated-Blood-Inquiry-FINAL.pdf

Overall, we believe that the Inquiry's Terms of Reference should be flexible enough to allow a closer investigation of specific circumstances and decisions around specific patients or group of patients as deemed necessary by the Chair and Panel.

The period of time to be considered by the Inquiry

Q1. On what time period or periods should the Inquiry focus?

We believe that the period of focus of the Inquiry must be broad enough to examine the totality of the development and use of blood derived pooled clotting factor products. We believe that adhering to this time period would cover the most relevant years for blood transfusion transmissions as well. Therefore, the primary period covered by the Inquiry cannot start later than 1969. Implicit in this approach is resisting any suggestion that the scope of the Inquiry be limited to Hepatitis C and HIV. We believe that all blood borne pathogens should be within the scope of the Inquiry, especially all viral hepatitis and CJD. Without considering CJD the Inquiry will not be able to address the contention, which has previously been made by Government, that all relevant lessons from the Hepatitis and HIV infections have been learnt.

Key dates which must be considered, including in setting the start date for the period of focus are,

1. 1941: First experiments in pooling blood for blood products which took place in Edinburgh and Oxford as early as 1941. These early products, Cohn Fraction, were developed for military use. This should include any commentary provided by early researchers into the therapeutic use of blood products about the inherent risks of the techniques. The infections caused by Cohn Fraction should have provided a vital warning for the later use of the plasma derived clotting factor products.
2. 1958: Judith Pool comments about the safety of therapies in 1958, following her work on cryoprecipitate.
3. 1963: From 1963 there was a liver enzyme test which allowed effective monitoring.
4. Up to 1965: The development of Albumin, heat treated, as a blood product to provide points of comparisons with the development of clotting factor product, with particular attention to the use of heat treatment.
5. 1968: The implementation of the public health legislation in relation to notifiable diseases, with particular reference to the Medicines Act 1968.
6. 1969: the start of the Hepatitis observation studies on Haemophilia.
7. 1973 to 1978: During these years the Australian antigen development required blood from people who were already infected and this was often drawn from people with Haemophilia.
8. 2005: This is thought to be the last point at which products implicated in relation to vCJD were given to people who received blood products in the UK.

Therefore, the wording of the terms of reference must not preclude hearing this relevant evidence from earlier periods. It also must not be restrictive to any identified dates and must also consider and allow the questioning of other dates wherever unfolding evidence leads. We also believe that to examine the response to the infections properly, the period the terms of reference cover must include up to the present day.

Blood and Blood Products

Q2. Do you agree with the provisional view of what should be covered?

The Inquiry's provisional view is that it will aim to find out:

A. why patients were given infected blood and blood products when treated by the NHS;

B. the extent to which this continued after the NHS and/or Government was or should have been alerted to the risks, and why it continued to happen;

C. why it was that blood products had to be purchased abroad rather than sourced locally; and

D. whether there was a deliberate attempt to conceal details of what had happened, both at the time it occurred, or later.

This means examining the commissioning of blood supplies, the roles of suppliers, the response at the time to complaints that individuals appeared to have been affected adversely, the selection of donors, screening and testing procedures, and whether any decision made by the Department of Health was influenced by commercial organisations or by commercial interests.

We will respond to each provisional view in turn.

A. We support the inclusion of terms of reference relating to this provisional view. We believe that the Inquiry will quickly establish that from a very early point both blood transfusion and early treatments for inherited bleeding disorders were known to cause transfusion hepatitis. While the precise pathogenic agents were not established until later, the knowledge that blood and blood products were transmitting disease appears to be almost as old as the techniques themselves. Therefore, the key question isn't why infected products were used, it would be more pertinent to ask if sufficient steps were made to make transfusions and blood products as safe as possible in response to the known risk. Patients have never had adequate explanations for why more effective steps weren't taken much earlier to,

   i. exclude blood donations from all groups with a known increased risk for blood borne infections;

   ii. invest more heavily in research to remove blood-borne pathogens from blood and blood products; and

   iii. restrict the therapeutic use of blood and blood products through patient choice or other measures

   It should have been assumed that the transmission route had the potential to cause hugely significant numbers of infections with commensurate health impacts, including leading to death, and policy directed accordingly.

B. We support the inclusion of terms of reference relating to this provisional view. Under this term of reference the Inquiry should examine potential steps which could have been taken to make the blood and blood products supply more resilient to pathological threats. It should investigate and comment on whether implementing them might have prevented infections with contemporary or future pathogens, and make relevant recommendations about current practice. The list below is indicative, not exhaustive.

   i. When was it known that incarcerated populations were at increased risk of being infected with blood borne pathogens and was the UK and commercial practice of using blood from these sources stopped immediately?

ii. When was it known that intravenous drug users were at increased risk of being infected with blood borne pathogens and were steps taken immediately that would reliably have excluded them from donating blood?

iii. Would the use of surrogate ALT testing have reduced the number of Hepatitis infections, particular those caused by infected blood transfusions? Furthermore, the Inquiry should examine how the voice of blood and blood product recipients is heard in decisions about when and how to introduce new blood donor tests, including surrogate testing.

iv. Were there effective systems for ensuring healthcare professionals, not working in specialist centres, had appropriate treatment protocols? We are aware of cases of people both with and without diagnosed bleeding disorders being treated with blood products inappropriately.

The issues of donor selection relates to both whole blood transfusions and to those with received blood products.

C. We support the inclusion of terms of reference relating to this provisional view. The issue of self-sufficiency and the decision-making arising from it were very different in Scotland. In contrast to its counterparts elsewhere in the UK, the Scottish National Blood Transfusion Service (SNBTS) maintains that it had the capacity to meet all Scottish demand for blood products and provided it without cross-charging to the NHS in Scotland. Given this situation, the question in Scotland is why were decisions taken to pay for and treat with commercial products from abroad rather than with the locally available alternative? The Inquiry might also usefully investigate why spare Scottish capacity wasn't more effectively used to meet demand south of the border. We further believe that the Inquiry should examine whether there was an effective, UK-wide, system to ensure that previously untreated people/patients were being treated with the safest possible blood product regardless of whether they lived in the UK, and if not, why not?

D. We support the inclusion of terms of reference relating to this provisional view. However, we would support a change to the wording by replacing the words 'a deliberate' with 'any attempts' as our collective view is that any attempt to conceal is inherently deliberate. Further, we believe the word attempt should be in its plural form, 'attempts'. We also strongly agree that by including the words 'or later' allows the Inquiry to look at any potential cover-up after the point at which the blood products and blood supply was deemed to be contaminated. In order to investigate if there have been any attempts of this kind to conceal we believe the following issues must be investigated,

i. The use of Crown Immunity to prevent domestic manufacturing standards being held to account. We do not believe that the use Crown Immunity was legitimate and would expect the Inquiry to comment on this. If the Inquiry agrees with us that it was not appropriate in domestic fractionation then this raises questions of why there were attempts to use it to circumvent regulations in place for the protection of blood product recipients, in whose interests the system was supposed to be operating.

ii. Was there any use of D-Notices or similar mechanisms to minimise the contaminated blood issue being openly reported in the press. If such steps were taken what were the justifications and motivations for these actions.

iii. Whether the gaps patients have noticed in their medical records disproportionately affect any type of information or period of time. We believe the Inquiry should systematically review medical records in order to establish if there are any grounds for believing they have been tampered with. Similarly, the Inquiry should investigate the delays and obstructions faced by patients in accessing their medical records. Patients suspect that these delays were to allow medical records to be

reviewed and materially altered to prevent patients obtaining legally significant information. Do the preponderance of patient assertions that their records (including GP, clinic and hospital records) were lost or destroyed indicate a non-haphazard destruction of medical records that could be construed as systematic or appear to be directed at some level in a co-ordinated fashion?

iv. Whether former Ministers, particularly in the Department of Health, have been able to access their papers. Perhaps the notable example being that of Lord Owen.

v. Whether it is appropriate for Government Departments to retain control of files relating to contested events, and whether there is sufficient safeguards and document control management systems to prevent documents being destroyed by junior members of the Civil Service. Indeed, whether such Government explanations around document destruction appear to obfuscate the real reasons or promulgate a false narrative. Specifically, incidents of official or internal government papers being 'shredded' or otherwise disposed of or lost.

vi. The extent to which the response to the infections by Government and governmental bodies was affected by legal considerations and a desire to avoid liability.

vii. The investigation into any attempt to conceal should include efforts made to prevent a full investigation. A heavily bereaved community with serious ongoing health problems has had to campaign for decades to achieve a UK statutory Public Inquiry. Issues such as the time bar and withdrawal of legal aid have prevented the issue being properly examined by the courts. The Inquiry should comment on the failure of the political and legal system to respond.

viii. Why none of the police investigations were taken forward by prosecutors? Within the Scottish context we are aware of a Lothian and Borders Police Investigation and an all Scotland investigation led by the Strathclyde Police. We believe similar investigations were conducted in the rest of the UK too.

ix. Those with a long history of campaigning report problems with their telephones at key times which led them to suspect they were being monitored. Similarly, post was tampered with.

x. Investigate whether there is a link between the possible material compensation claims made resulting from the Inquiry and the calls for reforms to cut the amounts of money awarded in criminal negligence claims as opposed to a cap on solicitors' costs and whether this may detriment and prejudice infected and affected people in their potential actions arising from the Inquiry.

Therefore, we would propose amending the paragraph after point D from:

This means examining the commissioning of blood supplies, the roles of suppliers, the response at the time to complaints that individuals appeared to have been affected adversely, the selection of donors, screening and testing procedures, and whether any decision made by the Department of Health was influenced by commercial organisations or by commercial interests.

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This means examining the commissioning of blood supplies, the roles of suppliers, the culture or relationships between suppliers and purchasers/users of blood and blood products including potential incentivisation or collaboration, the response at the time to complaints that individuals appeared to have been affected adversely, the selection of donors, screening and testing procedures, and whether any decision made by the Department of Health 'or other bodies' was influenced by commercial organisations or by commercial interests, either at the corporate level or individually.

Evidence Collection

Q3. Is there any type of evidence, such as documents, communications or expert reports that you think is essential for the Inquiry to obtain?

We believe it is essential that the Inquiry has access to,

1. Cabinet papers relating to the UK Government's response to infections. Including those not yet released under the provisions of the Public Records Act 1958, commonly referred to as the 30 year rule.
2. All documents withheld by Governments under Freedom of Information exemptions.
3. Legal advice obtained by the Government in relation to the infections, particularly any advice relating to minimising liability.
4. Files relating to any of the police investigations which were passed to prosecutors, and any documentation relating to the decisions of prosecuting authorities about whether or not to take the cases forward. We are aware of at least two police investigations conducted in Scotland but have been unable to locate neither set of papers through Freedom of Information requests.
5. Files relating to any investigations by the General Medical Council or other professional bodies.
6. Files relating to the involvement of public health authorities in response to the infections.
7. All commercial contracts for the collection of blood or supply of blood products to be used anywhere in the UK.
8. Any records held by the 15 NHS Health Boards, Common Services Agency (now NHS National Services Scotland) relating to decisions to purchase commercial clotting factor products in preference to using products produced by the Scottish National Blood Transfusion Service or elsewhere in the UK.
9. Records of the collection of blood in UK prisons or borstals.
10. Any of the blood transfusion services' hepatitis record books, held in relation to notifiable diseases legislation, which have not been destroyed. Andy Kerr MSP, when Scottish Minister for Health, gave responses in the Scottish Parliament indicating that many have been destroyed.
11. Medicines Inspectorate Reports into all blood products manufacturing facilities.
12. All papers received by Justice Ognall as part of the HIV litigation in 1990, including the waiver that HIV litigants had to sign in order to receive payments. Those involved in the litigation were told that Justice Ognall saw papers which were not released to the lawyers representing those infected. This may mean there are papers seen by Justice Ognall which weren't included in the documents recovered by Carol Grayson and returned to the Department of Health following it's destruction of the majority of the original documents.
13. All the documents collected by the Penrose Inquiry should be passed to the Infected Blood Inquiry, not just those which were included in the Court Book.
14. All documents submitted to the Archer Inquiry. As an independent Inquiry, the panel did not have legal protection and therefore could not publish all of the information that was submitted to them. We are particularly anxious that the Infected Blood Inquiry sees any correspondence from Professor Geoffrey Savidge.
15. The Living Stories Project at the British Library.

16. The evidence specified by Andy Burnham, the former MP and current Mayor of Manchester, in his valedictory speech as an MP at Parliament on 25th April 2017.
17. Any D-Notices or restrictions on media coverage of the infected blood issue.
18. Copies of documentation collected by campaigners over many years. It would be preferable to find a way of allowing those concerned to retain their documents due to the difficulty they have faced in acquiring them and the understandable low level of trust in large document control systems. Some campaigners believe that they have copies of documents for which the original has now been destroyed.

In relation to Section 17 of the Inquiries Act 2005, we would place pre-eminence on the taking of all evidence under oath, and to compel other evidence, reflecting the seriousness of the issues involved and lack of trust between infected and affected persons and many of the probable witnesses.

The care and support provided after infection

Q4. Should the Terms of Reference include consideration of the care provided, and the response of governments across the United Kingdom, and overseas?

We agree that the Inquiry should include these considerations.

The Inquiry should examine the extent to which the response of Governments was influenced by the needs of those infected and their families, and to what extent it was influenced by the desire to minimise Government's (or others) financial liability or exposure to negligence claims. Is it appropriate that, even including the Inquiry, that there has been no process competent to establish liability. The only exception being the HIV litigation of the early 1990s which patients were forced to settle without a ruling on liability by the decision to withdraw Legal Aid. The Inquiry should investigate if government(s) have taken steps designed to either avoid establishing liability or to minimise liability which have made it more difficult for affected families to get information or to pursue legal cases. The terms of reference in this section should specifically mandate an examination of the merits of lifting the time bar to allow liability to be determined. This has already been done by the Scottish Government in relation to the cases being investigate by the Scottish Child Abuse Inquiry.

We believe that across the UK there is an overwhelming demand to include an investigation of the fitness for purpose of the current ex-gratia support schemes, and to make recommendations for improvements. However, many affected people in Scotland now rely on the payments they receive from the Scottish Infected Blood Support Scheme (SIBSS) and we would not support a process which might be used to reduce them. Furthermore, it must be clear that Governments should not use the work of the Inquiry as a reason not to make improvements to the current ex-gratia support schemes.

We also believe that a broad interpretation of the provision of care is required in this context. The Inquiry should look at,

A. The medical care people received in relation to their infection including advice to prevent transmission to loved ones.

B. The monitoring of the health, including mental health, of affected families.

C. The provision of appropriate psychosocial support to affected families.

D. The impact of infections on the experience of medical care unrelated to the infection, including the relationship with haemophilia centres.

E. Whether a duty of care existed, or should have existed.

F. If there is consistent evidence of extensive delays and withholding of diagnoses to people whether they received a contaminated blood product or blood transfusion. The Inquiry should seek evidence in relation to unexplained and unreasonable delays between the key points of,

    a. The date of peoples' infection

    b. The date of their testing

    c. The date of their diagnosis; and

    d. The date of being informed of that diagnosis

    e. Were all patients given their diagnosis in an appropriate, sensitive, and confidential way?

Medical professionals who are new to this scandal are often surprised at the delays between points a and b, and between c and d above.

G. The appropriateness and sustainability of support services offered by the NHS and third sector organisations. In particular, should charities working with those affected be eligible to receive core Government funding to ensure that the community is supported.

To achieve this, we believe that a full impact assessment should be conducted covering the entire infected and affected community. It should include,

- Loss of earnings
- Potential loss of earnings (and career development that was halted or ended);
- Additional costs such as insurances, fuel bills, etc.;
- Quality of life detriments (with financial equivalences where possible) should be conducted.

The assessment should feature case study examples of the various cohorts of infected and affected people such as,

- Those with a well-established career
- Those too young to properly begin developing their career
- Widow and children of infected people including incidents of partners also stopping work to become a full-time unpaid carer, and
- Difficulties with accessing state benefits due to the policy frameworks and guidance documents that do not allow contaminated blood issues to be properly considered.

Identifying responsibility and making recommendations

Q5. Do you agree that the Inquiry should seek these individual responsibilities and make recommendations?

We strongly support this proposed terms of reference and that the Inquiry should have the power to make recommendations. The single recommendation of the Penrose Inquiry was little more than repetition of a recommendation made by the Lord Ross Expert Panel in March 2003. This brought the Penrose Inquiry, and the whole Public Inquiries process into disrepute. Therefore, we believe that each individual term of reference should call for a recommendation, or recommendations, in response to it. We believe that the Inquiry will ultimately be judged by the relevance and applicability of its recommendations.

However, we believe the investigation must go further than public authorities and contractors. It should encompass the response of all UK organisations including all relevant Governments, Government Departments, and all organisations providing advice to those bodies. The key issue is whether the UK's response was appropriate. If there is evidence that individual policy makers, civil servants, or healthcare professionals bear a share of the responsibility then they should be named.

Our experience of the Penrose Inquiry has led us to conclude that the current Maxwellisation process is not fit for purpose. From a patient perspective, it appears to be an opportunity for any criticisms of individuals or organisations to be watered down by the legal teams of those to be criticised. This process is entirely behind closed doors and not open to challenge by the representatives of those affected. The impression is created that the effect of the process is to remove key criticisms through an entirely one-sided process. We believe that legal representatives of the patient interest must have sight of the notification letters for the eventual Maxwellisation process and have the right to make representations to the Inquiry to address the responses the Inquiry receives to them.

The Inquiry should look at both the response in terms or protecting the health and interests of patients from the emerging threat, and whether the response to the campaign for justice has been appropriate.

We believe that justice delayed is justice denied, and that there have been successive incidences where attempts to have the infections fully investigated have been thwarted.

Additional Considerations

Q6. Please provide any additional views and information you would like the Inquiry to consider in developing the Terms of Reference.

We also believe that the provisional views for the terms of reference risk neglecting some vital areas, without which the Inquiry would be incomplete.

Communication of risk and patient choice.

- Were there sufficient systems for analysing the evolving understanding of the risks and for providing advice to treating clinicians? Where systems were not explicit, is it deemed incumbent on medical professionals and others to communicate risks explicitly?
- Did patients have the information they needed to give informed consent to each individual treatment? Were standards of consent high enough then, and are they high enough now? The use of all blood, tissues, and samples should require specific consent to be used in research, studies, or monitoring. Those who donate should be routinely informed of the results of that research (we are aware of patient assertions that they were blocked from receiving copies of some of their hospital records as they were being used for 'research purposes'). Were the standards of medical ethics at the time met and are standards of medical ethics sufficient to ensure patients are in control of their medical data?
- What guidance and advice was provided to primary care services and accident and emergency facilities. Were they warned about the risks from blood and blood products and if so was that guidance effectively disseminated and updated.
- Whether there were any research and development activities carried out under the auspices of treatment with blood and blood products, and whether any such research was carried out with or without the knowledge or informed consent or patients?
- Were patients who were receiving non-life threatening treatments given options for alternative treatments with a lower risk of transmitting blood borne pathogens? And in like manner, why were some people who did not have a bleeding disorder treated by clinicians with factor concentrates which were known to be contaminated when this was not actually necessary?
- Many of those who have lived through these infections now have strong views about the morality and ethics involved and the ownership of medical samples. The Inquiry is an opportunity to advance medical ethics in addition to the legal points.

Impact of infections

- Impact of infections on surviving individuals and families.
- Impact of deaths on bereaved widows, widowers, and families.
- Statistics. During the Penrose Inquiry there was some debate about whether it was necessary for the Inquiry to discover how many people were infected and how many of those people had died. We believe it should be explicit in the Term of Reference for this Inquiry that the final report will cover these basic statistics, stratified appropriately e.g. bleeding disorders, non-bleeding disorders, factor VIII recipients etc. and include an estimate of how many infected people are likely to be undiagnosed or lost to follow up.
- There are already a host of negative impacts on a person who is infected by a blood borne virus, but it is also important to include a consideration of the significant side effects of the anti-viral treatments that

were offered; in particular those involving Interferon and Ribavirin; including how there were presented to patients as viable options. It is additionally important not to allow certain over-simplified assertions to stand, such as the common statement by clinicians, politicians and the media that the new treatments are safe, without side-effects and produce a "cure".

Panel or Assessors

We agree with the All Party Parliamentary Group on Haemophilia and Contaminated Blood that the Inquiry should be conducted with a statutory Panel rather than by a lone Chair assisted by Assessors. The Penrose Inquiry structure was a lone Chair assisted by an assessor, and patients felt excluded from the process. Replicating the structure of the Penrose Inquiry would not have the confidence of affected people in Scotland. The expectations of the victims have already been raised by Damien Green who in meetings with victim representatives accepted the assertions about a fully empowered Panel, and spoke about "the Panel", and "the Panel Members" as if that was a "given", as well as there being separate advisors and assessors, not instead of. While assessors could play a role in assisting the Inquiry with the complexity of the issues, we believe a Panel offers several advantages,

- Inquiries with a lone Chair are vulnerable to the Chair becoming incapacitated by illness or bereavement. Panel members share the duty to conduct the Inquiry, in a way that assessors do not, making it much easier for the process to be completed in a satisfactory manner in those circumstances.
- The powers of a lone Chair are absolute. If decisions are taken which are against the interests of patients then those patients only have recourse to drastic options, such as withdrawing from process or seeking a judicial review. We believe a panel provides internal checks and balances to the decision-making process and would create an Inquiry which is more responsive.
- The Inquiry must be a thorough process but should not take any longer than necessary. Panel members would have the authority to hear evidence, and if sitting independently, could expand the capacity of the Inquiry. It would not be acceptable to us for patients to give oral evidence to an assessor without the Chair present.
- The Inquiry should provide a comprehensive record and a considered view on the holistic detriments caused to infected and affected people covering all aspects of the lived experience: physical health, mental health, financial losses, social impacts, reduced/lost opportunities across all spheres.

Procedures

Whatever the structure of the Inquiry, it is vital that it allows those representing the patient interest to pursue the lines of questioning that the patients need to be answered at Oral Hearings. In our view, the credibility of the Penrose Inquiry was damaged when witnesses were simply led through prepared statements at Oral Hearings without been subject to cross examination. Patients felt nothing had been gained on these occasions that wasn't already in evidence through the witness statement. Patients were also frustrated when witnesses were able to make statements they believed to be false without challenge. It was unnecessarily difficult for our legal representative to challenge statements due to requirements to pre-submit lines of questioning and no automatic right to cross-examine. Very few patients were called as witnesses, and those witnesses that were called were asked predominantly about their personal experiences and were unable to comment on the evidence given by non-patient witnesses. As a result, patients felt excluded from the process. It is imperative that these mistakes are not duplicated at the Infected Blood Inquiry.

We believe there are significant differences in the response in Scotland and that this should be reflected in the selection of Core Participants and legal representation.

All patients (victim/survivors) should be designated as core participants even if every individual is not called to give oral evidence; similarly, any charitable body or voluntary association people may be involved with should also be designated as organisational core participants.

There should be a literature review that builds on the work of the Penrose Inquiry to ensure all available knowledge and information is recorded. Perhaps this could be achieved by the Inquiry sponsoring a PhD studentship.

There should be a catalogue listing of all documents and other sources that were known to exist and were sought but were not able to be accessed for whatever reason. Similarly, there should be a catalogue listing of all medical records that were lost, altered or destroyed.

The Inquiry should complete a risk assessment of the likelihood and relative impact of a similar contamination situation involving blood sourced for medical purposes.

The Inquiry recommendations could usefully include practical aspects affecting the contaminated blood cohort including; underwriting of insurances, passporting to key benefits, ensured access to free prescriptions and other treatments, availability of bespoke supports such as counselling and access to health promoting services such as gyms and health spas, etc.

An arrangement to provide financial resources to patient/victim support organisations (at least those that are registered and incorporated charities) will be essential to: assisting people through the Inquiry process; helping to coordinate inputs such as documents and evidence statements; providing a two-way communication through trusted routes, reducing the amount of briefing to legal teams by acting collectively; etc. This arrangement could facilitate a forum or reference group to assist and inform the Inquiry, similar to those which have usefully been established by other Inquiries.

An arrangement to provide expenses (for travel, subsistence, accommodation, etc.) in advance must be available since many patient/victims have very limited personal resources and would struggle to engage as fully with the Inquiry and they would want. This could be managed through the existing support organisations in line with the previous point.

Recognition and arrangements put in place to take account of the specific needs of patient/victims such as fatigue, brain fog, varying mobility restrictions, chronic physical pain and discomfort, anxiety and stress (including PTSD), depression (with concomitant emotional lability including issues such as anger, tearfulness, etc.), variety in peoples' capacity to comprehend technical information, among other things.