THE STRATEGIC CHALLENGES FACING THE MACFARLANE TRUST:

THE EFFECTS OF DEMOGRAPHIC CHANGE AND LACK OF GOVERNMENT FUNDING ON HAEMOPHILIACS INFECTED WITH HIV–HEPATITIS C BY NHS ADMINISTERED CONTAMINATED BLOOD PRODUCTS

RUSSELL ORDE MISHCON

THE FACULTY OF
BUSINESS, COMPUTING &
INFORMATION MANAGEMENT
LONDON SOUTH BANK UNIVERSITY

THE STRATEGIC CHALLENGES FACING THE MACFARLANE TRUST:

THE EFFECTS OF DEMOGRAPHIC CHANGE AND LACK OF GOVERNMENT FUNDING ON HAEMOPHILIACS INFECTED WITH HIV/HEPATITIS C BY NHS ADMINISTERED CONTAMINATED BLOOD PRODUCTS.

Dissertation submitted in partial fulfilment of the requirement for the degree of: Master in Voluntary Administration (MVA)
Author: RUSSELL ORDE MISHCON
Student number: 2489169
Year of submission: 2008

EXECUTIVE SUMMARY

This dissertation seeks to address the challenges facing the Macfarlane Trust ('MFT'), a charity set up by the Government in 1988 to administer to the needs of haemophiliacs, infected with HIV and Hepatitis C by contaminated blood products dispensed by the NHS some 30 years ago.

The demography has changed in that those infected, who, at the time, faced an imminent death, now have an extended lifespan but many have deteriorating health, decreased mobility and employability, and evolving liver disease. They also suffer from the absence of proper compensation.

The perceived problem facing MFT is how best to meet the needs of the charity's community of care in its discretionary allocation of limited and insufficient resources, which are provided solely by the Government. The enquiry revolves around the extent that demographic change and lack of government funding have created strategic challenges for MFT. It has involved, inter alia, a detailed investigation by questionnaire of all of the survivors of the tragedy, the interviewing of several key individuals and enquiry of other UK charities, with similar cohorts, and of Haemophilia Associations in other countries, to ascertain how those who have suffered severe injury or illness have been 'compensated'.

Following an introduction, the aims and objectives of this enquiry are extensively set out, followed by a literature review and a detailed exposition of the design and methodology used in the research process. There follows a report and analysis of the data from the questionnaire and of the information obtained from other enquiries. Conclusions are drawn. One such conclusion involves a possible breach of fiduciary duty which, if confirmed, requires immediate action by the Board of Trustees.

In the final chapter, the author suggests the way forward with a number of strategies to meet the challenges currently faced by MFT, for implementation now and in the longer term.

Some of the proposals, such as life insurance provision and empowerment have been under very recent discussion, but the most radical suggestion, to change the basis of distribution of funds by ascertaining the real circumstances of each individual beneficiary, so as to evaluate financial need, has not previously been canvassed and is bound to be controversial, both amongst the Board of Trustees and MFT's community of care. In addition, political and other possibilities are put forward to provide a basket of strategies for the Board of Trustees to consider.

INDEX TO CONTENTS

VOLUME 1

5. REPORT & ANALYSIS

7. THE WAY FORWARD

LIST OF FIGURES

LIST OF TABLES

INDEX TO CONTENTS

VOLUME 2

APPENDICES

PREFACE

No man is an Iland, intire of it selfe;
every man is a peece of the Continent, a part of the maine;
……… *Any Mans death diminishes me, because I am involved in Mankinde;*

John Donne, ***Devotions upon Emergent Occasions, Meditation XVII, 1624***
English clergyman & poet (1572 - 1631)

'The compassion of a society can be judged by the measures it takes to reduce the impact of tragedy on its members. No amount of money can make up for the pain, suffering and premature death of those infected with HIV, Hepatitis C or any other blood related injury. The financial burden of living with HIV or other blood related illnesses can, however, be quantified for the purpose of providing financial assistance to injured persons or their families……'.

Judge Horace Krever
1997 Krever report into the Canadian Blood Service.

These two apparently very different quotations, from two very different eras, have haunted me throughout the months I have been working on this dissertation and it is, perhaps, because the message they carry is the same.

When the idea for this dissertation first came to me, it gave credence to the proverbial saying, 'Ignorance is bliss'. Since embarking on it, I have felt the need to try and keep the lid on Pandora's box, without much success, given that the outcome is disquieting and the solution proposed radical. That *hope* is all that was left in Pandora's box has profound significance.

I wrote, in the proposal for this dissertation, that as only one of twelve trustees, and newly appointed, I considered I was sufficiently far–removed from the Macfarlane Trust, in relation to the proposed, fixed research aspects, to avoid being 'self-evaluating'. In the fifteen months that have since passed, my knowledge of the work and workings of the Macfarlane Trust and of its community of care have increased enormously and it would be a callous author who remained emotionally unaffected by what they had learned.

The author of *Social Research* provides some comfort by suggesting that someone with an involvement like mine in the Macfarlane Trust is a "collaborator and a facilitator: the political nature, the participatory character, the emancipatory elements and the direct, committing and personal involvement of the researcher are at the front of the research activity" [1].

I can only hope that I have shown enough academic rigour to balance those emotions and to produce a piece of work that will be of value to the Macfarlane Trust, which I have the privilege to serve as a trustee, and to its community of care. It is my earnest hope that someone sufficiently senior in Government will take heed of the message that runs throughout this dissertation, so that John Donne's immortal words (taken from the same Meditation quoted above) do not have a lasting, ringing sound in their ears:

And therefore never send to know for whom the bell tolls; It tolls for thee.

---

[1] Sarantakos, S. (1998) Social Research at p.113

ACKNOWLEDGEMENTS

I acknowledge that I have paid little heed to political correctness in the language of this dissertation. John Donne's '*mankinde*', referred to in the Preface, remains just that and whilst a haemophiliac is a 'person with haemophilia', I hope that all those who read this dissertation will forgive the use of the single word, not because it reduces the word count but because, to me, it increases the stridency of the condition and those affected by it. My attitude is, in part, a reaction to the *political incorrectness* of successive governments that the research for this dissertation has unearthed.

The views expressed in this dissertation, unless attributed to a particular source, are my own and cannot be attributed to any other member of the Board of Trustees of the Macfarlane Trust or to any of its staff. Any errors, misunderstandings and omissions are entirely mine.

My sincere thanks to:

- Martin Harvey, Chief Executive of the Macfarlane Trust and to his fine team comprising (in no particular order) Roz Riley, Shane Baker, Linda Haigh, Nick Fish and Keisha Baker-Benjamin, who have been so helpful in answering my many questions.
- those who have given of their time to be formally interviewed, namely (but in no particular order) Rev. Prebandry Alan Tanner, Peter Stevens, GRO-A Dr. Mark Winter, Professor Uri Martinowitz, Lord Morris of Manchester and Baroness Kennedy of the Shaws.
- those, too many to mention by name, who spent time corresponding with me or on the telephone providing me with information and answering questions.
- Peter Jackling of IDA who compiled and reported on the data from the questionnaire, but left me to analyse it and draw the conclusions I have.

- Professor Alex Murdock of London South Bank University, for his infectious enthusiasm throughout the MVA course and for his help as my dissertation supervisor. Also to Alibeth Somers for her inspirational teaching.

And a final debt of gratitude is owed to Marcia, my wife, lover and best friend, who has had to put up with my sometimes enforced solitude and obsessive behaviour over the past three years, on top of the frequent ranting and raving as one computer glitch succeeded another.

1. Introduction: History and Definitions

The plight of haemophiliacs has been described as "the worst treatment disaster in the history of the National Health Service"[2]. Of some 6,000 known haemophiliacs in the UK in the early 1980s, one quarter was to become HIV positive and Hepatitis C ('HCV') positive through transfusion of contaminated blood products, administered by the NHS as part of the treatment for haemophilia; and more than three quarters were to become HCV positive although not infected with HIV. Of 1,236 known haemophiliacs with co-infection of HIV and HCV, there remain 358 survivors who receive support from the Macfarlane Trust ('MFT')[3]. The youngest was 3 months old when infected and is now aged 23. In addition, some partners of haemophiliacs were also infected and some 39 of them survive.[4]

In 1973, an expert group convened by the Department of Health recommended that the NHS should become self-sufficient in the production of Factor VIII, the clotting factor essential for the treatment of haemophiliacs[5]. In December 1974, funds were earmarked (and announced in Parliament on 22 January 1975) by Dr David Owen (now Lord Owen), the then Minister of State for Health, to make the UK self sufficient in such blood supplies[6], but were subsequently reallocated by civil servants in the Department of Health, without the Minister's knowledge[7].

Prior to this, the World Health Organisation had warned the UK not to import blood from areas with a high prevalence of hepatitis, such as the USA[8]. Despite this warning and because of long delays in achieving self-sufficiency, blood products, contaminated with HIV and Hepatitis C, continued to be imported and administered

---

[2] *Hansard*, Lords,26 May 2005,col. 567 per Lord Morris of Manchester. The title of Chapter 16 of the biography of Lord Morris entitled 'Alf Morris – People's Parliamentarian' by Derek Kinrade (2007) is 'THE WORST *EVER* TREATMENT DISASTER IN THE HISTORY OF THE NHS' (author's italics) but the original quotation is attributed to Lord Winston by Lord Morris in conversation with the author and also by others.

[3] This is the latest figure supplied by MFT at the time of going to print in April 2008.

[4] This is the latest figure supplied by MFT at the time of going to print in April 2008.

[5] Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991 Dept. of Health p.13.

[6] Ibid.

[7] Lord Owen's evidence to the Archer Inquiry – see http://www.archercbbp.com/hearing.php

[8] http:// www.taintedblood.info/timeline.php at p.7 quoting an article entitled WHO Warning in the Sunday Times Scotland (20 August 2000).

by the NHS to the haemophiliac population of the UK and to others. This continued, even after warnings of HIV and hepatitis infection amongst transfused haemophiliacs, partly because some Haemophilia Centre Directors considered that potentially contaminated blood was better than no blood for their patients[9].

However, it cannot be said with any certainty that the tragedy would never have happened, or would have been reduced in extent if the UK had been self sufficient in blood supplies[10]. What is now known is that Department of Health officials "knew in February 1976 that imported blood products were 'more costly' to the NHS and came with 'a higher hepatitis risk' – something that has been consistently denied"[11].

Haemophilia[12] is a rare blood condition in which an essential clotting factor is either partly or completely missing. It is a lifelong, inherited genetic condition, which affects females as carriers and males who inherit the condition. The main problem is internal bleeding into joints, muscles and soft tissues. People with severe haemophilia can experience spontaneous bleeding usually into the joints and, if left untreated, these bleeds cause acute pain and severe joint damage, leading to disability. Bleeding episodes have in the past caused difficulties with education and employment for the many who have been crippled by the effects of regular bleeding into joints, as well as with mobility problems. Nobody with haemophilia has contracted HIV or HCV from blood products since 1986[13].

HIV - 'human immunodeficiency virus' - attacks and infects cells in the body that are part of the immune system. In the United Kingdom, development of HIV into Acquired Immune Deficiency Syndrome ('AIDS') is no longer inevitable and doctors prefer to talk about 'late-stage' or 'advanced' HIV infection, rather than AIDS.

---

[9] Dr Mark Winter, Haemophilia Centre Director and Medical Trustee of MFT, in his evidence to the Archer Inquiry.

[10] Ibid.

[11] Article by Sarah Hull entitled 'Former minister raises fear of HIV blood cover-up' (11 July 2007) Guardian Unlimited at http://www.guardian.co.uk/uk/2007/jul/11/health.aids

[12] Haemophilia is spelt *Hemophilia* in other countries, particularly North America. The English spelling is used, except where reference is made to specific bodies, which use the alternative spelling.

[13] Haemophilia Society, 2005 [but there is one Primary Beneficiary of the Eileen Trust (not a haemophiliac) who appears to have contracted HIV in 1995 from a rogue batch of blood products].

HCV, more commonly known as Hepatitis C, is an infectious virus causing inflammation and/or cancer of the liver, which can lead to serious liver damage and death. It was first identified in 1989, but known about for many years before, and whilst there are vaccines to protect against Hepatitis A & B, there is none for HCV. There is still much to be learnt about HCV and its progression. Not everyone infected experiences symptoms, and symptoms can lay dormant for many years after infection before creating serious problems[14]. HCV is now thought to be the more likely cause of death in the future amongst co-infected haemophiliacs[15].

Co-infection refers to someone with more than one virus. Most people who were infected with HIV through contaminated blood products were already, unknowingly, infected with HCV, including all infected haemophiliacs. Some 4,800 people in the UK have been infected in this way with HCV[16] and the Government created The Skipton Fund in 2004 to provide the set sum of £20,000.00 for each such infected person, but only in respect of those who were still alive in August 2003. No such payment was made to relatives or dependents of anyone so infected, who had died prior to the establishment of the Fund, despite protests in both Houses of Parliament[17]. A further payment of £25,000.00 is payable to an infected person, who has received a liver transplant or is on a waiting list for one, or there is a diagnosis of liver cancer or cirrhosis.

The problem of co-infection of haemophiliacs with HIV and HCV by contaminated blood products is not unique to the United Kingdom. The source of the contaminated blood products was America, where it was usual for payment to be made to donors of blood, so that drug addicts and other persons at great risk of contracting HIV donated their blood frequently. Only after the introduction of virus inactivated concentrates in 1985 were blood products considered safe again.[18]

---

[14] Haemophilia Society Information Sheet (2006).

[15] Dr Mark Winter, Haemophilia Centre Director and Medical Trustee of the Macfarlane Trust, in his interview with the author on 16 January 2008.

[16] Haemophilia Society website www.haemophilia.org.uk.

[17] Lord Morris of Manchester in his telephone interview with the author on 11 January 2008.

[18] Dr Mark Winter, Haemophilia Centre Director and Medical Trustee of MFT, in his evidence to the Archer Inquiry.

Treatments - the daily drug treatment for each of HIV and HCV is considerable and each has significant, adverse side effects. The combination of such drug treatments has even more severe side effects, leaving many infected haemophiliacs unable to work. Severe haemophiliacs also have to inject themselves with recombinant Factor VIII on demand or, if a young person, upto three times a week. Each of HIV, HCV and severe haemophilia, as a separate illness, would place a difficult burden on any individual, whether in the context of ability to work or in a social, financial, emotional or psychological context. A combination of all three can have disastrous consequences both for the individual and their family.

Many of the survivors are known to suffer poor health, both physical and psychological, are unemployed and live in poverty.[19] When the infection of haemophiliacs first became known in the mid 1980s, their life expectancy was limited to a few years. That many are still alive today is due to the advances in HIV treatment, but the drug regime is such that there are serious side effects and it is now known that HCV infection is aggravated by the co-infection and such drugs[20].

"I have worked with HIV since 1983. I have known many of the patients with HIV personally and have worked with them closely. I know their problems well, and after all this time, even though their physical health may have improved, even though their treatment may have improved, even though the drugs are better, the most obvious thing you want to say about these people is that they are worn out. It is the only phrase you can use. Their spirits are worn out, their relationships are worn out, their resources are worn out, their finances are worn out, so although their physical health may be better, at the Macfarlane Trust we very much hope the Government will respond to this Inquiry by recognising the continuing needs of people with haemophilia and HIV and hepatitis, and will continue and indeed increase the amount of support that is given to them. These people have had the most unimaginable suffering over the past 20 to 25 years, and they have major problems in their lives"[21].

---

[19] The MFT Long Term Review, which is not a published document, but was commissioned by MFT in 2002 and completed in 2003 by an independent consultant, Hilary Barnard.

[20] Dr Mark Winter, Haemophilia Centre Director and Medical Trustee of MFT, in his interview with the author on 16 January 2008.

[21] Extracted from the transcribed evidence given to the Archer Inquiry by Dr Mark Winter, Haemophilia Centre Director and Medical Trustee of MFT. See Archer Inquiry website www.archercbbp.com/hearing.php

The Macfarlane Trust ('MFT') was set up as a charity in March 1988, at the behest of the Government, to administer to infected haemophiliacs an initial fund of £10m. provided by the Government (equivalent to £8,090.00 per person infected). Lobbying by the Haemophilia Society, dissatisfied with such a response, prompted the Government to increase its ex-gratia payment, the following year, to £20,000 per person directly infected by contaminated blood, although infected partners were excluded[22].

A subsequent capital fund was provided by the Government in 1991 amounting to almost £45m. (with distributions, set by the Department of Health, ranging from £21,500 to £60,500 depending on age, marital status and number of dependents) but was only administrable to those infected haemophiliacs who were willing to sign a waiver of their legal rights against the Department of Health[23]. No legal advice was offered nor was there any recommendation to seek legal advice before signing. Whilst those infected knew, at this time, that they were HIV positive, none had been made aware that they were also HCV positive, yet the Government's waiver document referred to claims for hepatitis infection. The Government clearly knew something that it was not prepared to share with those haemophilia sufferers that had been infected, or their medical practitioners.

The Government, through the Department of Health, provided further sporadic grants to MFT in the 1990s, with annual grants commencing in the fiscal year 2001-2. The current level of funding is circa £3.75m., from which administrative costs of circa £300,000 have to be taken. This is not much changed from the previous 3 years when it was fixed at £3m. per annum but there was, in addition, a section 64 grant to cover administration costs. Such funds are not considered sufficient by the trustees of MFT to provide an appropriate level of 'relief' to the infected survivors and their dependents within the Trust's objects.

The stated objects of MFT are "to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United

---

[22] This and the subsequent 1991 capital payment were administered by MFT, on behalf of the Government, but were established as separate non-discretionary trusts and did not form part of MFT's charitable funds.

[23] Macfarlane Trust, 2006.

Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and who are in need of assistance or the needy spouses parents children and other dependents of such persons and the needy spouses parents children and other dependents of such persons who have died".[24]

In 2006, MFT submitted a detailed Business Case to the Department of Health for substantially increased annual funding (from £3m to £7.5m) and for additional capital grants to its Primary Beneficiary[25] community, as there have been no additional capital payments since 1991. The Business Case was based on a Long Term Review, commissioned by MFT in 2002 and completed in October 2003 by an independent consultant, Hilary Barnard ('the MFT Long Term Review'). The Business Case fell on deaf ears, principally it seems, because of Treasury constraints[26]. MFT has no other source of funding and, unusually for a charity, has no fundraising function.

MFT has not materially changed its strategy towards its Primary Beneficiary community over the past 18 years. Currently, it provides fixed monthly sums and twice yearly small capital payments to all Primary Beneficiaries and administers a grant scheme for specific requests for additional support. It also provides some limited financial support for widows and children of Primary Beneficiaries.

Primary Beneficiaries, formerly called 'Registrants', are the current survivors of those haemophiliacs directly infected with HIV/Hep C by contaminated blood *and* those infected with HIV by such infected haemophiliacs, through sexual intercourse.[27]

The graph, which follows, indicates their current ages and, consequently, 'graphically' illustrates the age they were when first infected over 20 years ago.

---

[24] Extracted from the Consolidated Trust Deed of MFT (last amended 4 November 2006).

[25] See definition of Primary Beneficiaries below.

[26] At a meeting with officials of the Strategy and Legislation Branch of the Department of Health on 10 December 2007 the Chairman and Chief Executive of MFT were advised that another reason for the 'rejection' of the Business Case was the absence of any discussion of 'empowerment' of MFT's community of care.

[27] See Page 1 for details of total numbers involved.

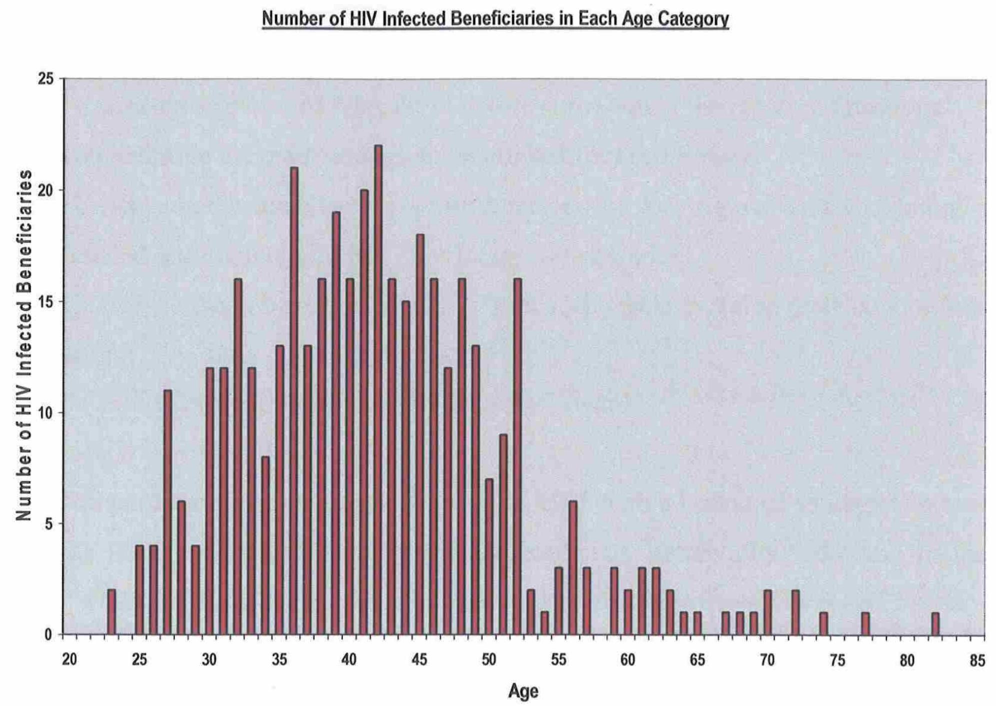

Figure 1 – Number of Primary Beneficiaries by Age[28]

The average age is 42.

---

[28] Data supplied by MFT as at February 2008

2. The Aims and Objectives of this Dissertation

Introduction

The principal aims and objectives are:

1. To identify the issues appertaining to the dissertation topic
2. To pose the questions to be researched in order to address such issues
3. To conduct a review of relevant literature surrounding the research questions
4. To determine the methodology to be utilised for such review
5. To better understand the issues by interviewing key figures and instigating a detailed questionnaire of MFT's Primary Beneficiaries
6. To analyse the information resulting from such research and to draw conclusions from it
7. To seek to provide strategies and the way forward.

The purpose of the enquiry is to provide MFT with a basket of strategies to best meet the needs and wants of its Primary Beneficiary community, now and in the future, which, in turn, should address such issues for widows/widowers of Primary Beneficiaries and for their dependents. This encompasses a potential re-allocation of present Government funding and the problem of tackling the Government over its past, present and future handling of the issue. The author is in no doubt that such tasks are far from easy. Primary Beneficiaries have become used to receiving financial support from MFT over the past 18 years, irrespective of their financial need, and the community is poorly placed, by reason of poverty and ill-health, to seek justice. There are also severe constraints at present on Government funding. All are relevant factors.

MFT is, in effect, an instrument of the Government, albeit an independent charitable organization, exercising discretionary powers and subject to the laws governing charities. Its sole source of funds is from the Government. When established, it was in no-one's contemplation that MFT would still be in existence, some 20 years later, with an onerous task still to discharge. All of its Primary Beneficiaries were expected to be dead. Whilst some of its trustees are still nominated by the Department of Health, they are not in a majority and act independently, as they must do under charity law. There have been some recent trustee appointments, of which the author is one, and a new chairman, appointed last year, who has substantial city and legal experience, but no previous association with MFT.

It is to be hoped that this dissertation will shed light on some of the real issues affecting MFT's unique constituency and might, through the new Board, make a significant improvement to the lives of those surviving haemophiliacs, infected with HIV/HCV, and their families, who are most in need.

Issues

The issues can be summarised as:

- The current needs and wants of the MFT community.
- The sufficiency of present Government funding to meet those needs and wants.
- Whether those needs and wants have changed over time and, if so, what has caused the changes.
- The present medical prognosis.
- What are the likely future needs and wants of the MFT community and is there a timeframe?
- Should MFT be planning for any such future needs?
- How have other Governments dealt with the funding/compensation issue?
- Has the Government acted appropriately in terms of provision for those affected by the tragedy?
- Have all legal avenues been explored or is it too late by reason of the Statute of Limitations and the waivers that were signed?
- What more can MFT do to perform its charitable objects?
- And most importantly, if MFT were to adopt a 'blue sky' approach, would it dispense its available funds in the same way as it does now?

The issue of 'need' cannot be ignored. 'Need' is regarded under English charitable law as meaning 'financial need'[29]. The current practice of MFT is to distribute monthly and twice yearly payments to all Primary Beneficiaries (as well as monthly payments to widows and children), irrespective of financial need. It also has

---

[29] Trustee Information Pack prepared by solicitors, Berwin Leighton Paisner , November 2006 at para. 2.2

a grant application system, which is not dependent on financial need but whether certain criteria are met. This may be in breach of the Trust's charitable function.

Furthermore, and as already stated, MFT has not materially changed its strategy towards its Primary Beneficiary community over the past 18 years. There seems to be no medium or long term strategy, either to increase resources or to meet the future needs of MFT's community of care, other than to look to the Government of the day. There is an Annual Plan, with various objectives, which are briefly reported on quarterly at the regular Board Meetings of the Trustees and revised annually, but it seems to be regarded more as a necessity of good governance than an effective management tool.

In 1998, and again in 2003, MFT commissioned independent consultants to survey its Primary Beneficiaries (but not its entire community of care) culminating in the Final Report of the MFT Long Term Review published in October 2004. This dissertation will explore to what extent the recommendations of the MFT Long Term Review have been implemented, and to what effect. It will look at a number of related issues to see if a different perspective can be conceived of. This might enable MFT's Board of Trustees to confront the strategic challenges it faces, brought about by insufficient government funding and the unexpected, prolonged life span and the deteriorating health and financial resources of many co-infected haemophiliacs.

The Research Question

This research project poses the question:

To what extent has demographic change and lack of government funding created strategic challenges for MFT?

Since this process started, there have been two significant events: the Archer Inquiry and developments in the UK litigation.

The Archer Inquiry

In March 2007, Lord Morris of Manchester, the former Minister for the Disabled, succeeded in establishing an independent Public Inquiry[30] into the contaminated blood issue, chaired by Lord Archer of Sandwell, a Labour peer and former Solicitor General. Many in this country and in Scotland have been demanding for years that the Government establish a full Public Inquiry[31], because of allegations of cover-up and maladministration by both Government and the NHS.

It has so far had 9 days of hearings and has taken evidence from many including MFT, the UK and Irish Haemophilia Associations, the scientific community, campaign groups and individuals from MFT's community of care, as well as from Lord Owen, a former Health Minister and Foreign Secretary, and Dr. Mark Winter, a Haemophilia Centre Director and MFT's Medical Trustee. Significantly, the Government has chosen not to participate in the Inquiry, which was meant to have reported by now, but there have been unexpected delays.

UK Litigation

The action, for some 300 claimants, has only recently been started in this country and is based in negligence against the American drug companies that supplied the blood products. Please refer to Section 5 sub-section VII of this dissertation (page 60).

---

[30] An independent Public Inquiry is an inquiry held in public but which is privately funded and usually chaired by a distinguished lawyer.

[31] A Public Inquiry is a legal investigation, funded by the Government, where witnesses are called and evidence is produced in a similar fashion to a court of law. Inquiries may be held into a matter of public concern, when they are usually headed by a senior judge or as part of legal procedure.

3. Literature Review

Introduction

Essentially, this dissertation needs to address:

- the strategic issues facing MFT arising from the demographic change in its community of care and the perceived lack of adequate Government funding.
- sufficient background to the medical issues facing MFT's community to understand need and the financial, economic, social and psychological consequences that may result.
- The potential consequences of Lord Archer's Report, once published, in respect of the ongoing, independent Public Inquiry and of the ongoing UK litigation.
- the position of other governments, in their dealings with identical communities in their midst, if only to be able to apply 'moral' pressure to the UK Government for additional help, if it can be established that other governments have been more generous. Such 'moral' pressure could also be applied if it can be established that other classes of victims have been paid substantially more compensation, such as those suffering from the drug, Thalidomide, the effects of Gulf War Syndrome, or those potentially at risk from variant CJD.
- the legal issues touched upon, which are an important factor, if only to ascertain the chances, if any, of pursuing legal redress for MFT's community and thereby securing additional compensation for it to offset, or do away with, the present funding arrangements.

Little has been published in respect of the specific case being addressed in relation to MFT. It has, therefore, been necessary to look for parallel and analogous cases to see if they can produce procedural, methodological and contemporary material, but unfortunately little relevant material has been found. Much, of course, has been published in medical journals on the medical issues involved, both with the instant case and with like cases, but little in relation to changing demography or the financial, social, welfare and personal implications of being a co-infected haemophiliac.

This dissertation will not be a treatise on haemophilia, HIV or HCV, nor an in-depth study of the history of the contaminated blood scandal or of the legal issues. Some background research of such matters, in part by way of literature review, is necessary to provide the knowledge to be able to ask appropriate questions of prospective interviewees.

Strategic change

To authors of tomes on strategic management, there appears to be no simple, clear-cut definition of 'strategy', although The New Oxford English Dictionary's, '*a plan of action or policy designed to achieve a major or overall aim*', seems simple enough. Its meaning is perhaps of less significance than the fact that it is an ongoing and forward-looking process and managing it is a process of change. According to Johnson *et al* (2006)[32], strategic management is the development of "a capability to take an overview, to conceive of the whole rather than just the parts of the situation facing an organisation". This includes understanding that organisation's strategic position, as well as its potential, and making that strategy happen. But for Bryson (2004), it only becomes such a process "to the extent that it is used to link planning and implementation and to manage an organisation in a strategic way on an ongoing basis".[33]

Mintzberg *et al* (1998) comment that strategic management "has commonly been portrayed as revolving around the discrete phases of formulation, implementation and control"[34]. However, they seek to depart from "this traditional view" and to inform on 10 schools of strategic management[35], although they are unsure "whether these schools describe different processes or different parts of the same process". However, they believe that "every strategy process has to combine various aspects of the different schools"[36], which formulate strategy utilising a process which is either:

---

[32] Johnson *et al* (2006) in *Exploring Corporate Strategy* at page 27.

[33] Bryson (2004) in *Strategic Planning for Public and Non Profit Organizations* at page 31.

[34] Mintzberg *et al* (1998) in *Strategy Safari: the complete guide through the wilds of strategic management* at page 19.

[35] The names of the 10 schools are in brackets and in italics in the list that follows.

[36] Ibid p. 367

- conceptual *(Design)*
- formal *(Planning)*
- analytical *(Positioning)*
- visionary *(Entrepreneurial)*
- mental *(Cognitive)*
- emergent *(Learning)*
- negotiated *(Power)*
- collective *(Cultural)*
- reactive *(Environmental)*
- transformative *(Configuration).*[37]

Many authors refer to the competitive advantage that effective strategic management can bring, but MFT is not strictly in competition with other charities, save for its annual grant from the coffers of the Department of Health. One of the challenges is to look at situations in different ways or from different angles. An example would be creating scenarios which, according to Mintzberg *et al* (1998), are "predicated on the assumption that if you cannot predict *the* future, then by speculating upon a variety of them, you might open up your mind and even, perhaps, hit upon the right one"[38]. Other challenges include the need to understand and address contemporary issues which test an organisation and the need to prevent strategic drift, where strategies fail to address an organisation's strategic position[39].

The theory and concept of managing change has been widely written about and "the sheer size and range of the academic and management literature on change can be daunting, particularly as few models have been rigorously evaluated".[40] Robson (2002) (referencing Bhaskar, 1986) asserts that "if false understandings, and actions based on them, can be identified, this provides an impetus for change"[41]. Whilst there has been no conscious intention to pre-judge the results of the research, there has been, as a result of this insight, an awareness that this might prove to be the case.

---

[37] The words in italics and brackets are the names given to the various schools by Mintzberg *et al.*

[38] Mintzberg *et al* (1998) in *Strategy Safari: the complete guide through the wilds of strategic management* at page 58.

[39] Johnson *et al* (2006), in *Exploring Corporate Strategy* at page 27.

[40] Ibid.

[41] Robson, C. (2002) *Real World Research* at p.41.

For example, treating all Primary Beneficiaries the same, irrespective of financial need, appears to be contrary to Charity Law[42]. If the results of the research make the Board of MFT consider that a change in strategy is necessary, then it has to be emphasised that "change is a process, not an event"[43] . It is, however, equally important "that the process fits the purpose".[44]

However, it is not the purpose of this dissertation to consider how change might be implemented but whether change is necessary and what that change might be. Furthermore, it is doubtful, although not impossible, that the results of the research will find that cultural or organisational change in MFT is necessary. It seems more likely that a strategic change in the use and direction of resources will result. This, too, would require careful and tactful management.

Demographic change

Demographic change, in the context of this dissertation, refers to the changes that have occurred in the relatively small, but clearly defined, population of surviving haemophiliacs co-infected with HIV/HCV, brought about by their unexpected, prolonged life span and their deteriorating health and financial resources. The only known source of directly relevant material is that commissioned by MFT in 1998 and 2003. The first led to a Strategic Review Final Report in January 1999, which was based on the findings of a survey of MFT Primary Beneficiaries undertaken in 1998[45], and the second culminated in the Long Term Review published in 2003, based on a questionnaire compiled by independent consultant, Hilary Barnard. No other literature on the subject has been found[46].

---

[42] General advice given at the MFT Trustee Development Day on 4 November 2006 by solicitors, Berwin Leighton Paisner ('BLP'). See also Charity Commission Guidance CC4 and Trustee Information Pack prepared by BLP (November 2006) at para. 2.2 .

[43] Robson, C. (2002) *Real World Research* at p.219 citing Fullan, M. (1982) The Meaning of Educational Change.

[44] Audit Commision Report '*Change Here!: Managing Change to Improve Local Services*' (2001).

[45] Survey designed and report written by independent consultant Lesley B. Oppenheim.

[46] The 1999 Final Report refers to two previous reviews, the first carried out in 1995, by Public Attitude Surveys on behalf of the MFT, aimed at discovering how effective the Trust was seen to be by Primary Beneficiaries and whether their needs could be more effectively met by the Trust and the second, by CAF Consultants on behalf of the Department of Health, which looked at administrative and financial aspects of MFT's work. Neither report could be traced at MFT.

HIV/HCV Co-infection

Whereas, as one would expect, there is considerable literature on the subject of HIV, AIDS and haemophilia, there is very little on the co-infection of HIV and HCV in haemophiliacs, other than in the field of medical research. What exists is limited to briefing notes from specialist organisations dealing with the issue, such as MFT, Terence Higgins Trust and the Haemophilia Society.

The research will concentrate on 'the needs and wants' of MFT's Primary Beneficiaries for the purpose of considering the strategic challenges facing MFT, and the literary review has confirmed that there is little primary information on the impact of co-infection in haemophiliacs upon their needs, other than that contained in the MFT Long Term Review and prior Strategic Review. Some articles have been listed in the bibliography [see, for example, Winter M. (2000)] and have been reviewed for this purpose.

Need

Significantly, the Oxford English Dictionary defines *need* as both 'circumstances requiring some course of action' and 'destitution or poverty'. '*Needs*' are defined by the Oxford English Dictionary as being 'of necessity'. Robson (2002) considers that whilst what is meant by 'needs' is apparent at a common-sense level, 'needs' represent the difference between an "observed state of affairs and a desirable or acceptable state of affairs"[47]. From a charity law perspective, however, *need* refers to financial need[48], which has particular relevance to MFT's community, as the current practice is to distribute monthly and twice yearly payments to all Primary Beneficiaries, irrespective of financial need. Furthermore, the single grant system in place does not have regard to financial need[49]. There has to be 'some form of objective assessment', even though 'financial need is not an absolute term and trustees [do] have a discretion as to how to assess whether a person is in need'[50].

---

[47] Robson, C. (2002) *Real World Research* at p.213.
[48] Trustee Information Pack prepared by Berwin Leighton Paisner , November 2006 at para. 2.2.
[49] MFT assumes there is such need if an application is made.
[50] Trustee Information Pack prepared by Berwin Leighton Paisner , November 2006 at para 2.2.

The Charity Commission has issued guidance (CC4[51]) suggesting that "trustees must make every effort to ensure that the benefits given to individuals are no more than those actually required to relieve their need", and " to give people benefits which do more than this would not be fulfilling the purposes of the charity and would be an improper use of charity funds". A recent decision, in July 2007, by MFT's Board of Trustees to make a distinction between those households earning above £30,000 p.a. (excluding MFT payments and earnings of any children) and those below, so that the latter now receive £57.00 per month more, may not be a sufficiently objective assessment and, therefore, may be a breach of MFT's charitable function.

Bradshaw (1972)[52] suggests dividing *needs* into four categories: "needs which individuals feel; needs which individuals express; needs which professionals identify (normative needs); and needs revealed by the difference across populations (comparative needs)." From this it is clear that *needs* may be defined from several quite different perspectives, all of which may conflict.

Stigma and Employment

It is a sine qua non to state that HIV infection has long been associated with prejudice and stigma, made all the worse for individuals within MFT's community because of their innocence in contracting it. This not only leads to secrecy about their condition (some even from their own families) but, for many, to social isolation and inability to get work[53]. Carlisle (2001) asserts that "fear of discovery can be high and even although *(sic)* HIV status is concealed, the very act of concealment can lead to a restricted social interaction and be a barrier to the development of intimate relationships"[54]. In many cases, the need for a carer/spouse/partner to maintain the secret of the infected person causes similar problems for that person.

---

[51] CC4 is a guidance pamphlet issued by the Charity Commissioners for England & Wales entitled 'Charities for the Relief of Financial Hardship'.

[52] Bradshaw, J., (1972), The concept of social need: it is not always clear what is meant by social need. A crucial problem facing the social services is how to identify it. *New Society*, **19**, pp.640-643.

[53] Terence Higgins Trust.

[54] Carlisle, C. (2001) *HIV and Aids in Stigma and Social Exclusion in Healthcare* at p.121.

A majority of MFT's community are unemployed and/or on Income Support[55]. Many of these describe themselves as unemployable and even though a substantial proportion would wish to be in work, for financial, social and psychological reasons, they do not have the confidence, the qualifications or the energy to seek and retain employment. Often they do not feel well enough for a sufficient period of time to do so, due to their daily intake of toxic drugs.

It is probable that one of the problems the research will identify is the apparatus of welfare benefit support and how this acts as a disincentive to seek work. This dissertation cannot examine the Benefits System in depth, but will endeavour, through a review of relevant literature and other enquiry, to clarify particular issues. There has been much discussion in academic circles on this topic, and recent tomes such as *Understanding Social Security: Issues for Policy and Practice*, published by Policy Press, *Understanding Poverty* written by Alcock, and Bateman's *Practicing Welfare Rights (Social Work Skills)* are all helpful guides.

Empowerment

This issue has been included following a meeting between the Chairman and Chief Executive of MFT with Department of Health officials on 10 December 2007, at which it was revealed that a principle reason expressed by the Minister for ignoring the Business Case submitted by MFT in 2006 for substantially increased funding, was the absence of any proposal to provide 'empowerment' to its community of care.

Empowerment involves the "principle of people moving towards improving their control over their circumstances"[56] and the development of confidence in a person's or group's capacity. This encourages and builds upon skills for self-sufficiency, with a view to eliminating the need for welfare benefits/charity and, in the context of MFT's community of care, it includes 'increasing ....positive image and overcoming stigma'[57]. There are, as a literature review indicates, innumerable books on the subject, including self-help books, but many within MFT's community of care

---

[55] Macfarlane Trust, 2007.
[56] Adams R. (1990) *Self-Help, Social Work and Empowerment* at p. 18.
[57] Wikipedia.

remain traumatised and sick and, consequently, ill-prepared to help themselves. If self-help is an unlikely stratagem, a question to be asked is whether MFT can do anything in terms of empowerment for its community of care, which is so diverse, as well as dispersed throughout the UK.

Families - and the making and breaking of them

It is one thing to know, as a parent, that you have genetically passed haemophilia to your child and entirely another to learn that that child has contracted HIV/HCV through contaminated blood products, transfused to remedy internal bleeding. The youngest recorded was only 3 months old. A decade ago, 44% of reported AIDS cases in teenagers related to haemophiliacs[58], which is a significant statistic. Some 60 women, partners of co-infected haemophilic men, have been infected with HIV through sexual contact, of whom some 39 survive[59]. Many parents/partners have been obliged to give up paid employment to care for the infected haemophiliac[60]. Carlisle (2001) acknowledges that "any disease or illness affecting one member of a family can exert an effect on other members of that family and cause changes in support systems, role expectations and interpersonal relationships"[61] That families and marriages suffer is an inevitable consequence and the break-up of families and marriages causes further distress.

There are numerous couples who wish to start families, but because of the risk of HIV infection have not been able to, until the relatively recent introduction of a sperm-washing procedure, which allows conception with minimal risk[62]. Here, cost is an issue and the procedure (or IVF) is not always available on the NHS, depending on the region in which the family lives. Requests have been made by Primary Beneficiaries for financial assistance, and where such procedures are not available under the NHS, contributions have been made.

---

[58] Forsberg A. et al., (1996). Maintaining Safer Sex Behaviours in HIV- Infected Adolescents with Haemophilia in *AIDS Care*, **8** (6) at page 629.

[59] Macfarlane Trust (April 2008).

[60] The MFT Long Term Review 2003.

[61] Carlisle, C. (2001) *HIV and Aids in Stigma and Social Exclusion in Healthcare* at page 123.

[62] Wilde J. et al, (1999) in Increased bleeding Associated with Protease Inhibitor Therapy in HIV Positive Patients with Bleeding Disorders. *British Journal of Haematology,* **107** pp. 556-559.

There is limited medical literature on the subject as it affects co-infected haemophiliacs (e.g. in *Haemophilia* and the *British Medical Journal)* but this dissertation will seek to ascertain, by enquiry of MFT's community and by interviewing those with knowledge of the issues of stigma, employment and families affected by HIV/HVC co-infection, in what way MFT could be of assistance, within its charitable objects, on such matters and, hopefully, to reach a conclusion whether such assistance would be justified as being a beneficial use of the limited funds available to it.

4. Research Methodology

Introduction

This dissertation topic is very much of the real world and the enquiry has been conducted in real-life settings. 'Real world research', according to Robson (2002), requires a "scientific attitude", which he defines as research carried out "systematically, sceptically and ethically"[63]. It attempts to answer questions, in the face of competing factors, from a range of sources that are part of a complex problem. In essence, it seeks to raise awareness of 'real' issues. At this stage, there are no hypotheses. Kumar (1996) does not consider them essential for a study, which this dissertation will essentially be, and "a perfectly valid study can be conducted without constructing a single hypothesis"[64]. The closest this enquiry gets to hypothesizing is in raising the issue of whether MFT would disburse its available funds in the same way as it does now, if it were to adopt a 'blue sky' approach.

An ontological approach has emerged because the proposed dissertation is concerned with what is believed to exist and can be investigated, and involves real life issues in a real world environment. Of the four main ontological approaches adopted by social scientists, *realism* is considered the most appropriate to utilise in relation to MFT's community and, more particularly, the variant which Robson (2002) refers to as *'critical realism'*[65], adopting the term used by Bhaskar (1989) in his book *'Reclaiming Reality'.*

Wikipedia defines *critical realism* as a "philosophy of perception, which posits that while some of our sense-data can and does accurately represent external objects, properties and events, other sense-data may not be accurate representations. In short, critical realism refers to any position that maintains that there exists an objectively knowable, mind-independent reality, whilst acknowledging the roles of perception and cognition". The same source defines a derivative, *naïve realism,* as "a common sense theory of perception, which it is claimed is representative of most people's understanding and method of interpretation of their perceptions".[66]

---

[63] Robson.C., (2002) *Real World Research* at p.18.

[64] Kumar R., (1999), *Research Methodology: A step-by-step guide for beginner.* at p.70.

[65] Robson.C., (2002) *Real World Research* at p.41.

[66] Wikipedia.

This dissertation is focused on finding and understanding the critical factors affecting MFT's community of care and to address the strategic challenges MFT faces as a result of demographic change in its constituency and lack of funding.

Robson (2002) advocates a pragmatic approach using "whatever philosophical and methodological approach works best for a particular research problem at issue". This, he asserts, "leads to mixed-method studies where both quantitative and qualitative approaches are adopted"(citing by way of example Brewer and Hunter (1989))[67].

Research Review

In part, the research is a study of the needs and wants of MFT's community, to try and encapsulate what it means to live with haemophilia *and* HIV/HVC and to make sense of their seemingly, blighted lives and the relative, closed world in which they live. It is, however, a wider enquiry as the research question posed indicates.

The following broad questions form the basis of the enquiry and have been incorporated, so far as relevant, in a questionnaire and in interviews.

- What are the current needs and wants of MFT's Primary Beneficiary community?
- What do they anticipate their future needs and wants to be?
- What is their financial position now?
- What is their employment situation now?
- What made them sign away their right to compensation from the NHS without legal advice?
- What was not known in 1991 that is known now?
- What did the Government know then that the Primary Beneficiary community was unaware of?
- What are the political issues?
- What are the economic issues?
- What is the environment in which most Primary Beneficiaries live?
- What are the social issues?

---

[67] Robson.C., (2002) *Real World Research* at p.43.

- What is the present medical prognosis?
- What have other Governments done with the same issue?
- Are there any legal avenues still to be explored i.e. human rights, class action?
- Can or should MFT fund/loan the Primary Beneficiary community monies to pursue any such legal avenues?
- Is there a course or courses of action that MFT can take to lobby the Government to be more generous than heretofore?

Consequently, the research to be undertaken is made up of the following components:

- The construction and implementation of, and the analysis of data from, the questionnaire, which comprise several distinct phases.
- The composition of proposed interviews, their conduct and the contextualized use of information provided by those interviewed, which also comprise several distinct phases .
- A comparison of the results of previous surveys with those conducted for this research.
- An analysis of the implementation of the recommendations of the last strategic review, undertaken in 2003, and contained in the MFT Long Term Review[68].
- An enquiry as to how some other Governments have dealt with the same issue.
- An enquiry of other charitable organizations caring for similarly affected cohorts.

The Questionnaire

It is important to have a theoretical framework for such a study “seeking to move beyond description to explanation” and to ensure that any questions in questionnaires are brief, explicit and unambiguous and “designed to help achieve the goals of the research and.........to answer the research question.”[69]

Only with an increased understanding, resulting from such enquiries, are new strategies likely to emerge, leading to possible change. There has been no detailed survey of MFT’s community since 2003 and such survey and previous surveys have

---

[68] See page 10 supra.

[69] Robson (2002) *Real World Research* p.240-1.

not covered most of the questions listed above and, as for the first six questions, up-to-date information is necessary. As the community is now only 400 strong (excluding dependents), it was considered feasible and beneficial to survey it in its entirety with a questionnaire that was reviewed ('piloted') with the assistance of members of MFT's Partnership Group, who are a small but active part of the Primary Beneficiary community. Such help was necessary in view of the sensitivities and ethics involved, as well as to ensure that no relevant question was omitted and that the questions were framed to elicit the best possible responses.

The self-completing, unmarked questionnaire was sent out by MFT in late October 2007 to 405 Primary Beneficiaries, representing the then entire surviving cohort of United Kingdom, HIV infected haemophiliacs[70]. This, and a pre-paid reply envelope, ensured anonymity and the questionnaire did not attempt to seek any information which would enable personal identity to be ascertained. No incentive was provided to complete and return the survey other than the opportunity to be involved in matters directly affecting them. 216 completed questionnaires, representing a 53% return, were delivered to IDA Independent Data Analysis Limited for data capture. Verbatim answers to 'open' questions were read and coded into groups for analysis in the tabulations. IDA used a specialist survey software package (MERLIN) on an anonymous basis and in accordance with the code of conduct of the Market Research Society, to produce aggregated tabulated results against a specification provided to them by the author.

Risk

Risks that were anticipated were:

- MFT's Primary Beneficiary community being sceptical of a detailed questionnaire in that they might perceive it as a precursor to change, which might be against their individual interest, as they have become used to and dependent upon their monthly payments. However, the 53% response rate clearly demonstrated that this was not the case and was perceived as a serious

---

[70] 405 includes 39 partners of Primary Beneficiaries who became infected with HIV by sexual intercourse.

attempt to understand their needs and wants, and to react to them within the limitations of the finances available.

- The Board of Trustees being unwilling to implement change and/or further challenge the government for additional resources that the research may highlight as necessary, for fear of upsetting either its community of care and/or the Government. It is, of course, the case that some of them have 'owned' the present strategy of distributing funds. To hedge against this possibility, the validity of the research has to be unquestionable, which in turn depends on the quality of the questionnaire and the interviews, as well as the scrupulous analysis and methodological checks of all data.

Methodology

As the major feature of the research is an investigation by questionnaire of MFT's Primary Beneficiary community, initial research was largely aimed at the construction of the questionnaire and the controls needed for its implementation and analysis.

The methodology for the research was:

- Reviewing research into parallel and analogous case histories
- Research into construction, implementation and analysis of questionnaires
- First stage analysis of the economic, medical and social situation ('needs') to be addressed by MFT, by reviewing previous survey results
- Construction of the questionnaire
- Implementation of the questionnaire
- Analysis of the questionnaire
- Review of first stage findings in the light of the results of the questionnaire and comparing them to the results of previous surveys
- Determination of the need for strategic change, its shape and strategies for implementation.

The questionnaire was designed as a series of closed and open questions, to provide up-to-date and accurate information on the nature and range of Primary Beneficiaries' needs.

It is divided into 4 sections:

- General data
- Changes
- The Present
- The Future

Research Objectives

The research objectives, as far as the questionnaire is concerned, are as follows:

- To get information as to the current status of Primary Beneficiaries, to include their physical and mental condition, their financial position and their thoughts, particularly as to the future.
- To identify what changes (if any) have taken place in the last 4-5 years that have impacted on health, employment/self-employment, learning skills/education, financial position, lifestyle, needs and aspirations, not only of Primary Beneficiaries but also of their partners.
- To identify the possible causes of any such change.
- To identify the ailments currently suffered by Primary Beneficiaries.
- To identify the extent of stigma/discrimination and whether there has been any change in the last 4-5 years
- To deduce the current needs and wants of the Primary Beneficiaries.
- To identify the likely future needs and wants of Primary Beneficiaries.
- To assess the effects and effectiveness of current funding and single grants employed by MFT and to identify what more MFT can do to perform its charitable objects?

Whilst questions raised in the questionnaire are different from the last major survey of MFT Primary Beneficiaries, undertaken by an independent consultant in 2003, as is the emphasis, an attempt will be made to compare the results where appropriate. It must also be said that the questionnaire goes further than the stated research objectives. This is because there are limited opportunities for gathering extensive information on Primary Beneficiaries, and the process is expensive. There was no compunction from MFT to extend the questionnaire, but it will provide MFT with upto-date data on non-strategic matters. Such data will not form part of this dissertation, although it is included in the Appendices[71].

Design

The questionnaire is of fixed design and essentially quantitative, but not exclusively so. It has both an evaluative and an action research basis. Its purpose is, *inter alia*:

- to assess the effects and effectiveness of the current funding and single grants process by MFT (evaluative) and,
- by involving the MFT community in an assessment of their needs and wants, both present and future, to produce data, which might influence the MFT Board to change its policy process (action).

The findings have, therefore, been used to consider the efficacy of existing strategies and to develop, where necessary, new strategies.

Weighting and Skew

The data elicited from the questionnaire requires careful analysis and interpretation in order substantially to address and question the current assumptions made by MFT, which have determined its existing policies for meeting the needs of its community. An attempt has been made to synthesise some of the issues, resulting from analysis of the data. However, it is possible that some respondents might not have been truthful about financial matters, both as to income and capital, because they might fear withdrawal of their regular monthly payments, despite the questionnaire being anonymous. It is also possible that those really in need, financial or otherwise, might, proportionately, have been more likely to respond to the questionnaire than those who are getting on with their lives, thereby producing a bias in the responses to some of the questions. Consequently, in the analysis, reference is made to the percentage of those responding rather than predicating a percentage of the entire Primary Beneficiary community.

---

[71] See Volume 2, the Appendices at Tab F.13.

Objectivity

The potential for being 'self-evaluating', with regard to the fixed research aspects, is something that the author has constantly borne in mind, in particular when drafting the questionnaire. The responses to the questionnaire, whilst being necessarily subjective, require objective analysis. As Robson (2002) emphasises, the need is "to introduce rigour into all aspects of enquiry so that we achieve a justified credibility and trustworthiness in what we find and write up". But he also asserts that "the 'real world enquirer' needs to have knowledge, skills and expertise in areas outside the likely competence of most laboratory-orientated researchers".[72]

Methods, such as standardization, are usually employed by quantitative researchers to achieve objectivity, which, according to Robson (2002) (citing and abridging Sarantakos (1998)), are regarded as "one of the most important properties of social research". However, he also cautions that "standardization and distance from the research object do not guarantee objectivity because the perceptions and meanings of the researcher penetrate the research process in many ways"[73].

Ethical considerations

It is appropriate to raise the issue of whether a detailed and investigative questionnaire is appropriate to address to a cohort, most of whom have suffered hugely and continue to suffer physically, mentally, emotionally, socially and financially. It is a very sensitive topic, involving as it does the infections of HIV and Hepatitis C and the stigma attached, particularly to HIV.

This particular community has been the subject of many medical studies, not all voluntarily, because it is virtually finite in number and its history is well documented. Whilst an additional survey might well have caused anxiety and stress to some and, because of its detailed nature, have been regarded by some as an invasion of their privacy, it was this author's considered opinion that the number so affected was likely to be very low. This has been borne out by the response to the questionnaire (53% of MFT's Primary Beneficiaries responding) with not one letter or email to MFT complaining about the questionnaire.

---

[72] Robson (2002) in *Real World Research* at p.7.
[73] Ibid at p.23.

This was probably because the questionnaire was very clearly stated to be anonymous and its potential was seen as a serious attempt to understand and anticipate the needs of MFT's Primary Beneficiary community, as well as exploring, through this dissertation, the means of meeting those needs. It was vetted by members of MFT's Partnership Group before finalization and it had the full support of MFT's Board of Trustees, who were supplied with pre-publication copies. Furthermore, the respective Chairmen of the Board of Trustees and of the Partnership Group co-signed a letter, which accompanied the questionnaire, supporting it and urging Primary Beneficiaries to respond to it.[74]

The proposed dissertation topic was also approved by the Ethics Committee of London South Bank University.

Although it is hoped that the results of the research involved in this dissertation will benefit MFT's community of care and assist the Board of Trustees, it was clear to this author that, as MFT is a charity, the entire cost of printing the questionnaire (including accompanying and follow-up letters) and the cost of postage (including pre-paid reply envelopes) should be his total responsibility. This fact was referred to in the letter to MFT Primary Beneficiaries accompanying the questionnaire[75] and re-affirmed in the joint letter from the Chairmen referred to above and both letters stressed the anonymity issue.

The questionnaire also asked for permission to quote from any comments made by a respondent, notwithstanding that they would be anonymous in any event[76]. Only a handful declined to give such consent.

Robson (2002) refers to codes issued by various professional bodies with which it is necessary to conform[77]. The author is not aware of any particular code which would be relevant in this context.

---

[74] See Letter in Volume 2, The Appendices at Tab F10.

[75] See Letter in Volume 2, The Appendices at Tab F11.

[76] See final page of the Questionnaire in Volume 2, the Appendices at Tab F9.

[77] Robson (2002) in *Real World Research* at p.65.

The Overall Research Design

Although the questionnaire is of fixed design, the overall research design is mixed. As the research review suggests, the proposed topic demands a considerable amount of information concerning the political, social, medical and legal arenas.

The Interviews

Inevitably, most of the face-to-face interviews needed to be structured with an underlying theme and their nature has been outlined above:

- the interviews were intended to be qualitative in nature.
- each prospective interviewee was given, at least a week before the interview, a list of questions indicating the nature of issues expected to be discussed.

This enabled interviewees to give some consideration to such matters in advance and, hopefully, made the interviews more worthwhile and rewarding. This did not stop a new avenue being explored during the interview, if circumstances so dictated[78].

However, it is essential to be aware, in analysing the interviews, which were recorded and subsequently transcribed, that giving such advance warning could possibly have led some interviewees to lay particular stress on specific issues in order to exercise undue influence on the enquiry. This is a further reason for adopting a naïve realism, ontological approach.

Face to face interviews were conducted with the following individuals, divided into the following categories:

Historical/Environmental/Economic/Social

The Reverend Prebandry Alan Tanner, a former Chairman of MFT (1988-2000), Chairman of the World Federation of Hemophilia (1971-1996) and Chairman of the Haemophilia Society (1975-1997) and Peter Stevens, the immediate past Chairman of MFT (he retired in 2007), have both had haemophilic sons, who died as a result of HIV/HCV co-infection. Together, they have chaired MFT since its inception in 1988 until last year (2007), and have been instrumental in conceiving and implementing its

---

[78] The transcribed interviews are to be found in Volume 2, the Appendices at Tabs C1 to C6. The 'set' questions are in normal type, additional questions/comments are in italics and the responses are in bold type.

strategy for administering the funds provided by government. There is a need to understand from them the reasoning behind MFT's strategies and what caused change, if any, over the years, and whether they believe circumstances have since altered to warrant consideration of a different strategy or strategies.

GRO-A is Chairman of the MFT Partnership Group, which is an 'action' group of infected haemophiliacs, of which he is one, which seeks to influence MFT. He is an intelligent and eloquent young man and being of a younger generation was likely to express forthright views on the present strategy of MFT and, hopefully, to indicate his ideas and reasons for a new one, given that he probably has a long-term, vested interest.

Medical

Dr Mark Winter is the MFT Medical Trustee and foremost expert in the field of Haemophilia and HIV/HCV co-infection in the UK. It is important to understand the present physiological and mental condition of many of the surviving, infected haemophiliacs and their current prognosis. This is essential for comprehending, from a medical standpoint, the probable timeframes involved and the likely physical and support needs of this community.

Professor Uri Martinowitz, head of Israel's Haemophilia Institute, is acknowledged as one of the foremost medical experts in the world on haemophiliacs infected with HIV/HCV by contaminated blood products and was instrumental in getting a law passed in Israel in 1992, providing compensation for those afflicted in that country.

Political

Lord Morris is President of the Haemophilia Society and long time parliamentary campaigner on behalf of the Haemophilia Society and MFT. He has a comprehensive knowledge of the history of infected haemophiliacs, has raised many questions in both Houses of Parliament on the subject of compensation for them and is familiar with the Business Case that was recently put to and ignored by the Government for a doubling of current funding. He is also the architect of the Archer Inquiry, an independent Public Inquiry chaired by Lord Archer of Sandwell, a former eminent Solicitor General, set up in 2007 and expected to report sometime in 2008. It will be useful to understand from him the current political climate and whether he considers that pursuing the Government of the day through parliament has any real prospects of success.

Political/Legal

Baroness Kennedy of the Shaws, formerly Helena Kennedy QC, the well-known human rights lawyer and parliamentarian, is known to be highly critical of the present Government, on whose benches she sits. She is well placed to comment on the potential uses of the Freedom of Information Act regarding allegations that there has been a 'cover-up' by the Department of Health relating to the issue of contaminated blood. She is also able to comment on the human rights aspects of the condition imposed by the Department of Health, which required all recipients of its subsequent capital fund in 1991 to sign waivers of rights before receiving 'compensation'. Given that such recipients were under an effective death sentence, there is a question as to whether such waivers would be enforceable or should be set aside on the grounds that they were given under duress.

Government

An interview was sought with Rt. Hon. Dawn Primarolo, Minister of State for Public Health Protection, in order to seek the Government's perspective on the issues and to provide a degree of balance. As with the other interviews, a set of questions was prepared together with a covering letter to the Minister[79], which gave the Minister the opportunity of responding in writing if she did not want to be interviewed, and she availed herself of this offer[80].

Whilst it had been intended to conduct a face-to-face interview with Lord Morris of Manchester, it ultimately had to be conducted by telephone and, therefore, was not recorded but notes were taken. Furthermore, the 'interview' with Professor Uri Martinowitz was less structured than the other interviews and took place on two

---

[79] See Volume 2, the Appendices at Tab D7.
[80] See Volume 2, the Appendices at Tab D8.

occasions, neither of which was recorded because of the particular circumstances in which they were conducted, and he did not have prior notice of the questions. However, notes were taken and questions (that were in writing), which he felt unable to answer were referred to colleagues of his, whose written responses were then précised and added to the interview notes[81].

The other research components

The methodology behind the other components of the study follows the same naïve realism, ontological approach.

- A comparison of the results of previous surveys with those conducted for this research necessitates ensuring, as far as practicable, the comparison of like with like. As very few of the questions were the same, this exercise is limited to an extrapolation of the results.
- The recommendations made in the MFT Long Term Review (2003) were extracted and information sought from MFT as to which have been implemented, and whether in full or in part, and the success or otherwise of such recommendations that were implemented has been examined.
- The enquiry as to how some other Governments have dealt with the same issue, involved reviewing numerous web-sites, making written requests for information to the Haemophilia Associations of various countries and conducting an interview with Professor Uri Martinowitz, head of Israel's Haemophilia Institute and the former Chair of Israel's Haemophilia Association, who is acknowledged as one of the foremost medical experts in the world on haemophiliacs infected with HIV/HCV in the late 1970s and early 1980s by contaminated blood products and who was instrumental in getting a law passed in Israel in 1992, providing compensation for those afflicted in that country.
- The enquiry of other charitable organizations caring for similarly affected cohorts was done by telephone interview with their Chief Executives/Directors.

---

[81] See Volume 2, the Appendices at Tab E.

It is to be hoped that the research methodology undertaken for the proposed dissertation will provide a better understanding of the very real issues confronting MFT's Board of Trustees in determining the necessity or otherwise for new strategies.

5. Report and Analysis

Introduction

This section is divided into the following sub-sections:

I	The Questionnaire.
II	A brief comparison of results with the previous questionnaire in 2003
III	A report on the recommendations made in The Long Term Review (2003).
IV	The interviews.
V	What some other countries have done.
VI	What some other UK charities have done.
VII	The current legal position.
VIII	The welfare benefits system.
IX	The Business Case – 'Funding long-term survival'.
X	What might have been done differently.

I The Questionnaire

This dissertation is enquiring into changes in the population MFT serves and its needs and wants. The response rate of 53% to the questionnaire is supposed to provide 95% confidence limits of around +/- 4.5% points against all Primary Beneficiaries[82]. The level of return can reasonably be taken as representative of all Primary Beneficiaries, and a corresponding percentage for those directly infected by contaminated blood and by partners and the broad spread of ages, confirms the representative character.

The questionnaire also sought data on a much wider enquiry, to benefit MFT, and all data has been analysed in tabular form and cross-profiled by:

- Gender
- Age group
- Marital status
- Employment
- Housing
- Income
- Current health

---

[82] Information supplied by IDA Independent Data Analysis Limited.

The questionnaire and all the data can be found in Volume 2, The Appendices at Tabs F9 and F13 respectively[83]. There follows a summary of the main findings of the enquiry, as it is not the purpose of this dissertation to report in too much detail. Included, in quotation marks and italics, both in the text and in footnotes, are comments made by respondents to open questions in the questionnaire.

Of general interest is the following in respect of those who responded[84]:

- 90% are male, 61% are under 45, 59% are single, 26% are married or have partners and 12% are divorced, separated or widowed.
- 42% said they could not work or were unemployable and a further 13% were not working.
- 33% are in full-time employment or are self-employed: a further 10% part-time.
- Of their partners (where there is a partner), 20% were either not working or could not work, a further 17% were acting as carers (88% full-time), 37% are in full-time employment or are self-employed and a further 21% work part-time.
- 78% are in owner-occupied accommodation, although this figure may include some single men living in their parents' home, and only 13% are in Council or Housing Association property.
- 44% have children, but of those who do not, 58% say this is out of choice and 75% of those refer to their HIV infection as the reason.
- 30% would consider assisted conception particularly those under 35, when the percentage rises to 60%.
- 67% of those diagnosed with Hepatitis C still have it. 68% of those who have had treatment for it are now clear.
- Only 18% have used the Terence Higgins Trust for support of whom 74% found the experience 'good' (21%) or 'very good' (53%).
- 34% regard MFT as controlled by the Government.
- A third of those who went to University did not graduate

---

[83] The verbatim comments to the Questionnaire by question are in Volume 2, the Appendices at Tab F12

[84] Percentages can give a wrong impression. It is essential to look at the precise wording used to see what the percentage relates to. In this section, for example, reference is made to the Terence Higgins Trust. The percentage of 74%, which appears high, relates only to 18% of those respondents who answered the question, i.e. 13%, which equates to only 28 people.

The response to the questionnaire revealed considerable, 'noticeable' changes over the past 4-5 years. About three-quarters say that their health, financial position, lifestyle and needs have all changed in the time, whilst nearly two thirds report a change in their employment and just over half feel their aspirations have changed. Similar but not so large changes are noted for partners where applicable.

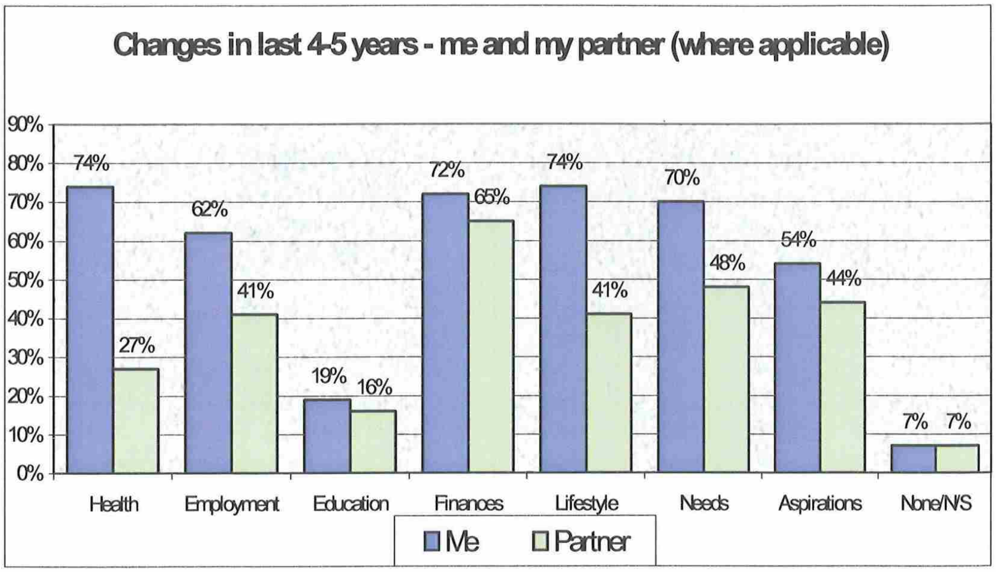

Figure 2. Changes in the last 4-5 years

Those who have noted a change in their health (74%) have mostly suffered a deterioration (four-fifths of them - but one fifth has improved), whereas, surprisingly, over 90% of partners in whom a change has been noticed (by 27% of respondents) have deteriorated. This should be seen in the context of the following chart in response to an enquiry about current state of health [Q.2.2].

Although it has been mooted that those who are getting on with their lives may have been less inclined to respond to the questionnaire and those who are very sick might not have been able to complete it, 61% of those who did indicate that they can do normal activity, even if it entails effort and some symptoms. Only 13% require considerable or special assistance, are severely disabled or very sick.

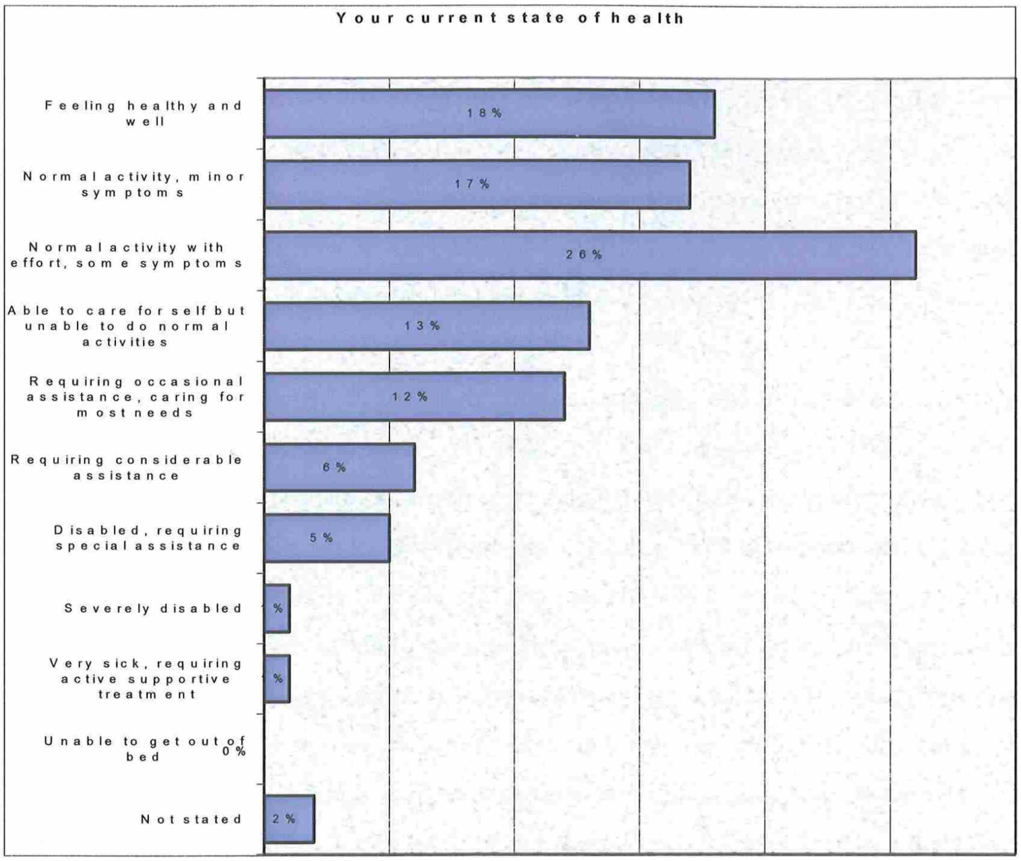

Figure 3. Current state of health.

As for employment status, of those currently in paid employment, almost half are confident they will be able to work consistently for the foreseeable future, but this is balanced by an almost equal percentage who are not so confident. When it comes to change, 11% indicate that they are no longer working full-time, a further 19% are not currently working and 22% anticipate long term unemployment. Many say that they have retired for medical reasons (24%), but it is not thought that all such retirements are in the last 4-5 years. Some are in better paid (18%) and some in more fulfilling employment (14%) than 4-5 years ago, but this is balanced by those in worse paid (17%) and those in less fulfilling work (9%).

Among those respondents who say that they are feeling healthy and well or are able to perform normal activity with only minor symptoms, the situation is more positive with 42% now in better paid jobs, although this declines with age, and 32%

have more fulfilling jobs. Those that fit into the above categories, with the added category of being 'able to perform normal activity with effort and some symptoms', represent 61% of respondents. What is of concern, however, is that of those in these categories who are under 45, 21% have apparently retired for medical reasons in the last 4-5 years and a further 17% anticipate long-term unemployment (the apportioned percentages for those under 35 are 16% and 11%). 25% of respondents say that their health and/or drug regime has caused them to give up or change work in the past 4-5 years.

72% of respondents felt that their financial position had changed and most are worse off with 46% being at least 25% worse off. This response needs to be seen in the context of the question concerning net annual income after deduction of tax, [Q.3.5], which included taxed income of any partner as well as regular income from MFT and welfare benefits (which are not taxable). 79% have an income under £30,000 and 56% under £20,000. A surprising figure, which may not be an accurate reflection, is the 16% who say their annual net income is under £10,000, given that MFT provided regular monthly payments, in the year before the questionnaire, of circa £4,400 p.a. for a single person receiving Disability Living Allowance (since increased), and welfare benefits or pensions should take income over this level. An even more surprising figure is the 19% that had an income over £30,000, of which 6% had over £30,000, 4% over £40,000, 5% over £50,000 and 4% over £75,000. If reflected across all Primary Beneficiaries, more than 75 Primary Beneficiaries could have net incomes in excess of £30,000 and 50 more than £40,000. But the stark reality is that 315 could have annual incomes of less than £30,000 and 223 below £20,000[85].

When asked if they could manage without financial support from MFT [Q.3.15], 77% of respondents said they could not, 13% did not know and 10% said that they could. These percentages are not far removed from the 79% whose annual income is less than £30,000 and the 9% receiving over £50,000 (see above). However, of those with incomes over £50,000, as few as 72% say that they could manage (100% would

---

[85] MFT's own figures, as at February 2008, taken from the Report of the Support Services Manager to the Board of Trustees for its Board Meeting on 21 April 2008, indicate approximately 68 Primary Beneficiaries with a household income in excess of £30,000 and 329 Primary Beneficiaries with a household income of less than £30,000. This 'verifies' the findings of the survey undertaken for this dissertation.

be the expected 'honest' response) but this reduces to only 4% of those with incomes under £50,000.

Of the 70% of respondents who felt their needs had changed, the following chart shows that 72% are concerned about finances and 50% about home comforts and keeping warm. The need for a carer or some home help is a requisite for about 40% and roughly the same percentage also need family and emotional support, advice on health, diet and benefits, whilst some 30% have transport needs.

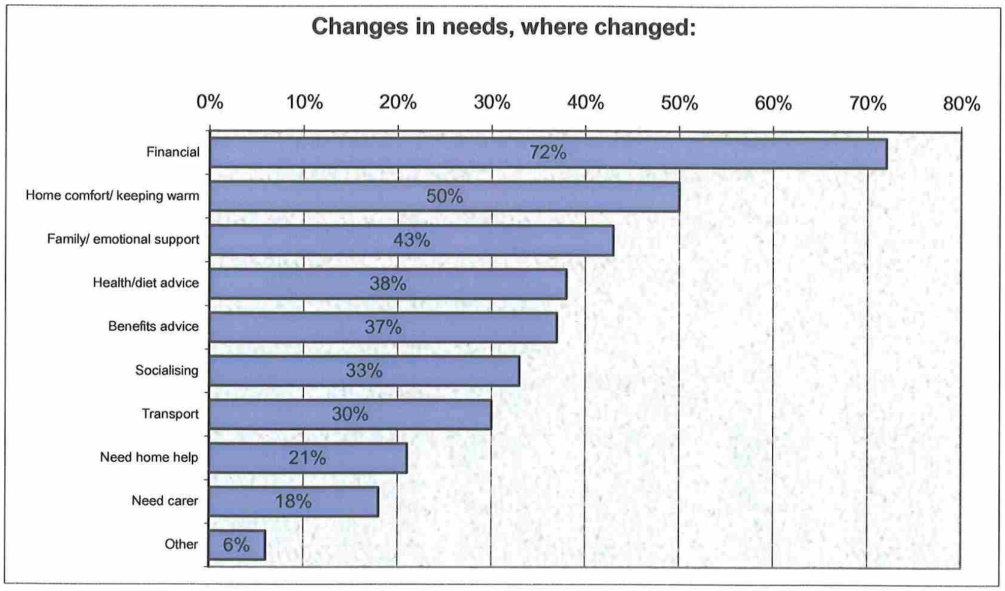

Figure 4. Changes in Needs – where changed.

When subsequently asked what they saw as their future needs that were not current needs [Q.4.3], financial assistance remained clearly the most important (54%) followed, as before, by home comforts and keeping warm (36%).

74% of respondents considered their lifestyle had changed, with as many as two thirds of these getting out less and being less mobile, whilst a third felt less intellectually stimulated. 4% are home-bound. As for aspirations, only 54% considered these had changed, with respondents, possibly reflective of their response to their changing lifestyles, mainly concerned about being more active, getting out more and being independent. Only a quarter of those responding were interested in learning a skill, a fifth in starting a business and less than a sixth in getting a job.

When asked what, if anything, affects their attitude to work, 5% did not answer and 18% said 'nothing or not applicable'. Of the remainder, most (88%) said health was the key factor, whilst 56% cited a lack of energy, 43% the stigma of HIV and 40% mentioned confidence.

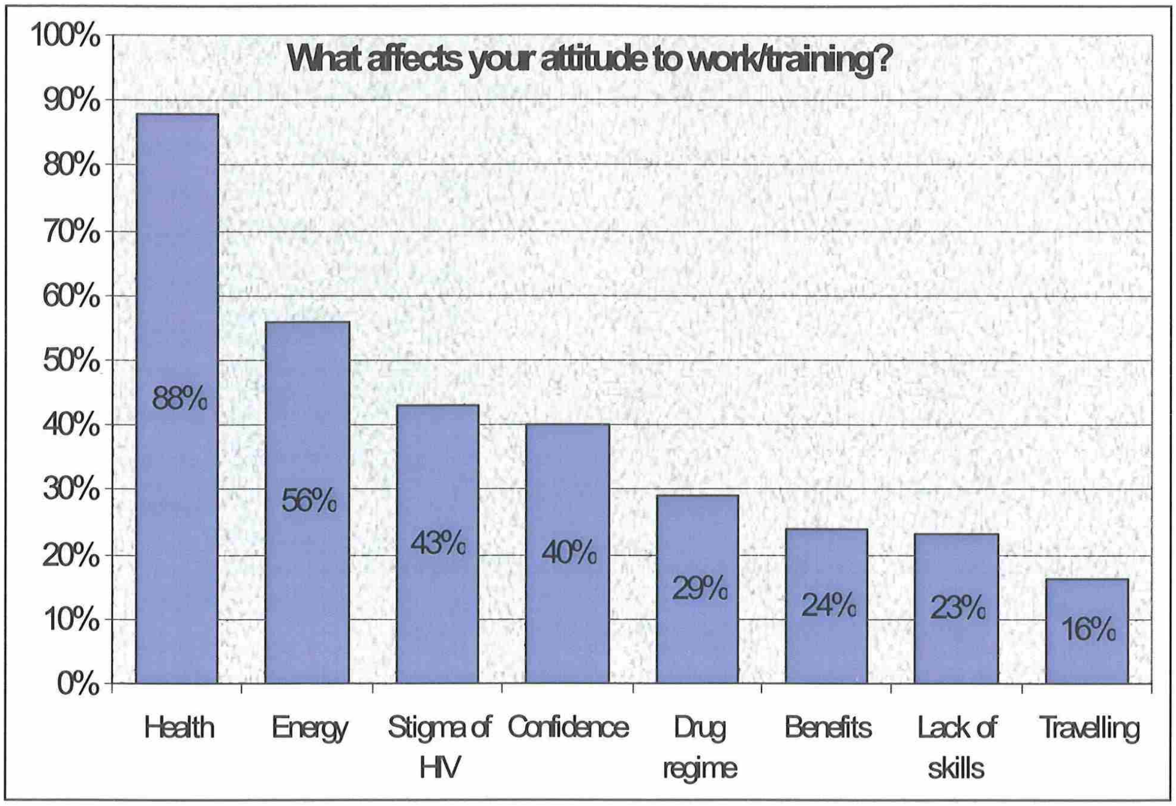

Figure 5. What affects your attitude to work/training?

Asked to indicate up to three of their predominant feelings 4-5 years ago and now, 'angry' and 'depressed' were, and still are, the most common responses, although both have fallen significantly over time. The graph that follows emphasizes that negative feelings far outweigh positive ones and that none of the positive feelings have improved significantly. This may, in part, be attributable to the finding that a clear majority of respondents (57%) consider that their debts are higher than 4-5 years ago, with more than a quarter considering their debts to be higher by 50% or more.

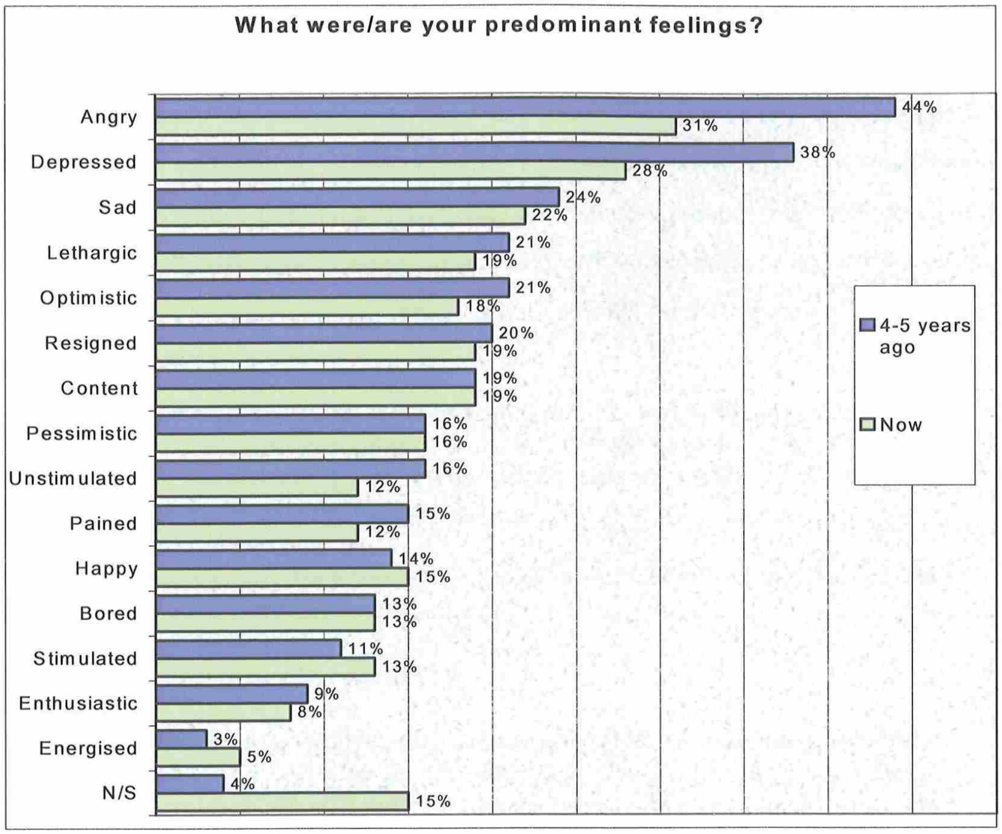

Figure 6. What were/are your predominant feelings?

One third of respondents believe that they are making more applications to MFT for single grants than 4-5 years ago but 56% are not, which could mean that they are not making any applications. This reflects MFT's records, which indicate that less than 20% of those entitled actually make applications (and of these, there is believed to be a hard-core of around 10%). Respondents expressed themselves vociferously as to their thoughts on the grants system, such as:

"Some of us have pride and don't like asking as it feels like begging and others it seems don't mind asking and seem to get what they want."

"Single grants system favours those that are good letter writers, are happy to ask, and have a good relationship with their doctor/nurse & the MFT. I have always maintained it would be better to just give us more money to be independent."[86]

---

[86] For further comments see page 44 (footnote 88).

Those who are less healthy seem to suffer slightly more discrimination, but only 18% say that they have experienced discrimination in the past 4-5 years and only 12% are currently experiencing it. 'Only' is a relative word and any discrimination, for the person suffering it, is unacceptable. The fact that, overall, 5% say that such discrimination comes from close family and 6% from neighbours indicates the effect of stigma and the element of isolation that is clearly suffered by a not insubstantial number of MFT's community of care. Many expressed their feelings on the subject, such as:

"I do not inform anyone of my status because I do not want to become a victim of discrimination. I have never told my children, now adults, not because of the stigma; I would not put the distress & hurt it would cause onto my children's shoulders - rightly or wrongly I have never told them".

"Even my two sons don't know about my illness & status, and we have not told our neighbours in case of having to move away".

"Kept at arms length by close family".

"Son and daughter-in- law particularly; they both felt they should have been told years go, which is true. My wife felt it might affect her as a teacher should the facts leak from the children. My son and his wife don't speak or communicate and I don't see my 18 month old granddaughter"[87].

---

[87] For further comments see following page (footnote 88).

[88]

---

[88]

Footnote 86
A further selection of verbatim comments, extracted from the responses to the Questionnaire, follows:
For all responses on this topic, see Volume 2, the Appendices at Tab F12 Question number 2.13

"I tend not to apply for grants because I think there are other registrants in a worse position to me who are in greater need of the limited resources of the trust."
Continuation of previous page footnote 87:
"My parents help me with most of my needs. Applying to MFT seems degrading and stressful".
"MFT is an under-funded hardship fund and the grants system a game which some play and others don't. It is demeaning and makes me angry because my needs are not met."
"We should not have to apply to the social fund in the first instance for e.g. white goods. Social Fund applications are degrading and demoralising."

Footnote 87
A further selection of verbatim comments, extracted from the responses to the Questionnaire, follows:.
For all responses on this topic, see Volume 2, the Appendices at Tab F12 Question numbers 1.9.1, 1.9.2, 2.10.1 and 2.10.2

"We started trusting our friends with the truth. Told the children, as our neighbour's found out, and thought they would tell the children first.".
"Over recent years I have disclosed it to my two best friends."
"Yes - I have told a lot of people over last 5 years. The living stories project gave me confidence & the Archer Inquiry gave me a reason to tell others."
"I recently told my partner of my infection. This incident has caused tremendous distress."
"I don't work in jobs that need a medical or offer healthcare/pensions that reveal my status."
"Our is the best kept secret EVER and it is to keep it that way, particularly now because of our children.".
"It may be that I am paranoid but I always feel that my friends are uneasy if they come to my apartment i.e. using cups for drinks etc".
"I have never discussed this with our friends, not even closest."
"I lost some friends who I told."
"I experienced considerable discrimination at a previous job which nearly led to a nervous breakdown. Previous relationships have always ended due to HIV, Hep B and C; and some have had terrible repercussions i.e. being threatened of violence by previous girlfriends' families."
"The worst example was a nurse who put on mask, goggles, apron & thick gloves to bandage a cut finger."

Health and the financial security of respondents are the two most significant concerns for the future, followed by their family's future and maintaining a regular income. Many of these are related matters. 3% say they don't think about it.

"Having had a terminal diagnosis directly due to HCV/HIV infection, leading to liver cancer, my expectations for the future are not likely to be relevant."[89]

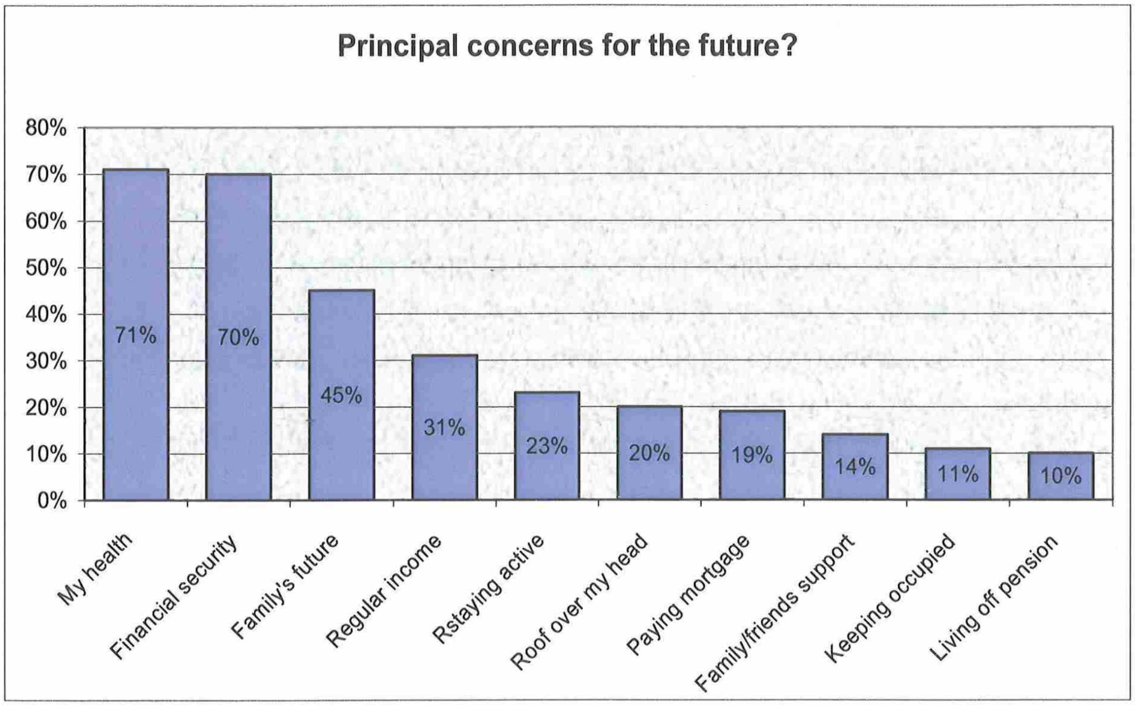

Figure 7. Principal concerns for the future.

---

[89] A further selection of verbatim comments extracted from the responses to the Questionnaire follows:
For all responses, see Volume 2, the Appendices at Tab F12 Question numbers 4.2 & 4.3.
"Continuing to try and accept what has happened to me and try and not wish for the life I should have had."
"Doing something useful, rather then wasting my time."
"Finding a partner."
"Finding a lasting relationship & starting a family."
"Children. Will we be able to have them?"

Such concerns are confirmed by the graph which follows, relating to a question in the present, seeking to ascertain factors affecting future planning [Q.3.3]. Health and finances again head the field, but stigma and drug regimes are also important factors. Both graphs should be looked at in the context of the following data:

- 25% of respondents have no savings and a further 17% have savings of less than £1,000, whereas 23% have savings in excess of £25,000 and 13% in excess of £50,000
- 45% of respondents have no mortgage and 20% have a mortgage of less than £50,000 but 12% have one in excess of £100,000
- 40% of those with a mortgage have no life insurance or mortgage protection insurance and only 13% have full cover
- the average outstanding mortgage is a third of the market value of the property
- 37% of respondents have another medical condition, which adversely affects their drug regime, lifestyle or their ability to obtain gainful employment.

Many respondents expressed their concerns about planning for the future, such as:

"Fear of the future - I've had it taken away on several occasions and the horrific events in my life have made me fear the future not seek it."

"Cannot recover from all the years of trauma and near death experiences - can believe I'm here, but don't really believe I will be here long either - Future is tomorrow."

"I am worried sick about both of my brothers who also have HIV. I am also worried about confidentiality. I live in a constant state of fear that I may accidentally infect my partner. These factors prevent me from being optimistic and planning a future." [90]

---

[90] A further selection of verbatim comments extracted from the responses to the Questionnaire follows: For all responses, see Volume 2, the Appendices at Tab F12 Question number 3.3.
"I have worked in IT in the public sector for 20 years. I could double my salary by moving to the private sector or contracting. However I feel constrained to stay due to: 1. Who would employ somebody with my issues? 2. Absences due to ill health would be frowned upon. 3. Harder to take extended absences to undertake treatment regimes. 4. The Civil Service provides a very good "death in service" benefit that will provide for my wife and son."
"I am managing to work full time currently, but this is getting harder and harder due to extreme fatigue. I do not envisage being able to work in the future."
"Isolated - unable to find either voluntary work or social activities."
"Mental attitude towards my status. I can't be positive about being HIV+".

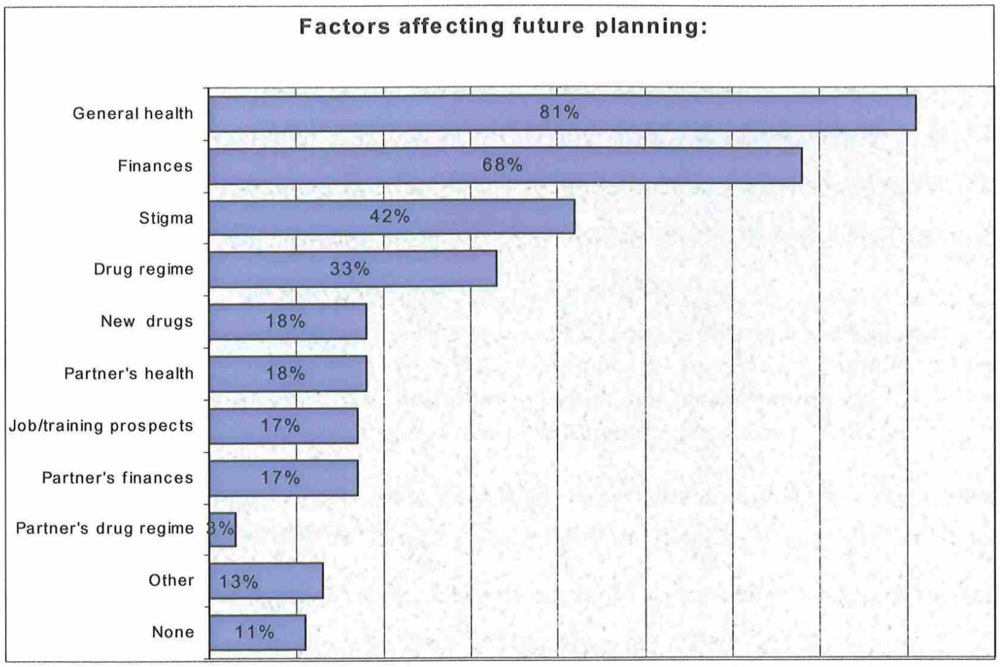

Figure 8. Factors affecting future planning.

When asked if they could manage without any financial support from MFT, one respondent replied that he could, *"but should not have to!"*. 77% of respondents said that they could not manage, with 13% indicating that they 'did not know'. Of those with a household income over £50,000 (8% of those responding), 72% indicated they could manage, but this reduced to only 4% with an income under £50,000.

Two questions enquired into additional forms of help that MFT might provide, one directed at the individual and the other to MFT's community of care [Q.3.16 & Q.3.17]. There was, unfortunately, a limited positive response[91].

---

[91] Examples of the more common responses are listed below and in the footnote overleaf: For the remainder see Volume 2, the Appendices at Tab F12 Question numbers 3.16 & 3.17
"Greater support for assisted conception. The role of the MFT should be restore people's lives to the potential that they had before infection, as far as that is possible."
"MFT will only pay for one IUI/ICF. Sadly, through personal experience, we can use many more attempts and it is very expensive finding it by yourself."
"Our only disappointment is the insufficient funding for the sperm washing".
"Support for training and loans and grants for small business."
"I also think more money should be made available for psychological help."
"Holiday insurance could be provided by MFT instead of trying to get private insurance".

As to the future, nearly half of all respondents have some confidence in the future, but 11% do not think about it. Younger respondents show significantly more confidence than do older ones. Financial assistance dominates their needs for the future and their aspirations are focused on staying healthy (or recovering their health), being independent, remaining active and in work. 10% of respondents are interested in learning a new skill, teaching or going to university and a further 10% to get into work. Some have expressed their aspirations, as follows:

> *"To achieve a place in life where I feel peaceful in my head, not bitterness and sadness. I have cried all the way through filling in this questionnaire and have reread it to be sure I've got my points across in as honest and succinct a way as I am able. I search for peace and for compensation for this horror."*
>
> *"To enjoy what time I have left without worrying about finances or how my partner will cope after I have died."* [92]

What is most apparent from the response to the questionnaire is the importance of MFT to Primary Beneficiaries, as is evident from the following:

> *"If it wasn't for the MFT I would have lost everything I own, I only have praise for everyone concerned that has helped me through everything."*
>
> *"The MFT has helped us in the past and we shall need them in the future. They give us reassurance and financial help when we need it most."*

An overall analysis of the results of the Questionnaire indicates that:

- there is likely to be a strong and continuing need for MFT's services for many years to come, given the age and projected longevity of Primary Beneficiaries
- MFT needs to plan and consider its services for the long term, having regard to the changing needs of its community of care

---

Footnote 91 continued
"I believe that the MFT should help by creating a very individual survey and assessment of every registrant and provide financial support for the needs of the person ……… This way everybody will get help for the things they need most…… "
"Make it possible for MFT registrants to be able to do work that is therapeutic in nature/ Part of our illness is being stuck inside with no outlook or stimulation, which can only be detrimental to our health.,Being able to do some sort of activity, even if only on a limited basis, would help alleviate the mental anguish that we suffer because of our infections."

[92] For a further selection of verbatim comments extracted from the responses to the Questionnaire, see Volume 2, the Appendices at Tab F12 Question number 4.4

- longevity and the 'price' of illness create greater demands on loved ones and impacts heavily upon their lives
- MFT should not be satisfied with the bare survival of many Primary Beneficiaries and must seek from Government funding at the level it can demonstrate is necessary to perform its charitable function adequately
- this should embrace adequate funding or NHS provision for assisted conception, including sperm washing, to avoid risk to partner and child
- most Primary Beneficiaries are dependent on the monthly payments received from MFT and would like them increased to enable them to make decisions as to how it is spent
- other assistance, such as financial advice, debt counseling, information on treatments and their side effects, are all useful functions of MFT.

II. A comparison of results with the previous questionnaire in 2003

Only a few comparisons are possible because the Questionnaire was different in both content and context:

- The previous questionnaire had a response rate of 45% compared to 53% for the Questionnaire.
- An almost identical question concerning current state of health surprisingly produced the same result, given that three quarters of respondents had indicated in the current survey that their health had changed in the last 4-5 years, and four-fifths of those had said it had deteriorated.
- The proportion of those that have cleared Hepatitis C with treatment has doubled since 2003.
- There has been a reduction (5% of those responding) in those working full-time but equally a reduction (also 5%) of those unemployed. However, there has been a 50% increase from 28 to 42% of those who say they cannot work.
- The proportion of MFT income to total household income in both surveys was very similar (but prior to recent increases taking effect).
- The average mortgage debt was also similar, with a slight reduction from £38,000 to £34,000.

III. A report on the recommendations made in The Long Term Review (2003)

The recommendations made in the Long Term Review, for MFT to implement, are précised below in Table 1.

To prepare an overall case for presentation to the Government for further resources.
To seek a more generous system of support for widows and dependents.
To define its priorities for the single grants system on an annual basis.
To provide both direct support and lobby the NHS for funding for assisted conception.
To commission a 'return to work' initiative.
To encourage more user participation.
To change the constituency of its trustee body.
To make changes to its staffing resources to undertake more home visits and occupational therapy services.
To adopt the PQASSO system of quality assurance.
To develop collaborative partnerships and networking.
To promote communications internally by developing its newsletter and externally its website.
To inculcate these recommendations in its planning documents to foster integrated planning.

Table 1 – Long Term Review Recommendations

It is interesting to compare these with the 1998 Strategic Review recommendations[93], which are précised below in Table 2, in so far as they relate to MFT, and which are stated to be in order of priority.

To provide cost effective and efficient administration.
To maintain the principle of regular payments in response to Principal Beneficiaries' changing needs.
To continue with single grants, particularly related to increasing health needs.
To respond to newly identified areas of need e.g. carers' respite, lifestyle choices and take-up of education and training opportunities.
To continue to provide effective benefits advice and support.
To continue to offer advice on mortgages, pensions, personal finances and debt counseling.
To set out clear grant giving policies.
To provide guidance and policies on fertility treatment.
To further develop an effective and responsive Helpline service.

Table 2 - 1998 Strategic Review Recommendations

---

[93] The Final Report was published in January 1999.

There are few similarities in the recommendations. Out of 9 recommendations in the 1998 Review, 4 suggest continuing existing policies and 1 suggests further development of an existing policy. There are only 2 that are similar with the 2003 Review, the first concerning single grants and the second fertility treatment. It is safe to say that all the 1998 recommendations have been 'implemented' and continue to this day, but none of them was particularly innovative or groundbreaking.

As for the 2003 Long Term Review, a Business Case was presented to the Government in 2006, some 2 years after the suggested date for submission. It sought substantially increased annual funding (from £3m to £7.5m) and additional capital grants for its Primary Beneficiary community, as there has been no additional capital payments since 1991. It was ignored by the Government principally it seems, because of Treasury constraints[94].

MFT has succeeded:

- in defining its priorities for the single grants system.
- in providing some direct financial support for assisted conception
- partially, in encouraging more user participation, by organising weekends away for Primary Beneficiaries and 'Women only' weekends, but the take-up benefits only a very small proportion of the community of care. The MFT Partnership Group is currently an unelected body, but should it become democratically accountable, MFT has indicated that it will engage more with it.
- in changing the constituency of its trustee body by increasing the number of trustees from 10 to 12, reducing the number appointed by the Haemophilia Society from 6 to 4, leaving the Department of Health with 4 appointees and creating the right to appoint 4 of its own trustees.
- in making changes to its staffing resources by no longer employing or seeking to employ a social worker and part-time benefits officer. An attempt was made to establish 5 part-time regional support workers, but considerable opposition

---

[94] At a meeting with officials of the Strategy and Legislation Branch of the Department of Health on 10 December 2007 the Chairman and Chief Executive of MFT were advised that another reason for the 'rejection' of the Business Case was the absence of any discussion of 'empowerment' of MFT's community of care.

was encountered from the community of care, which resulted in this work being outsourced to the Terence Higgins Trust and to the appointment of an independent welfare benefits adviser. Financial advice is also outsourced.

- in improving communication with its community of care by publishing policy guidelines and by developing its newsletter and website.
- and is currently reviewing its support for widows and dependents.

However, it has not effectively carried out any of the other recommendations, which were to lobby the NHS for support for assisted conception, to commission a 'return to work' initiative, to adopt a system of quality assurance, to develop collaborative partnerships and networking, and to implement integrated planning.

IV. The interviews

All formal interviews were recorded and transcribed[95], with the exception of those of Lord Morris of Manchester and Professor Uri Martinowitz, where notes were taken and subsequently edited[96]. Information gleaned from other research data, such as the results of the questionnaire and literature review, was introduced informally into the interviews for comment and clarification. The resulting interviews provide useful background information and comment on issues relevant to this dissertation and, where appropriate, have been integrated within this dissertation. They have influenced some of the conclusions reached and recommendations made, and make interesting reading in their own right.

Some key observations are, as follows:

- Peter Stevens opines that "successive Governments have been entirely pragmatic. They've dealt with the issue at the time in a way that was, by the standards of the time, probably acceptable in political terms and they haven't really had to do anything since."
- Rev. Prebandry Alan Tanner considers that "the Government has only ever moved, with regard to Haemophilia and these particular situations, after intense

---

[95] See Volume 2, the Appendices at Tabs C1 to C4 and C6.
[96] See Volume 2, the Appendices at Tab C5 and Tab E.

campaigning and …… it would call for another intense campaign by the Haemophilia Society, coupled with the Macfarlane Trust."

- Dr. Mark Winter points out the medical profession knows nothing "about potential long term side effects of HIV therapy" and that there is "quite significant clinical concern about the evolving Hepatitis C epidemic in haemophilia patients…". He is hopeful that "the Archer Inquiry will generate some pretty powerful, albeit short term, media activity".
- [redacted] believes that "people have become much more aware of their liver problems than they need to be of their HIV viral status" and asserts that "this infection, beyond taking our lives and our health, has taken away many of our rights and that has impacted on the rights of our families …..".
- Dr.Winter and [redacted] have reservations about MFT's single grant system.
- Baroness Kennedy believes that what is needed is "a campaign of public informing", which "would have an upsurge of people feeling that proper compensation should be given here".

V. What some other countries have done

It has to be conceded that some countries have done little or nothing for their haemophiliacs infected with HIV and/or HVC by contaminated blood, the most prominent being the United States, the probable source of the infection in the first place. However, the following counties have done something material.

Canada[97]

The first payments made were by the federal government through the Extraordinary Assistance Program set-up in 1989 and were ex-gratia. There were four lump sum payments, each of C$30,000 (£15,000), paid in each of the following years (upto and including 1993) to those infected with HIV by blood or blood products. Such payments did not affect social assistance benefits.

Provincial and territorial governments (with federal contribution) have made ex-gratia payments under the 1993 Multi Provincial and Territorial Assistance Program

---

[97] Information provided by David Page, Executive Director of the Canadian Haemophilia Association in correspondence with the author.

('MPTAP'), which were open-ended so that C$30,000 (£15,000) per year is paid to those infected with HIV by blood or blood products, C$20,000 (£10,000) per year for 5 years is paid to surviving spouses and C$4,000 (£2,000) per year for 5 years is paid to surviving dependents, without affecting social assistance benefits. These payments have recently been indexed to reflect cost-of-living changes in almost all provinces, making annual payments approximately C$39,000 (£19,500).

Furthermore, as a result of class actions for Hepatitis C infections, a C$1.1 billion (£550m.) negotiated settlement was reached with the federal government and approved by the Courts in 1999. The settlement is only for those infected with Hepatitis C through blood or blood products between 1986 and 1990 and to hemophiliacs who received blood products during that time.

It:

- is open-ended
- is indexed to the cost of living
- allows for individuals to request adjustments as health status changes
- does not affect social assistance benefits

and it provides:

- six levels of compensation based on health status
- lump sum payments of C$10,000 (£5,000) to C$225,000 (£112,500) based on health status
- for income replacement if disabled
- for compensation for loss of services in home, if applicable
- for compensation for cost of care, if applicable, and
- reimbursement of out-of-pocket medical expenses

In a side agreement, this settlement also included significant lump sum payments for those secondarily-infected with HIV (e.g. spouses).

A subsequent, similarly negotiated, C$1billion (£500m.) settlement was reached in 2007 for the so-called, forgotten victims, infected with Hepatitis C through blood or blood products before 1986 and after 1990. This provides for a single payment, calculated on current and projected health status, and is supposed to correspond to the total value of the earlier settlement, but it does not allow for individuals to request adjustments as their health status changes.

It is understood that Canadian haemophiliacs are generally satisfied with these settlements. The only outstanding issue relates to indexation of MPTAP, where provinces have adopted different stances. Almost all haemophiliacs are in the first Hepatitis C settlement, but some, it appears, would like the single lump sum payment offered by the subsequent settlement. It is unlikely that there will be any additional financial provision, given that medical costs are covered and payments are annual and indexed-linked.

Israel[98]

The 1992 Compensation of Victims of Blood Transfusions (HIV Virus) Act provided compensation for victims of HIV infection, consisting of 2 elements:

- a lump sum of about $100,000 (£50,000) index-linked
- a monthly sum, payable through social security, of circa 7500 shekels, which approximates to almost £1,075 a month, of which 50% is a disability pension and 50% compensation. The compensation element is related to the average national wage ('ANW'). In addition, if there is a partner, there is an extra 12.5% of ANW and for each child up to 3 in number (aged 18 or less or 21 if in the army) an extra 5%. Following the death of a victim, the partner receives 35% of ANW for a period of 3 years after the death, but not the disability pension, and remarriage will cause monthly payments to cease. Each child (as before) will receive 5% of ANW, but if they are orphaned, children under 18 are entitled to 40%.

Provided a claimant is incapable of working, there is, in addition, a Disabled Persons Allowance of a basic 2,000 shekels (£285) per month with a maximum 2,500 shekels (£360) a month dependent on the degree of disability. There is also an Immobility Fund.

A spouse or child, infected by the original victim, is entitled to receive the same compensation. In the case of death before receipt of compensation, a partner (but not one separated more than a year before death) receives half the original lump sum

---

[98] Information provided by Professor Uri Martinovitz, Director of Israel's Hemophilia Institute, Dr Jonathan Schapiro of Israel's Hemophilia Institute and Professor Daniel More of Tel Aviv University in interview and/or correspondence with the author.

entitlement (and the percentage of ANW referred to above) and the other half is divided in equal shares between any children and parents of the deceased (the latter are regarded as one unit and the period after death is limited to 2 years) e.g. if there are 3 children and 2 parents, the parents get 25% of 50% (or 12.5% each) and each child gets 25% of 50%. Although the total payment is the same as a living victim would be entitled to, the monthly payments are less.

Payments made under the Act are not regarded as 'income' for tax purposes or for National Insurance pensions. Importantly, however, there is a waiver of income tax on earnings of victims, which is not unique to, but applies to almost every haemophiliac infected with HIV, as it does to all disabled persons with over 90% disability, who are thereby encouraged to be productive rather than living off the state.

A person who receives compensation is precluded from pursing further civil action. It should be noted that Israel has not paid, and has no present intention to pay, HCV infected persons, mainly because of their number.

Ireland[99]

Eire had only 104 haemophiliacs that were co-infected, of which 39 survive. A further 221 were infected only with HCV. An initial trust fund of £1m. was established in 1989 but, in 1991, the Government paid compensation on an ex-gratia basis as follows:

- £101,000 to a married person with 2 children
- £94,000 to a married person with no children
- £77,000 to a single adult or child
- £20,000 to the parents of a deceased child

In 1995, the Hepatitis C Compensation Tribunal was established on a non-statutory basis and compensated victims either on a full and final settlement basis or a provisional one. In 1999, the Lindsay Tribunal was established by the Dail (Parliament) to enquire into the contaminated blood scandal but, prior to the publication of its report (issued 4 September 2002), the Irish Government accepted

---

[99] Information provided by Brian O'Mahoney, Chief Executive Officer of the Irish Haemophilia Association, and extracted from correspondence, documentation and telephone interviews with the author.

that the HIV compensation awarded in 1991 was inadequate and passed further legislation in 2002 and 2006, under the guise of Hepatitis C compensation.

The former now produces a current average payment of €400,000 (currently £300,000) within a current range of €50,000 to €2.5m. (£38,500 to £2m.), although the highest single award was €3.1m. (£2.385m.)[100]. The latter, most importantly, provides life insurance (upto a maximum of €525,000 [£400,000]), mortgage insurance (upto a maximum of €394,000 [£300,000]), re-mortgage insurance (upto a maximum of €100,000 [£77,000]), as well as travel insurance for haemophiliacs infected with HIV and/or HCV and to close members of their family, whose premiums are loaded by reason of the relationship. If the 'victim' is insurable, the premiums payable by the victim are the same as would be paid by any perfectly healthy member of the population of the same age, with the government paying the loading, but if uninsurable, the government assumes the risk.

In addition, many of the recommendations of the Lindsay Report have been implemented, increasing and permitting priority access to improved medical facilities for haemophiliacs.

VI. What some other UK charities/trusts have done

Thalidomide[101]

The Thalidomide Trust, which was established in 1973 and is funded by Distillers[102], who manufactured the drug, currently supports some 450 beneficiaries. The amount paid to each beneficiary varies only according to disability so that parents' means, and any other financial or dependency aspects, are disregarded. The complex assessment of categorising disability is made following a formal interview by a senior member of the Trust's staff (often the Director) together with a chaperoning, trusted member of the beneficiary community, utilising a detailed questionnaire comprising four scales. A beneficiary can request a re-assessment if

---

[100] Figures apparently derived from Department of Health in Ireland and quoted by Brian O'Mahoney, Chief Executive Officer of the Irish Haemophilia Society, in his statement (dated 30 August 2007) to the Archer Inquiry.

[101] Information obtained from the Thalidomide Trust's website www.thalidomide.org.uk and supplied by Dr Martin Johnson, Director of The Thalidomide Trust in telephone interviews with the author on 18.1.08 & 7.2.08.

[102] Distillers is now part of Diageo Plc.

there has been any deterioration in their condition. Once assessed, their entitlement cannot be reduced, only increased. The median grant allocation is some £18,000 per annum, paid annually, and the range is from less than half that figure to a doubling of it. Benefits from the trust are not taxed because the trust is an 'accident damage settlement scheme'. Probably over 50% of beneficiaries are now welfare dependent and are entitled to all usual welfare benefits, but must not allow their annual allocation from the Trust to accumulate i.e. they must spend it, otherwise capital thresholds for welfare benefits may be exceeded.

There is no single grant system but the trustees are willing to capitalise future grant entitlement, enabling beneficiaries to draw-down up to 5 years future entitlement and to repay it over say a 10 year period. This enables special cars to be purchased (costing over £30,000), or deposits on or conversions to property to be made. Reserves are currently £133m.

vCJD

In 2000, the Government announced that it would pay compensation to the victims of vCJD *and their families* and established a Trust in 2002 with a fund of upto £67.5m. for the first 250 cases (which equates to £270,000 per case), out of which £8m. has been allocated to a Discretionary Fund for individuals (victims and/or members of their family), who have incurred:

- an identifiable psychiatric condition lasting longer than a month
- particular financial or emotional hardship caused by such a psychiatric condition
- care, travel and accommodation expenses
- particular hardship arising out of care i.e. carer's loss of earnings
- particular hardship if unable to obtain life insurance or mortgage protection insurance, except at a premium.

Last year's distribution schedule of the Trust indicates that there are 171 known victims. The most paid to a victim and/or their family was £549,403; 3 others have received over £400,000 and 10 others have received over £300,000. The average payment to date is £215,000 per victim[103].

---

[103] Extracted from the Trustee's Annual Report to the Accounts for the year ended 5 April 2007 of vCJD Main Trust

It has to be noted that this is a Trust, not a charity, and victims and their dependents are not precluded from taking legal proceedings, although sums paid to them by the Trust will be taken into account if successful. The Trust's accumulative administrative costs exceed 20% of funds disbursed so far, but substantial legal costs were incurred in the early years and, as the Trust continues, this percentage is expected to fall considerably, as have the number of new cases. According to the Trust's solicitors, Charles Russell, the scheme has proved expensive, complicated and difficult to implement, because it seems the Government gave the trustees too much discretion, which then has to be exercised appropriately. A simplified scheme has been proposed for people diagnosed in the future, but the Government has failed to respond[104].

At the time the scheme was established, Alan Milburn, Secretary of State for Health, is reported as saying, "I hope that these payments go some way towards recognizing the pain and trauma experienced by victims and their families.....vCJD is a national and personal tragedy for those affected. It is right that the families receive this compensation"[105]

Gulf War Syndrome

It was only following the efforts of Lord Morris of Manchester, over 15 years, to gain compensation for veterans suffering from Gulf War Syndrome, which included the instigation of an independent Public Inquiry (setting a precedent for the Archer Inquiry), and a war pensions tribunal in November 2007 that found "the term Gulf War Syndrome [to be] the appropriate medical label to be attached"[106] to a veteran's condition, that the Government accepted it as an umbrella term for people who are ill, due to their service in the Gulf. The Government is still not prepared to offer additional compensation for victims stating that "appropriate medical treatment is provided, and financial support is available through pensions and no-fault

---

[104] Information supplied by Jonathan Zimmern of Charles Russell, Solicitors to the Trust in telephone interview 10.3.08.

[105] http;//www.bbc.co.uk/devon/news/102001/01/mcvey.shtml (10.3.08).

[106] http://www.independent.co.uk/news/uk/crime/former-soldier-wins-landmark-case-over-gulf-war-syndrome-513491.html (10.3.2008).

compensation arrangements"[107]. However, it is now likely that many veterans, who were previously refused disability pensions, will appeal to the war pensions tribunal and receive some recompense. The value of awards is, as yet, unknown. This follows the collapse in 2004 of a case against the Ministry of Defence by more than 2000 veterans, because there was insufficient scientific evidence to prove their case in court.

VII. The current legal position[108]

There is at least one court case currently running in the English courts, which is being run as a class action, on behalf of some 300 infected haemophiliac claimants, by two law firms. It was initiated in America against four American drug companies that manufactured and supplied the blood products, believed to be the cause of HIV and HCV infection in haemophiliacs around the globe. The UK claims were dismissed on the grounds that the American courts were not the appropriate forum. The UK action is based in negligence, is in its infancy and has substantial hurdles to overcome, amongst them the Limitation Acts (which can prevent actions being brought after a specified period of time), the waivers (that the UK Government insisted were signed as a condition of the second payment to Primary Beneficiaries in 1991)[109], the system of applicable law (American or English[110]), and causation (the need, under English law, to prove a direct link between the defendant's negligence and the claimant's loss and damage).

The claim seeks 'aggravated and exemplary damages' and damages for deceit and conspiracy. One of the allegations made is that despite the risk of blood-borne viruses being present, blood products exported to the UK and elsewhere were not screened or heat-treated, unlike those produced for the American market[111].

---

[107] Hansard 8 June 2006 per Lord Drayson, Parliamentary Under-Secretary at the Ministry of Defence at Column 1379.

[108] Information supplied by Laurence Vick of Michelmores, Solicitors, one of two firms acting for Claimants, in a telephone conversation with the author.

[109] Baroness Kennedy, in her interview with the author, expressed the opinion that the waivers could be set aside on the issue of whether there was 'informed consent'. See Volume 2, the Appendices at Tab C6.

[110] England & Wales has a separate legal jurisdiction from Scotland and Northern Ireland.

[111] http://medneg.michelmores.com/news/default.asp?Display=323

The greatest obstacle, however, is the funding of class actions. Legal Aid has recently been granted for one interlocutory hearing and there is the slim possibility that Legal Aid may be granted for further steps in the action, which might allow the claimants to pursue the litigation towards a substantive hearing. Public funding is, however, rarely available for expert evidence, which is essential to this case[112].

Although the firms of solicitors have, what are known as, Conditional Fee Agreements with their clients, no 'after-event insurance' has been obtainable. This puts the claimants in jeopardy should the action fail and costs are awarded against them. The granting of Legal Aid will put additional pressure on the American drug companies to reach a financial settlement, but this is only likely if settlements are reached with all claimants globally. If it is refused, the UK action may be stillborn.

However, documents very recently disclosed under the Freedom of Information Act are said to evidence a Government cover-up, which has long been suspected and may, therefore, prompt the Government into a further, face-saving settlement, either in anticipation of the Archer Report or to satisfy its recommendations. It must not be forgotten that the last capital payments made to Primary Beneficiaries in 1991 were in response to the High Court ordering disclosure of certain documents, which were consequently never disclosed, or that the Government admitted to the 'inadvertent' destruction of numerous, relevant documents in the 1990s.

VIII. The Welfare Benefits System

The system is hugely complex and not often fully understood by those working for the Department of Work and Pensions ('DWP') with responsibility for providing benefits. The current major issues are[113]:

- the reform of Incapacity Benefit
- a nationwide review of those receiving Disability Living Allowance 'DLA' (on which many Primary Beneficiaries depend)
- poor service from Jobcentre Plus

---

[112] Information supplied by Sally Booth of Irwin Mitchell, Solicitors, one of two firms acting for Claimants, in a telephone conversation with the author.

[113] According to Neil Bateman, author of *Practicing Welfare Rights,* with whom the author had a lengthy discussion.

- lack of understanding by DWP staff of MFT payments, which should not be taken into account
- gaps in in-work benefits and tax credits.

The basis of the poverty trap is the withdrawal of benefits over and above any increase in income earned. The Tax Benefit Model Tables[114] on the DWP website[115] do illustrate this, but not in an easily comprehensible fashion. The present Government professes to want 'welfare to work solutions' and has undertaken a number of initiatives, but this country suffers from a major skills deficit. This is certainly the case amongst the younger members of MFT's community of care, who had no reason to learn a skill, profession or trade as their life expectancy then was not as it is today.

Tax credits, which are means tested, do improve financial support through work, but are undermined by appalling administration, with DWP staff ignoring or misunderstanding the law[116]. Income Support is also means tested, whereas most other benefits, such as Incapacity Benefit, are not. The latter is so low that many need Income Support in addition and are thereby caught by means testing, as is the case with other benefits. Means testing is also expensive to administer.

The Government is currently requiring further assessments of those in receipt of DLA, which is causing concern amongst, and may adversely affect, many Primary Beneficiaries. Linked to this, in his last Budget Speech, the Chancellor indicated that everyone on Incapacity Benefit was to have a medical review. It has also been reported that DLA may be removed if someone is in paid employment, which scares people from working and is technically false. A guarantee should be given that DLA will not be lost if someone goes into work, because, for example, they will have additional traveling costs. It is, however, true that a single parent with a mortgage on Income Support would lose the payment of mortgage interest if they went into paid employment.

The problem for many Primary Beneficiaries is that their health pattern is so variable, as are their energy levels. For example, an enforced change in drug regime

---

[114] The Tables are produced on a spreadsheet, which calculates the interaction between income tax, National Insurance, tax credits and certain benefits.

[115] See Table for April 2007 at http://www.dwp.gov.uk/asd/tbmt.asp

[116] See footnote 113 above.

can spark a period of poor health, making continuous, full-time employment difficult. Many have no desire to tell prospective employers that they are HIV positive and taking too many days of sick is unacceptable.

What is needed is a change in attitude of the public towards people on benefits. Many are not abusing the system but are genuinely incapable of work. An additional tax allowance for those on Incapacity Benefit or DLA might encourage more to find work. Governments of all persuasions have for decades tinkered with the system but have only made it more complicated. The last means test review was in 1988, which left people worse off[117].

A radical suggestion, proposed by Neil Bateman[118], author of *Practicing Welfare Rights (Social Work Skills)* [119], is for Child Benefit to be increased dramatically for those with children, as it avoids the complexity surrounding tax credits. It does not, however, solve the problem of those without children and gives the same benefit to those who are not in financial need, as Child Benefit is available to all with children. The argument in support of the suggestion is that statistics show that the earning power of those between 20 and 40 is at its lowest, whereas children of those over 40 need less financial support.

What might help solve the problem, but much research would be necessary, is Israel's system of absolving from income tax the earnings of a person with over 90% disability.

IX. The Business Case – 'Funding long-term survival'[120]

The Business Case, submitted in November 2007 to the Department of Health, called for increased annual funding for MFT from £3million to £7million, in addition to further direct capital payments to Primary Beneficiaries. It expressed very clearly the plight of Primary Beneficiaries and their families, consequent upon their unexpected longevity, but in the view of this author, made some 'demands' that were unsubstantiated or unwarranted, despite the use of statistics and detailed, though not necessarily convincing, argument. The Business Case also failed to prioritise its

---

[117] See footnote 113 above.

[118] Made during a lengthy discussion with the author.

[119] Bateman, N., (2005), *Practicing Welfare Rights (Social Work Skills).*

[120] Based on the MFT Long Term Review commissioned by Department of Health in late 2002 and completed in 2004, devised and written by Hilary Barnard, an independent consultant.

proposals and made no suggestions for financial provision to take people out of unemployment or to provide training or further education.

It did make the following requests, representing 'revised annual need':

Housing costs, including repairs and maintenance	£3m.
Diet, heating, domestic materials, clothing & communications	£1.5m.
The needs of bereaved dependents	£1m.
Dealing with stress, including costs of respite breaks/holidays	£1.1m.
Childcare costs and help with assisted conception	£0.25m.
Cost of living up-grade	£0.25m.
Mobility, trends in type of grant and debt relief	£0.15m.

This totals £7.25m. annually

The Government ignored it in its entirety, leaving MFT's trustees, and its community of care, angry and frustrated.

X. What might have been done differently.

- An original intention was to conduct some of the interviews ahead of drafting the Questionnaire, but time constraints and logistics made this impossible. There would have been some changes to the Questionnaire, particularly in relation to income and benefits. However, this failure did allow some data to be used in the interviews.
- The Questionnaire was reviewed by members of the Partnership Group and amendments were consequently made. A proper 'pilot' requiring them to complete the Questionnaire, may have elicited some misunderstandings that some respondents appear to have had.
- The Questionnaire was directed at and sent to Primary Beneficiaries. Whilst this would have included widows who had become infected and were Primary Beneficiaries in their own right, no data was obtained from other widows, who are part of MFT's community of care. Some of those interviewed for this dissertation expressed their particular concern at the treatment of widows.

- Parts of the Questionnaire sought information about partners and a clearer distinction should have been made to cover those partners, who might also be Primary Beneficiaries, that had become infected with HIV through sexual intercourse, not contaminated blood. If they have also completed their own questionnaire and answered the questions relating to partners, some of the data may be skewed.
- A more detailed question was required concerning dependent children.

6. Conclusions

The conundrum that this dissertation has presented is how to reconcile, within the legal confines of a charity, and with limited and uncertain funding from Government, the very disparate needs of Primary Beneficiaries, whose ages range over a 50 year lifespan, whose physical health, psychological attitudes, household incomes and savings, amongst many variables, can be so different; that, whilst some are in work, most may never work again and that many have partners, and some children, whilst others live solitary lives with no dependents and few friends, having only themselves, and sometimes aging parents, to worry about.

There is a further issue, which has a compelling argument. Every Primary Beneficiary's life has been irredeemably damaged by this tragedy, as have the lives of their immediate family. Only some 400 survive with an uncertain future. Should not the resources of the MFT, however limited, be spread amongst all of them as equitably as possible? That has been MFT's basic strategy towards its Primary Beneficiary community, which has not changed materially over the past 18 years.

Last year, it made the following changes:

- Changed the existing two tier system of, and increased, regular monthly payments, so that a Primary Beneficiary, whose household income is less than £30,000.00 p.a. (excluding MFT income[121] and earnings of any children), now receives £57 per month more than a household whose income is in excess of £30,000.00. The current monthly figures are now £420 and £363 respectively, a difference of only 15%.
- Increased the regular monthly payment to non-infected widows for the first dependent child (meaning a child under 18 or in full-time education) by £150 per month to £250 and by £70 to £100 per month for each subsequent child.
- Increased the regular monthly payment to guardians of orphans under 18 or in full-time education by £150 per month to £250.
- Provided a one-off payment of £150 to Primary Beneficiaries on the higher monthly payment to cover increases in utility bills.

---

[121] According to the Chief Executive of MFT, MFT payments are excluded from household income because they are not taken into account for means tested benefits and the intention was to be consistent.

- Provided a one-off winter fuel payment of £150 to both non-infected and disabled widows receiving regular monthly payments (not due to stop) to cover increased costs
- Increased the winter payments to Primary Beneficiaries on the higher monthly payment by £100 to £625 and added, to the current summer payment of £1,000, £250 for each child of a Primary Beneficiary.[122]

The rationale behind the choice of £30,000 p.a., as the level at which the two tier system mentioned above would operate, was the charity law requirement of determining financial need. Trustees are entitled to take a considered view and it was felt that there was definitely a 'financial need' for a person suffering with haemophilia, HIV and HCV, to account for extra physical and medical needs, if household income was below a 50% uplift on the national average wage (which was presumed to be £20,000)[123]. The previous basis for the two tier system was whether a Primary Beneficiary was in receipt of Income Support.

There is no apparent logic for this stance, because the £30,000 level *excludes* MFT's regular payments and takes no account of the number within the household i.e. it does not discriminate between the single person or the family with dependent children. Furthermore, the vast majority of Primary Beneficiaries, (the response to the questionnaire indicates 79%), have a net, annual household income of less than £30,000, *including* MFT payments *and* welfare benefits. Moreover, any household with income over £30,000 arguably has no financial need and should not receive any support from MFT, although trustees are entitled to consider that there may still be some financial need.

Therefore, notwithstanding the desire by MFT's Board of Trustees to be inclusive towards all Primary Beneficiaries, payment to a member of MFT's community of care who is not in financial need, as determined by The Board of

---

[122] Information supplied by Chief Executive of MFT.

[123] According to Government statistics, the results of the 2007 Annual Survey of Hours and Earnings show a median weekly pay for full-time employees of £457 equivalent to £23,764 p.a. (for men this increased to £498 per week or £25,896 p.a.). See http://www.statistics.gov.uk/cci/myjet.asp?id=285

Trustees[124], would appear to be a breach of a trustee's fiduciary duty to have regard to charitable need[125]. If confirmed by legal opinion, action will need to be taken[126].

It is also difficult to understand the rationale behind the giving of £250 a month to a non-infected widow with a dependent child or to the guardian of an orphan (with £100 a month for subsequent children), when regular pay to a Primary Beneficiary (which may include an infected widow) provides for only an additional £30 a month for the first dependent child and £15 a month for subsequent children.

Whilst some benefits have been increased substantially by MFT during the past year, the increases have not kept pace with the Retail Prices Index over the years (there has been much recent publicity that the Index has little bearing on real inflation affecting the general public). Notwithstanding that such increases have been welcomed by MFT's community of care, there has been no strategic plan behind them.

A major source of concern amongst Primary Beneficiaries, particularly those who are married and/or have dependents, is their inability to procure Life Insurance or Mortgage Protection Cover, which leaves their families at risk with a mortgage and/or without adequate financial provision. The Irish Government has recently introduced a scheme[127], but there is little likelihood of the UK Government doing so. Recent attempts[128]to obtain a collective insurance policy in the Lloyds market, even for only £10,000 per Primary Beneficiary under age 55, have proved prohibitively expensive and MFT may consider some kind of in-house 'insurance' scheme, if funds permit.

It is also evident that, because MFT has always administered the funds it has received from Government within a budget set by that amount and has built up not inconsiderable reserves in excess of £4m., the Government considers that it is discharging its obligations to MFT's community of care. The Business Case, submitted to the Government by MFT in November 2005, asked for more than a doubling of funds but did not seek to prioritise its demands and, arguably, was insufficiently specific in how it calculated its figures.

---

[124] This should be in the form of a written policy, adopted by the Board, with appropriate guidelines if it is not possible to assess individual needs.

[125] See Charity Commission Guidance CC4 'Charities for the Relief of Financial Hardship' at pages 2-3.

[126] See next section, 'The Way Forward'.

[127] See page [68] supra – upto a maximum of €525,000 (£400,000) and mortgage protection upto €394,000 (£300,000).

[128] Instigated by the author.

Those who have been involved from the very beginning of MFT with its function have long considered that both the Government's initial and subsequent response to the plight of the victims has been "pitiful..., parsimonious, niggardly [and] insensitive"[129], responding only when political force is applied. This is clearly the case when the UK's response to this tragedy is compared with other countries that have been pro-active[130] and should also be seen in the context of the Government's generous response to victims of vCJD and their families. Consequently, much more determined pressure needs to be applied to the Government, through all available sources. Those sources include individual Members of Parliament and, particularly, the All Party Parliamentary Groups on Haemophilia and Hepatology, which need to be galvanised, in collaboration with the Haemophilia Society.[131]

The Report of the Archer Inquiry will be the most effective time to lobby support, given the likely media interest and possible public sympathy. This is certainly the view expressed by Lord Morris, Baroness Kennedy, Dr. Mark Winter and Reverend Tanner during their interviews[132]. The outcome of the class action litigation is far from certain, is probably a long way off and, consequently, will be ignored for the purposes of this dissertation[133].

It is also apparent from the research that those who were very young when they were first infected have had the rawest deal both from the Government and, in relative terms, from MFT i.e. the least amount of capital payments, the limited expectations of life and having a family, no training, no further education and becoming dependent on welfare benefits. Attempts must be made to empower the younger Primary Beneficiaries and, where applicable, provide further financial assistance for assisted

---

[129] See The Rev. Preb. Alan Turner's interview in Volume 2, the Appendices at Tab C1.

[130] The Department of Health's letter to the author dated 25 March 2008 (see Volume 2, the Appendices at Tab D8) states: "It is important to note, when making international comparisons, that the situation in Canada and the Republic of Ireland is quite different, as it was established that wrongful practices were employed in both countries. This is not the case in the UK". The awaited Archer Report will, hopefully, comment on such matters as the unauthorised destruction of Lord Owen's papers when he was Minister of Health and thousands of other DoH papers, the removal from patient's health records of relevant information and upon other allegations of cover-up.

[131] The view of Dr Mark Winter, MFT Medical Trustee, in his interview with the author. See Volume 2, the Appendices at Tab C4.

[132] The interviews are in Volume 2, the Appendices at Tabs C1 and C4-C6.

[133] Research has indicated that there may be the possibility of using charitable funds to help fund litigation brought by beneficiaries of the charity (as a class) to recover compensation, but MFT's trustees would need to exercise their discretion very carefully in such regard.

conception. If the Government is unwilling to recognise this by making additional capital payments available, particularly for this cohort, then MFT should be doing something that is both significant and meaningful for them. The Department of Health's written response to the request for an interview with the Minister indicates that neither further capital funds, nor an increase in annual grant, are likely. The one ray of hope is the indication that the Department "will consider the recommendations made by the [Archer] Inquiry when it reports".[134]

A scheme, such as that developed by the Thalidomide Trust, which has a team of volunteer visitors, nearly all of whom are beneficiaries of the Trust who assist fellow beneficiaries in a number of ways, including advice, support and advocacy, and specialist assistance with health and independent living[135], would have considerable benefits for MFT's Primary Beneficiaries, particularly the younger contingent. A few Primary Beneficiaries already undertake this important work, without reference to MFT and, in March 2008, an MFT Working Party[136] recommended that a designated fund of £35,000 be allocated for such a scheme and £100,000 designated to help dependents of Primary Beneficiaries get a start-up in life (each fund to be reviewed and topped-up annually). Hopefully, these 'empowerment' projects will be adopted and prove contagious.

The strategic challenges arising from these conclusions can, therefore, be summarised, as follows:

- Providing a viable and accurate assessment of financial need for each Primary Beneficiary and seeking solutions to meeting that need
- Mobilising parliamentary and media support for additional financial assistance (both capital and income) from the Government
- Empowering those in MFT's community of care, who want a future.

MFT has not, historically, been strong on strategy with a consequent lack of strategic management by its Board of Trustees. It now has an excellent, very

---

[134] See Department's letter dated 25 March 2008 in Volume 2, the Appendices at Tab D8.
[135] Information supplied by Dr Martin Johnson, Director of The Thalidomide Trust.
[136] The author chaired this Working Party and was a prime mover in making these recommendations.

professional, Chief Executive and supporting staff, but the Trustees meet together only quarterly and the last 'brainstorming' session was 18 months ago and lasted a few hours[137]. It then discussed a paper prepared by Peter Stevens, its then Chairman, whose aspirations were:

- A clearer targeting of funds
- The need to question automatic payments
- The stage where non-infected widows should no longer get support.

A second paper sought to establish objectives that might form the Annual Plan for 2007/8, but the debate on both papers was inconclusive save for decisions to make a supplementary payment to *all* households to meet higher fuel costs and that there should be a clearer definition of convalescence and respite, neither of which were particularly relevant to the issues that were meant to be discussed[138].

It is in this context that a need for effective strategic management is expressed. Johnson *et al* (2006) believe that it is the development of "a capability to take an overview, to conceive of the whole rather than just the parts of the situation facing an organisation" [139] that defines strategic management. This includes understanding MFT's strategic position, as well as its potential, and making that strategy happen. It requires the development of appropriate strategies, that may change over time if, for example, the Government were to react positively to the Archer Report.

To achieve this, it is necessary:

- to determine which issues are more important than others
- to have an ability to reconcile conflicting pressures
- to assess MFT's strategic capability, and
- to assess the expectations of its community of care and the Government, as its sole funder, which together comprise its principal stakeholders.[140]

MFT should recognise that it needs to review its overall strategy in the knowledge that it is probably here for the long term, which is very different from the time of its conception. It may be prudent to adopt a 'blue sky' approach, accepting

---

[137] This refers to a session at the Trustee Development Day held on 4 November 2006.

[138] Aide Memoire of Trustee Development Day held on 4 November 2006.

[139] Johnson *et al* (2006) in *Exploring Corporate Strategy* at page 15.

[140] Ibid.

that MFT's present distribution of the Government's annual grant is no longer appropriate. The present angle of approach may be wrong. The new strategy – the new angle – perhaps, should be to ascertain what MFT needs, by way of annual Government grant, to provide an element of independence and of empowerment to those in its community of care, by supplementing other household income (whether from employment or welfare benefits) to an acceptable, individual level 'to relieve'[141] financial need.

---

[141] Taken from MFT's charitable objects as set out in the Consolidated Trust Deed (last amended 4 November 2006).

7. The Way Forward

The immediate priority

First and foremost a legal opinion from MFT's lawyers needs to be obtained, as a matter of urgency, to determine if there has been a breach of fiduciary duty by the Board of Trustees. Subject to that advice, it might be prudent to enter into discussions with the Charity Commission to determine the best way forward. The Board would probably consider it inappropriate to cut-off the regular monthly payments to some Primary Beneficiaries without notice[142], and a transitional policy may well have to be put in place, hopefully, with the approval of the Charity Commission.

If it is accepted that a new policy is required, that policy will have to be determined and MFT's community of care consulted on its content and implementation. This will take time but its urgency cannot be over-emphasised[143]. This issue is relevant in both the short and medium term.

The next stage

Once this most urgent matter is underway, it would be prudent for MFT's Board of Trustees to undertake, as a group, a strategic analysis of the future environment[144], for which the Report and Analysis and Conclusion of this dissertation can provide a starting point. Such an analysis helps make sense of an existing situation and would

---

[142] MFT currently gives at least 3 months notice of reductions in payments.

[143] Trustees can be personally liable for breaches of fiduciary duty, which lead to financial loss to the charity. The recent incorporation of MFT's trustee body does not affect that liability. If a complaint was made to the Charity Commission, it would undoubtedly make enquiries and could open an inquiry. If it did so, it would then publish a report on its web-site. Proceedings under the Charities Act 2006 can be brought by trustees (or any one of them), or by any person interested, which could include the Government as funder or anyone who qualifies as a beneficiary. The Act allows charity trustees to apply to the Charity Commission, as well as the courts, for relief from personal liability for a breach of trust where the trustees have acted honestly and reasonably, which obviously only applies where mistakes have been honestly made. There is a defence of 'acting in good faith' which, in the circumstances, is likely to carry much weight. If a breach of fiduciary duty is discovered, trustees must take urgent action to remedy the breach.
[This footnote is the result of a perusal of the provisions of the Charities Act 2006 and a telephone conversation on 2 April 2008 between the Head of the Charity Law department at Berwin Leighton Paisner and the author].

[144] Richard Piper's article in Governance (September 2007) headed 'Don't get left behind', itself based on *'Looking Out: How to analyse your organisation's external environment'* commissioned by The Performance Hub.

allow MFT to anticipate the need for change and to prepare for it, as well as possibly move in a new direction. It must look at situations in different ways or from different angles by, for example, creating scenarios.

At least a full day (preferably a weekend) should be set aside specifically for such a brainstorming session, initially to plan for the outcome of the forthcoming Archer Inquiry Report and, subsequently, to deal with other strategic issues[145]. It would require the Board to think creatively about what it might do and the likely impact (financial and otherwise) of all such ideas, as well as the external implications that might affect or influence that impact. The Board would need to consider, in respect of each idea, what effect it would have on MFT's ability to deliver it successfully, what opportunities it presents and how feasible is the idea.

With each idea, there will be a number of response options, such as improving what MFT does now, e.g. increasing the Bereavement Grant currently paid to next-of-kin to provide some form of life insurance cover or lobbying, more forcefully, members of the All-Party Parliamentary Groups on Haemophilia and Hepatology; or innovating, e.g. promoting a public policy; or improvising, e.g. devising an exit strategy.

Decisions can then be made on a cost/benefit basis and/or MFT's ability to deliver. Whatever the decisions made, plans must be made to implement them, personnel allocated to perform specific tasks and progress must be regularly reviewed.

It is a question of meeting current needs and delivering aims into the future and the challenges outlined above could be addressed strategically, as follows:

- Ensuring that MFT has a strategy, for immediate implementation, to cover all possible scenarios which may emerge from the Archer Inquiry Report[146]. This would best be served by a brainstorming session of all trustees.
- Determining if a strategic change in regular payments policy is appropriate and, if so, constructing a strategy to implement and manage it in the medium term[147].

---

[145] Such days, or weekends, should recur regularly or be instigated ad hoc.

[146] Interestingly, whilst 84% of respondents to the Questionnaire are aware of the Archer Inquiry, only a quarter consider that its report will have a beneficial impact on the Government. Its positive impact, however, on public opinion is thought to be twice as great.

[147] This is separate and apart from the legal issue. This refers to whether an individual assessment of need is determined as necessary or the setting of guidelines affecting those who might qualify as being in financial need.

- Lobbying the All Party Parliamentary Groups on Haemophilia and Hepatology in collaboration with the Haemophilia Society[148]. In the past, Lord Morris of Manchester and the Haemophilia Society have been in the vanguard of parliamentary lobbying, but not so recently. Closer collaboration to this end with the Society and forming new links, and re-establishing old ones, with members of the All-Party Parliamentary Groups, and with individual members of Parliament in both Houses, is essential to raise questions (for both written and oral answers) and to lobby ministers from the Department of Health[149]. This requires a very pro-active approach and everyone concerned needs to speak 'with one voice' to get an agreed message over.
- Regular and persistent contact with Department of Health officials and with the Minister, reminding them constantly of the need not only to maintain their annual grant but to increase it, as well as demanding additional capital payments, particularly for younger Primary Beneficiaries. Alternative arguments should be put forward for tax breaks[150] and welfare reform[151].
- Designating a specific but substantial fund for the purpose of empowerment, to be overseen by a sub-committee, with volunteer beneficiaries and others acting as mentors[152].
- Designating a fund for assisted conception.
- Investigating if there is, or commissioning, a 'self-help' book or course on positive thinking/cognitive therapy, which would be appropriate and potentially beneficial to Primary Beneficiaries and making it available at no cost.

On the assumption that MFT has determined that a change in its regular payments policy is appropriate, ascertaining the environment in which each individual Primary Beneficiary lives, their respective financial circumstances, medical condition

---

[148] Baroness Kennedy, in her interview with the author, also recommended the Science and Technology Committee. In the House of Commons, its name was changed in November 2007 to the Innovation, Universities, Science and Skills Committee.

[149] Baroness Kennedy volunteered, following the conclusion of the formal interview with the author, to raise questions in the House of Lords, particularly in relation to the Archer Inquiry.

[150] As in Israel. See page 55 supra.

[151] See page 61 supra.

[152] Recommendation in March 2008 of a Working Party, chaired by the author, to be considered by the Board of Trustees shortly, if approved by the NSCC.

and prognosis, mobility and their needs and wants, including any aspirations for further education/training and employment/self-employment, is a realistic possibility. The services of the Terence Higgins Trust, with whom MFT has an existing contractual arrangement to provide a wide range of services to its community of care, could easily be utilised. It would necessitate either the services of a University[153] or a consultant to compile a detailed questionnaire or computer tool to make the comprehensive assessment. It must not be self-completing and those carrying out the assessment may need some training. It would also be a rolling program, so that automatic re-assessments would take place every few years.

Such an assessment could also be used for any widow(er) or partner of a deceased who asks MFT for financial assistance, before or after the monthly payments have ceased.

The idea of such a detailed assessment is bound to be controversial and looked upon as invasive and with suspicion by Primary Beneficiaries. Whilst there is clearly an element of 'means testing' in such a proposal, it needs to be promoted as much more than that and as part of the general duties of trustees of a charitable trust[154]. Having regard to MFT's relationship with its community of care, there will need to be a consultative process and its implementation will need careful thought and tact. Some may accept that they are not in need of further MFT support (for the time being) and, therefore, not need an assessment. Others may refuse to participate and an appropriate response, with pre-determined consequences, will need to be considered.

The assessment will be most complex. What currently appear to be disregarded in the assessment of 'household income' are the *hidden* benefits that some Primary Beneficiaries receive, such as relief from Council Tax and payment of mortgage interest or rent (which is paid by Social Services directly to the mortgagee or landlord). These, and other benefits, need to be added back in to achieve a fair and accurate assessment of 'total income'. It will also need to factor that different amounts, for the same welfare benefit, are payable in different areas of the country, that living costs also vary around the country, that some will have easy access to

---

[153] Leeds School of Medicine devised in 2001 a computer tool for The Thalidomide Trust, which has a complex assessment system based exclusively on the extent of disability.
[154] Charity Commission Guidance CC4 entitled *Charities for the Relief of Financial Hardship* at page 2.

public transport and others will not. There also exists a post-code lottery in the provision of NHS services to Primary Beneficiaries.

With such information to hand, the limited resources of MFT can be targeted at those currently most in need, which better accords with its charitable purposes and legal obligation. Those who are not currently in financial need, to be determined by the Trustees in the proper exercise of their discretion, would receive nothing from MFT. However, the strategy must make provision for urgent action in the case of a change of circumstance, likely to cause hardship, such as loss of employment through illness or redundancy. A process must also be in place to enable individuals to require a re-assessment, if there is a change in their circumstances[155]. Designated funds must be made available and effective office systems put in place for such eventualities.

There will be winners and losers[156], and amongst the latter a very considerable anger and concern from those who have become dependent on MFT for support, whatever their circumstances, and particularly from those who see such payments as a form of compensation, however inadequate. This has to be factored into the management strategy and a fair lead-in time for cessation or reduction of payments will have to be determined. "Change is a process, not an event"[157] and it is equally important "that the process fits the purpose".[158]

It is not for this dissertation to determine the level at which financial need might be considered to have been met, but for MFT's Board of Trustees. It could be a blanket figure[159]. However, for the purpose of exploring this particular strategy, it is suggested that a benchmark be set for an annual household income comprising a single person without dependents, with accretions for a partner and any dependent children. It may be considered appropriate to have different parameters relating to age, as someone in their twenties or thirties may be considered to warrant more than someone who has retired. There may also be other considerations, such as current housing costs or London Weighting.

---

[155] Limited to one in any given period (say 1 year).

[156] At first sight, approximately 80% would be winners and only 20% losers, but not if there are insufficient funds to meet the benchmarks set by the Board of Trustees, and those benchmarks need to be lowered pro rata.

[157] Robson, C. (2002) *Real World Research* at p.219 citing Fullan, M. (1982) The Meaning of Educational Change.

[158] Audit Commision Report '*Change Here!: Managing Change to Improve Local Services*' (2001).

[159] Such as taking the current £30,000 as the benchmark for the present two tier system.

Around 70% of Primary Beneficiaries are single, divorced, separated or widowed and approximately 30% are married or have partners. The number of dependent children in each household is not readily ascertainable[160]. 79% of Primary Beneficiaries, who responded to the Questionnaire, say that they have a household income of less than £30,000 but how that assessment has been made is unclear. A third are in full-time employment or self-employed (a further 10% part-time) and some have partners in work.

It is clearly impossible to ascertain how much it would cost MFT annually to bring each Primary Beneficiary upto whatever are the agreed benchmark levels, until such time as the detailed assessment of every Primary Beneficiary is complete. It may be affordable but, more probably, it will far exceed the Government's current annual grant. If the latter, MFT can take a first step by theoretically reducing the benchmarks proportionately for everyone, and use the evidence to lobby the Department of Health for additional funds.

Such a strategy, if implemented, would allow the single grants system, which was considered inequitable by several interviewees and received critical comment from many respondents to the Questionnaire[161], to be scrapped. However, provision will need to be made, from the annual grant, for grants to widows and dependents of Primary Beneficiaries, in addition to the currently proposed, designated funds for widows, empowerment schemes and assisted conception. If the single grants system was to be scrapped, it is probable that Trustees would wish to put in place a designated Hardship Fund as a contingency.

<u>In the longer term</u>

If a major difficulty facing MFT is the Government's unwillingness to increase its funding to MFT's community of care or to provide additional capital payments[162], MFT must consider what it can do to change the Government's mind. One such strategy would be to look forward, beyond the short term funding difficulties facing

---

[160] As advised by MFT.

[161] See footnote 79 at page 53 and the transcribed interviews of Messrs. Stevens, Evans and Winter at Volume 2 the Appendices at Tabs C2, C3 & C4.

[162] See letter from Department of Health to the author dated 25 March 2008 Volume 2, the Appendices at Tab D8

MFT, to the medium and long term. It probably has to be acknowledged that these funding difficulties are likely to remain for so long as MFT is dependent on an uncertain, annual hand-out from the Government in the funding round, unless the result of the Archer Inquiry produces a significant sea change in Government thinking.

The Board of MFT faces a dilemma. MFT was set-up by the Government and is funded exclusively by the Government. It is, in effect, an agency of government but, as a charitable trust, it is governed by charity law and its funds must be used exclusively for charitable purposes. Its trustees, therefore, are beholden to the Government for funding but have no legal obligations towards it, whereas they have explicit legal duties towards its community of care. The Charity Commission has, however, published guidance (publication CC9) covering the campaigning and political activities of charities so that what is suggested hereafter is permissible.

A Government Strategy Unit report[163] entitled 'Private Action, Public Benefit'[164] highlights the benefits to be had if charities are encouraged to play an advocacy and campaigning role because, it suggests, charities are often well placed both to monitor, evaluate and comment upon policies as they are implemented and to offer alternative ways of engaging with the public policy debate.

It would be a radical change in current MFT policy, but not something too radical for the Board to refuse to consider, if it were to become involved in the political process and, in particular, to promote the concept of No Fault Compensation ('NFC'). This was an idea explored and rejected by the Pearson Commission[165] in the

---

[163] The Strategy Unit was established in 2002 as part of the Cabinet Office with the role of facilitating 'joined-up' thinking and government.

[164] *Private Action, Public Benefit – a review of charities and the wider not-for-profit sector*, Strategy Unit (September 2002) available at www.number-10.gov.uk/su/voluntary/report/index.htm

[165] A Royal Commission on the Civil Liability and Compensation for Personal Injury. Chairman: Lord Pearson. Cmnd 7054-1, 1978. A Royal Commission is an independent non-departmental government body financed by Parliament to investigate and report on whatever subject matter it is established for.

1970s,[166] but Lord Archer, the chairman of the Archer Inquiry, is a strong proponent of NFC[167] and Baroness Kennedy believes such a proposal worthwhile[168].

It has been adopted in, for example, Scandinavia and New Zealand, albeit using different methodologies. The Compensation of Victims of Blood Transfusions (HIV Virus) Act, passed in Israel in 1992 is a 'No Fault' law and, whilst the compensation package might be regarded as small, in comparison to similar tort cases decided in Israel, the problems involved in such litigation are enormous. It is also fair when compared to other State compensation packages for similarly sick persons[169].

In a no-fault liability system relating to clinical negligence, the claimant must show that the medical error was a causative factor in the resultant injury, irrespective of who is to blame, so that it is necessary only to prove causation, not fault[170]. In the case of haemophiliacs infected with HIV and/or Hepatitis C, the Government could still argue that there was no negligence i.e. no medical error that was 'a causative factor'[171].

The allegations of a Government cover-up and destruction of evidence by civil servants have been raised in the Archer Inquiry with consequential, wide media publicity for the plight of MFT's community of care. MFT gave evidence to the Inquiry, but was not disposed to enter into the political debate in such an arena, although it hoped to inform public opinion with its evidence.

---

[166] There has been subsequent, limited exposure, with the NHS Redress Act in 2006 (yet to come into force 18 months after its enactment), which is limited to care given in hospitals and not by GPs or dentists in surgeries, nor to ophthalmic or pharmaceutical services. Liability, however, has to be established, albeit not by the patient and there is a maximum compensation limit of £20,000.

[167] See transcribed evidence of Lord (David) Owen at the Archer Inquiry on 11 July 2007 at page 10 at website http://www.archercbbp.com/hearing.php

[168] See Baroness Kennedy's interview with the author at Tab C6.

[169] The view expressed by Professor Daniel More of Tel Aviv University in a written memorandum to the author (December 2007) – see additional notes to Professor Martinowitz's interview in Volume 2, the Appendices at Tab E.

[170] An alternative concept of 'public tort liability' was conceived in 2002 by academic, Hassan El Menyawi, currently Assistant Professor at the United Nations University for Peace, whereby the state compensates the claimant and seeks to recover some or all of the compensation paid from any wrongdoer, which is somewhat akin to the criminal justice system. El Menyawi asserts that such a scheme could provide for all injured, ill and disabled people, irrespective of the cause of their condition, but based on their relative need for support. Furthermore, the likely costs of such a scheme would be less costly than the present tort-based system. See Article by Hassan El Menyawi entitled *Public Tort Liability: Recommending an Alternative to Tort Liability and No-Fault Compensation* in Global Jurist Vol:3 (2003) Issue 1.

[171] As the Government still appears to be doing. See letter from Department of Health to the author dated 25 March 2008 Volume 2, the Appendices at Tab D8.

An objective of promoting an NFC policy would be to make the Department of Health refocus on how such a system might work and what it would cost. But, the principal reason behind this idea is for MFT to gain a higher public profile, which may lead to the Government accepting its moral, if not legal, obligation to offer further compensation to MFT's community of care and/or to be more generous in its 'annual' award. Perhaps, from a political perspective, it might be seen as more effective for the Government to settle with MFT's beneficiaries, so that the issue goes away. The Government is clearly not going to make additional payments to Primary Beneficiaries and their dependents without parliamentary and/or public pressure. There are considerable Treasury constraints on departmental budgets and the Government is currently entrenched with substantial borrowing to fund public expenditure. MFT, consequently, needs to be subtle in its approach. Those who it may have approached to lobby for support in Parliament and with the Government, on behalf of MFT's community of care, should be sounded out for their possible interest in NFC.

There are likely to be numerous other organisations with whom MFT could collaborate on such a project to share resources, experience and cost. The greater the number of similar, or even disparate, organisations brought under one umbrella, the greater the political pressure and the wider the access to public opinion, but there are, considerable, potential difficulties in working with several organisations or groups, whose aims and aspirations may differ. A working party of those interested and like-minded could be established to formulate a strategy and tactical campaign, but it would need a strong and determined leader to keep everyone focused. Organisations and groups that could be approached are the Haemophilia Society, victims of Gulf War Syndrome, asbestosis, vCJD and those at Porton Down exposed to nerve gas experiments. There are many other industrial diseases, where campaigns have been launched.

A charity can provide its supporters with material to send to MP's and central government, provided it can justify that its decision to engage in such activity was a considered one and there is a rationale for the chosen material. It can also organise and present a petition to either House of Parliament or to the Government, which may be another effective way of getting public support and media coverage[172], and is entitled to support the passage of a Bill, if such support can reasonably be expected to further its charitable purposes and, on the same basis, can promote the need for a particular piece of legislation[173].

Such political activity is not prohibited by MFT's trust deed and may, therefore, be carried out within Charity Commission guidelines, as it is a legitimate means of furthering MFT's charitable purposes. Furthermore, it is arguably in "the overall best interests of the charity and its beneficiaries", given the Government's reluctance to provide adequate funding, but the MFT Board should only authorise the application of resources for such activity to a justifiable extent and ensure that any expenditure is exclusively for its charitable purposes[174].

If the idea of promoting NFC, for its potential to benefit MFT's community of care and to gain wider public recognition, is considered by the Board a worthwhile idea, then a briefing paper should be drafted for both internal and external use. Such a project would need to be run pro-actively by an appointed sub-committee but, by adopting such a policy and operating within such guidelines, MFT may well succeed in achieving a further capital payment as compensation for Primary Beneficiaries and their dependents.

Russell Mishcon
April 2008

---

[172] Charity Commission Publication CC9 entitled *Campaigning and Political Activities by Charities* p.18.
[173] Ibid p.19.
[174] Charity Commission Publication CC9 entitled *Campaigning and Political Activities by Charities* p.11.

8. References

Adams, R., (1990), *Self-Help, Social Work and Empowerment.* London: Macmillan Education Ltd.

AIDS Update (March 1985) *Aids and Hemophilia: Your Questions Answered.* The National Hemophilia Foundation.

Audit Commission (2001) *Change Here! Managing Change to Improve Local Services.* London: The Stationary Office.

Bateman, N., (2005), *Practicing Welfare Rights (Social Work Skills).* London and New York: Routledge.

Bryson, J.M. (2004) *Strategic Planning for Public and Non Profit Organizations.* San Francisco U.S.A: Jossey-Bass.

Carlisle, C., (2001), HIV and Aids. In T. Mason, C. Carlisle, C.Watkins and E. Whitehead, eds., *Stigma and Social Exclusion in Healthcare.* London and New York: Routledge.

Charity Commission CC4 (2003), *Charities for the Relief of Financial Hardship.* London: The Stationary Office.

Charity Commission CC9 (2004),*Campaigning and Political Activities by Charities.* London: The Stationary Office.

Consultation paper from the Chief Medical Officer, (2003), *Making Amends - Clinical Negligence Reform.* Department of Health. London: The Stationary Office.

Forsberg, M. *et al.,* (1996), Maintaining Safer Sex Behaviours in HIV- Infected Adolescents with Haemophilia. *AIDS Care*, **8** (6), pp. 629-640. Blackwell Science.

Hudson, M. (2002) *Managing without profit.* 2nd ed. London: Directory of Social Change.

Johnson, G. *et al* (2006) *Exploring Corporate Strategy* 7th ed. London: Pearson Education Limited.

Kinrade, D. (2007), *Alf Morris: People's Parliamentarian – Scenes from the Life of Lord Morris of Manchester.* London: National Information Forum.

Kumar, R., (1999), *Research Methodology: A step-by-step guide for beginners.* London: Sage Publications Limited.

Mintzberg, H. *et al* (1998) *Strategy Safari: the complete guide through the wilds of strategic management.* London: Pearson Education Limited.

Piper, R., (2007), Don't get left behind. *Governance.* (September 2007). Governance Publishing.

Report of the Royal Commission on the Civil Liability and Compensation for Personal Injury. (1978). Chairman: Lord Pearson. London: The Stationary Office: Cmnd. 7054-1, 1978.

Research Note for the Health and Community Care Committee of the Scottish Parliament. *Hepatitis C Virus in Blood and Blood Products.* (6 November 2000) Reference RN 00/85 (Revised).

Research Note for the Health and Community Care Committee of the Scottish Parliament. *The Macfarlane Trust & No-Fault Compensation.* (3 September 2001) Reference RN 01/80.

Robson, C., (2002), *Real World Research.* London: Blackwell Publishing.

Sarantakos, S., (1998), *Social Research.* London: MacMillan

Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991 Department of Health. London: The Stationary Office.

Strategy Unit, (September 2002), *Private Action, Public Benefit a review of charities and the wider not-for-profit sector*. [Online]
Available from www.number-10.gov.uk/su/voluntary/report/index.htm
[Accessed 18 April 2007]

Wilde, J. *et al.,*(1999), Increased bleeding Associated with Protease Inhibitor Therapy in HIV Positive Patients with Bleeding Disorders. *British Journal of Haematology,* **107** pp. 556-559.

9. **Bibliography**

Adams, R., (1990), *Self-Help, Social Work and Empowerment.* London: Macmillan Education Ltd.

AIDS Update (March 1985) *Aids and Hemophilia: Your Questions Answered.* The National Hemophilia Foundation.

Alcock, P., (2006), *Understanding Poverty.* Basingstoke: Palgrave Macmillan.

Audit Commission (2001) *Change Here! Managing Change to Improve Local Services.* London: The Stationary Office.

Balcelis, M. & Ribalta, T., (2000), Factors Influencing Anxiety Levels in Haemophiliac Patients Co-infected with the HIV and Hepatitis C Viruses Treated with Interferon and Ribavirin. *Haemophilia,* **6** (4), p. 413. Blackwell Science.

Bardach, E., (2005), *A Practical Guide for Policy Analysis.* Washington, D.C.: CQ Press.

Bateman, N., (2005), *Practicing Welfare Rights (Social Work Skills).* London and New York: Routledge.

Berridge, V., (1996), *AIDS in the UK – The Making of Policy 1981-1994.* Oxford: Oxford University Press.

Bhaskar, R., (1986), *Reclaiming Reality.* London:Verso.

Bradshaw, J., (1972), The concept of social need: it is not always clear what is meant by social need. A crucial problem facing the social services is how to identify it. *New Society*, **19**, pp.640-643.

Bryson, J.M. (2004) *Strategic Planning for Public and Non Profit Organizations.* San Francisco U.S.A: Jossey-Bass.

Burns, D. and Taylor, M., (1998), *Mutual aid and self-help: coping strategies for excluded communities.* Bristol: The Policy Press University of Bristol.

Carlisle, C., (2001), HIV and Aids. In T. Mason, C. Carlisle, C.Watkins and E. Whithead, eds., *Stigma and Social Exclusion in Healthcare.* London and New York: Routledge.

Catalan, J. *et al.*, (1992), The Psychosocial Impact of HIV Infection in Men With Haemophilia – Controlled Investigation and Factors associated With Psychiatric Morbidity. *Journal of Psychosomatic Research*, **36** (5), pp. 409-416. Pergamon Press.

Charity Commission CC4 (2003), *Charities for the Relief of Financial Hardship.* London: The Stationary Office.

Charity Commission CC9 (2004),*Campaigning and Political Activities by Charities.* London: The Stationary Office.

Consultation paper from the Chief Medical Officer, (2003), *Making Amends - Clinical Negligence Reform.* Department of Health. London: The Stationary Office.

Djolbegovic, B., (1996), Comparison of the Quality of Life Between HIV Positive Haemophilia Patients and HIV Negative Patients. *Haemophilia*, **2** (3), pp 166-172. Blackwell Science.

Dorey, P., (2005), *Policy Making in Britain.* London: Sage Publications Limited

El Menyawi, H., (2003), Public Tort Liability: Recommending an Alternative to Tort Liability and No-Fault Compensation. *Global Jurist*, **3** Issue 1

Evatt, B.L., (2006), The tragic history of AIDS in the hemophilia population, (1982-1984). *Journal of Thrombosis and Haemostasis,* **4:** 2295-2301

Fenn, P, *et al*., (2004), Making Amends for negligence. *British Medical Journal,* 2004; 328:417

Fetterman, D.M., (1989), *Ethnography.* London: Sage Publications Limited

Forsberg, M. *et al.,* (1996), Maintaining Safer Sex Behaviours in HIV- Infected Adolescents with Haemophilia. *AIDS Care*, **8** (6), pp. 629-640. Blackwell Science.

Freeman, R (2001) 'The United Kingdom', in Albaek, E (ed) IV: Critical challenges in managing crises, in Bovens, M, t'Hart, P and Peters, B G (eds) Success and Failure in Governance. A comparative analysis of European states, Cheltenham: Edward Elgar.

Gaine, W.J., (2003), No-fault compensation systems: experience elsewhere suggests it is time for the UK to introduce a pilot scheme. *British Medical Journal,* 2003;326:997

George, D. and Mallory, P., (2006), *SPSS for Windows Step by Step: A simple guide and reference.* USA: Allyn & Bacon

Goldman, E. *et al*., (1993), A Family with HIV and Haemophilia, *AIDS Care*, **5** (1), pp. 79-86. Blackwell Science.

Gordon, J. *et al*., (1993), Staff Distress Among Haemophilia Nurses, *AIDS Care*, **5** (3), pp. 359-367. Blackwell Science.

Hudson, M. (2002) *Managing without profit.* 2nd ed. London: Directory of Social Change.

Johnson, G. *et al* (2006) *Exploring Corporate Strategy* 7th ed. London: Pearson Education Limited.

Jones, Q. *et al.*, (1994), A Controlled Study of Anxiety and Morbid Cognitions at Initial Screening for Human Immunodeficiency Virus in a Cohort of People with Haemophilia, *Journal of Pyschosomatic Research*, **39** (5), pp. 597-608. Pergamon Press.

Kinrade, D. (2007), *Alf Morris: People's Parliamentarian – Scenes from the Life of Lord Morris of Manchester.* London: National Information Forum.

Kumar, R., (1999), *Research Methodology: A step-by-step guide for beginners.* London: Sage Publications Limited.

Lee, C. et al (1997), High cost, low volume care: the case of haemophilia. *British Medical Journal,* 1997;315:Editorial

Lesens, O. et al (1998), Hepatitis C Virus Is Related to Progressive Liver Disease in Human Immunodeficiency Virus-Positive Hemophiliacs and Should Be Treated as an Opportunistic Infection. *The Journal of Infectious Diseases,* 1999;179:1254-1258

Madsen, D., (1992), *Successful Dissertations and Theses.* San Francisco: Jossey-Bass.

Martin, L., (2006), Tainted blood victims allege official cover-up. *The Observer* 23 April 2006

Millar, J. (ed), (2003) *Understanding Social Security: Social Issues, Policy & Practice.* Bristol: Policy Press.

Miller, R., (1995), Guidelines for Counselling Adolescents with Haemophilia and HIV Infection and Their Families, *AIDS Care*, **7** (3), pp. 381-389. Blackwell Science.

Miller, R., (2001), The Responsibility of Separating Truth from Myth to Patient and Family, *Haemophilia*, **7** (1), pp. 91-95. Blackwell Science.

Mintzberg, H. *et al* (1998) *Strategic Safari: the complete guide through the wilds of strategic management.* London: Pearson Education Limited.

Norman, R. *et al.*, (1998), Close Relationships and Safer Sex Among HIV Infected Men with Haemophilia, *AIDS Care*, **10** (3), pp. 339-354. Blackwell Science.

Piper, R., (2007), Don't get left behind. *Governance.* (September 2007). Governance Publishing.

Ragni, M., (1998), Progression of HIV in Haemophilia, *Haemophilia,* **4** (4), pp.601-604. Blackwell Science.

Report of the Royal Commission on the Civil Liability and Compensation for Personal Injury. (1978). Chairman: Lord Pearson. London: The Stationary Office:
Cmnd. 7054-1, 1978.

Research Note for the Health and Community Care Committee of the Scottish Parliament. *Hepatitis C Virus in Blood and Blood Products.* (6 November 2000) Reference RN 00/85 (Revised).

Research Note for the Health and Community Care Committee of the Scottish Parliament. *The Macfarlane Trust & No-Fault Compensation.* (3 September 2001) Reference RN 01/80.

Robson, C., (2002), *Real World Research.* London: Blackwell Publishing.

Sarantakos, S., (1998), *Social Research.* London: MacMillan

Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991 Department of Health. London: The Stationary Office.

Stewart, M. *et al.*, (1995), Living With Haemophilia and HIV/AIDS – Support and Coping, *Journal of Advanced Nursing*, **22**, pp. 1101-1111. Blackwell Science.

Strategy Unit, (September 2002), *Private Action, Public Benefit a review of charities and the wider not-for-profit sector*. [Online]
Available from www.number-10.gov.uk/su/voluntary/report/index.htm
[Accessed 18 April 2007]

Thompson, C. *et al.*, (1996), A Controlled Neuropsychological Study of HIV Seropositive and HIV Seronegative Adolescent Haemophiliacs, *Haemophilia,* **2** (3), pp. 145-152. Blackwell Science.

Vicenzi, P. *et al.*, (1997), Haemophilia and Nonprogressing Human Immunodeficiency Virus Type 1 Infection, *Blood*, **89** (1), pp. 191-200. The American Society of Hematology.

Wilde, J. *et al.,*(1999), Increased bleeding Associated with Protease Inhibitor Therapy in HIV Positive Patients with Bleeding Disorders. *British Journal of Haematology,* **107** pp. 556-559.

Winter, M., (2000), The Ever Changing Needs of Those with Long-term HIV Infection, *Haemophilia,* **6**. World Federation of Haemophilia.

10. **Websites**

http://www.haemophilia.org.uk/index.php?content_id=87&parent=278
[Accessed on 14.4.07]
http://www.cbc.ca/news/backgound/taintedblood/bloodscandal_timeline.html
[Re-accessed on 12.3.08]
http://www.taintedblood.info/timeline.php
[Re-accessed on xxxxxx.08]
http://www.statistics.gov.uk/downloads/theme_health/DH1_38_2005/DH1_No_38.pdf
[Accessed on 7.3.08]
http://www.statistics.gov.uk/cci/nugget.asp\?id=654
[Accessed on 7.3.08]
http://www.statistics.gov.uk/cci/nugget.asp\?id=952
[Accessed on 7.3.08]
http://www.statistics.gov.uk/cci/nugget.asp?id=285
[Accessed on 7.3.08]
http:/www.statistics.gov.uk/census
[Accessed on 7.3.08]
http://www.peterboroughtoday.co.uk/business/Report-It-pays-to-work.3822803.jp
[Accessed on 7.2.08]
http://www.vcjdtrust.co.uk
[Accessed on xxxxx.08]
http;//www.bbc.co.uk/devon/news/102001/01/mcvey.shtml
[Accessed 10.3.08]
http://www.archercbbp.com/hearing.php
[Re-accessed on 25.3.08]
http://www.mesothelioma.uk.com/index.php?pageno=97&sub=61
[Accessed 11.3.08]
http://medneg.michelmores.com/news/default.asp?Display=323
[Accessed 11.3.08]
http://www.thalidomide.org.uk/history.aspx
[Accessed 15.1.08]
http://www.dwp.gov.uk/asd/tbmt.asp
[Accessed 28.3.08]