

# ‘The H in HIV Stands for Human, Not Haitian’<sup>1</sup>: Cultural Imperialism in US Blood Donor Policy

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Ethical reflection on the justice/injustice of past public health policy can inform current and future policy creation and assessment. For eight years in the 1980s, Haitians were prohibited from donating blood in the USA due to their national origin, a supposed risk factor for AIDS. This case study underlines the racial stereotypes and cultural ignorance at play in risk assignment—which simultaneously marked Haitians as risky ‘others’ and excluded them as significant participants in policy-making. This article also discerns Haitian understandings of justice related to this donor policy and explores how dimensions of this past policy relate to current blood donor policy.

## Introduction

On 20 April 1990, more than 50,000 persons marched across the Brooklyn Bridge into the streets of Manhattan to protest a policy of the Food and Drug Administration (FDA) that designated Haitians in the USA as ‘at increased risk’ for AIDS due to their national origin and then prohibited them from donating blood (Lorch, 1990). That same day dozens of similarly inclined persons gathered in a meeting room in Rockville, Maryland to testify at a special meeting of the FDA’s Blood Products Advisory Committee (BPAC). While New York protestors waved signs asserting, ‘Federal Discrimination Agency’, BPAC presenters called on the FDA to justify its exclusionary donor policy. These speakers offered epidemiological data and moral arguments that challenged the bases of the policy, described the harmful personal and collective consequences of the policy, and demanded that the policy be rescinded (Blood Products Advisory Committee, 1990). Later that year, and eight years after the policy was established, the FDA ended its policy of excluding Haitians as blood donors.

So why examine this policy now two decades later given that Haitians are no longer excluded for HIV risk

<sup>1</sup> This phrase was Ron Medley’s of ACT-UP in his testimony to the Blood Products Advisory Committee (BLAC, 1990, 136). His full sentence was ‘We at ACT-UP hope that we as a country never lose sight of the fact that the H in HIV stands for human, not Haitian.’

on the basis of national origin? (i) To document and understand this little known story of FDA policy in the current context of (a) ongoing racial and immigrant discrimination in the USA, (b) the potential for significant Haitian emigration to the USA due to the grim economic conditions in Haiti, recently exacerbated by the January 2010 earthquake, and (c) the recent revival of the theory that the HIV virus spread to the USA from Haiti (Gilbert *et al.*, 2007). (ii) To explore the nature of this unjust policy as an example of cultural imperialism. (iii) To identify Haitian understandings of justice related to this policy. (iv) To explore how this 1980’s FDA exclusion of Haitians relates to contemporary blood donor policy, expressly to the current exclusion of men who have had sex with men since 1977. Thus not about blood donation policy in general, this ethical analysis focuses on a specific, historical, and previously neglected FDA blood donation policy using a particular conceptual lens that adds to our understanding of why this policy was implemented and later withdrawn.

## FDA Donor Deferral Policy in Context

Dire economic and political conditions in Haiti in the late 1960s through the 1980s motivated several hundred thousands of Haitians to emigrate to the USA. Some arrived in the early 1980s in boats landing on the south

Florida coast. On the whole, the US welcome of these ‘boat people’ and other Haitian immigrants was less than hospitable: nearly all were refused political asylum and some were held in detention centers (Stepick, 1982; Laguerre, 1984; Farmer, 1992). Even before this influx, Laguerre notes, ‘the *New York Times* portrayed them as refugees with “endemic problems of lack of education, unemployment, inability to speak English, being foreigners to U.S. blacks and being in the U.S. illegally”’ (Laguerre, 1984, 10).

In July 1982, the Centers for Disease Control (CDC) reported that 34 Haitians living in the USA, mostly in Miami and New York City, had fallen ill or died with unusual opportunistic infections or Kaposi’s sarcoma (Centers for Disease Control, 1982a).<sup>1</sup> These 30 men and four women exhibited disease and mortality patterns previously identified primarily among homosexual men and IV drug users, yet nearly all of these Haitians denied both homosexual activity and IV drug use. Soon the CDC began to refer to ‘Haitian origin’ as an ‘identified risk factor’ for AIDS (Centers for Disease Control, 1982b). The following year the Public Health Service officially named ‘Haitian entrants to the United States’ and their sexual partners as persons ‘at increased risk for AIDS’ (Centers for Disease Control, 1983a).

Following suit, the FDA issued specific regulatory guidance to blood-collection centers that identified ‘Haitian entrants to the United States’ as a risk group for AIDS and prohibited them from donating blood (Food and Drug Administration, 1983: 290). The FDA’s justification for excluding Haitians as blood donors was based on CDC data showing that Haitians made up approximately 6 per cent of all AIDS cases in the USA while representing only 0.3 per cent of the US population (Centers for Disease Control, 1982b; Sullivan, 1983). Soon thereafter in 1984 the FDA narrowed the Haitian risk group to Haitians entrants *since 1977* based on its understanding that 85 per cent of Haitians with AIDS in the USA were recent immigrants (Blood Products Advisory Committee, 1990: 24). This deferral of recent Haitians immigrants remained in effect from March 1983 until February 1990 when the FDA reverted back to the policy’s original scope of excluding *all* Haitian immigrants (Blood Products Advisory Committee, 1990: 25; Lambert, 1990). This expanded exclusion triggered strong claims of injustice from Haitian immigrants as well as demands for the FDA to not only retract this latest policy amendment but also to end the entire policy that labeled Haitians as a risk group and then deferred them.

Resistance to the original FDA deferral policy had been launched back in 1983 by the Haitian medical community and government officials (Farmer, 1992;

Wilke, 1983; Cineas, 1983; Blood Products Advisory Committee, 1990: 82, 127). Despite their arguments that the policy was unjustified by scientific data and was discriminatory in its targeting of the Haitian community, the policy had remained in place (Altman, 1983a,b).<sup>2</sup>

The 1990 expanded exclusion prompted a wider group of US public health officials, blood centers, elected public officials as well as AIDS activists to join Haitians in a heightened policy critique. Increasingly vocal opposition prompted the FDA to call a special April 1990 BPAC meeting to hear testimony from concerned persons and to review the scientific basis of the policy.

At this BPAC meeting presentations by CDC and FDA officials were followed by testimony from two dozen representatives of the National Haitian-American Health Commission, the Haitian-American Public Health Initiative of Boston, the Center for Haitian Studies—University of Miami, the American Red Cross, the National Hemophilia Foundation, the Catholic Commission of Social Advocacy—the Archdiocese of Miami, the Gay Men’s Health Crisis, the Office of the Mayor—City of Boston, the New York City Commission on Human Rights, the NAACP and others (Blood Products Advisory Committee, 1990). Their testimony was in near unanimous agreement: the current policy was scientifically and morally unjustified both in its identification of Haitians—any Haitians—as a risk group for AIDS, and in its subsequent exclusion of them as blood donors.<sup>3</sup>

At the meeting’s end, BPAC recommended that the FDA eliminate its donor deferrals based on geographic or national origin (Blood Products Advisory Committee, 1990: 186).<sup>4</sup> Eight months later then Secretary of Health and Human Services, Dr. Louis Sullivan, rescinded the Haitian deferral policy effective January 1991 (Hilts, 1990). Several national newspapers took notice (Hilts, 1990; Jackson, 1990) though federal health officials did little to publicize this policy change.

## Injustice as Cultural Imperialism

Cultural imperialism, as described by Young, helps to illumine the under-analyzed dimensions of injustice embedded in this FDA policy—dimensions that extend beyond those associated with the conventional notion of justice as the fair distribution of benefits and burdens (Young, 1990). This distributive paradigm of justice obscures certain tangible, non-distributive issues as issues of *justice*, and culture and decision-making are two such justice issues salient to this FDA policy.

Cultural imperialism ‘involves the universalization of a dominant group’s experience and culture, and its establishment as the norm’ (Young, 1990: 59). According to Young, ‘To experience cultural imperialism means to experience how the dominant meanings of a society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it out as the Other’ (58–59). These dominant group experiences, perspectives and meanings are assumed to be universal, neutral and normative, while ‘others’ are labeled as different, particular and biased. But these ‘others’ are rarely understood as simply different, but rather their difference ‘becomes reconstructed largely as deviance and inferiority’ (59). Also their ‘otherness’ is often associated in some way with their bodies, as if they had been ‘stamped with an essence’, thereby legitimating fear and avoidance of them and making denial of their ‘difference’ difficult (58–60). Thus ‘the injustice of cultural imperialism’ is ‘that the oppressed group’s own experience and interpretation of social life finds little expression that touches the dominant culture, while that same culture imposes on the oppressed group its experience and interpretation of social life’ (60).

So what dominant group experiences, perspectives and meanings were embedded in this FDA policy and assumed to be universal and normative? In what ways were Haitians both marked as different or ‘other’ and made invisible? The dominant group in this policy debate was comprised largely of White, male, medical professionals and federal health officials from both the FDA and the CDC. The 1990 BPAC meeting and related debate amply illustrate the cultural ignorance and racial stereotyping of the dominant group, as well as their exclusive policy-making practices that invisibilized Haitians. Haitians were marked as a group at higher risk for AIDS, initially based on national origin and later, ostensibly, based on heterosexuality. Their permanent deferral as blood donors represented yet another form of invisibility. In the next section I draw primarily from the presentations and discussion at the 1990 BPAC meeting to illustrate the dominant group’s cultural ignorance, racial stereotyping and exclusion of Haitians as policy participants. I do this through the lenses of the risk categories applied to Haitians.<sup>5</sup>

### Haitians as a Risk Group Based on National Origin

The FDA’s designation of Haitians as a risk group for AIDS based on national origin was this policy’s most obvious ‘marking’ of Haitians (Centers for Disease

Control, 1983a; Food and Drug Administration, 1983). In March 1983, the CDC noted that ‘Very little is known about risk factors for Haitians with AIDS’ (Centers for Disease Control, 1983a). Federal health officials were perplexed about how Haitians were getting sick given that most Haitians denied exposure to the two most recognized AIDS transmission routes at the time: homosexual activity among men and IV drug use among women and men.

The Haitian-American medical community was less confused than the FDA about how Haitians were getting AIDS. They believed that Haitians got AIDS the same ways that non-Haitians did (or were thought to at the time): primarily through homosexual activity and IV drug use. Haitians with AIDS, they said, did not report these behaviors to health officials because of strong cultural taboos against them. Furthermore, early medical researchers were linguistically and culturally unprepared to do this sensitive research. As one physician with the Haitian Medical Association put it,

American doctors ask Haitian patients: “Are you homosexual or an IV drug user?” and then wait for a yes or no answer,.... They get a no answer because homosexuality and or even IV drug use is a tough subject to accept in Haitians. (Altman, 1983a)

Such ignorance of Haitian culture signals dominant group perspectives at work, likewise described by CDC epidemiologist, Harry Haverkos, who traveled to Miami to study early AIDS cases there:

I found an anthropologist because I didn’t know enough about the culture. .... There was the fear of being deported. I walk in and say I’m from the federal government and I want to talk to you, and immediately they figure it’s the Immigration and Naturalization Service. Also there were problems with language. Their word for gay is transvestite, so you’re really asking if they are a transvestite, and you have to assume that if they are, they’re probably gay too. You have to find out the number of sexual partners, but you have to define what you mean by sex and draw pictures. . . . (West, 1983, 40)

Despite the CDC’s lack of knowledge about AIDS transmission to Haitians, the CDC created a distinct risk group based on national origin, ‘Haitians’ (Centers for Disease Control, 1982a).

Racial stereotypes compounded the cultural ignorance of this designation. As Dr. Larry Pierre of the University of Miami’s Center for Haitian Studies bluntly put it:

Today the classification of AIDS goes something like this: You have AIDS. You are black, with an accent. Then you are Haitian. It could also go: If you are white, not American, and you are denying IVDU and you are not a hemophiliac, then you are “undetermined” or “other”. (*Blood Products Advisory Committee, 1990: 97*)

Risk group status based on national origin was an unwelcome label for Haitians who felt held to a double standard. The general populations of some large US cities had higher prevalence rates of AIDS but those groups were allowed to donate blood (*Antoine et al., 1990; Jackson, 1990; Blood Products Advisory Committee, 1990: 116*). Some other racial and ethnic communities in the USA also had higher rates and were not deferred (*Antoine et al., 1990*). Said one BPAC presenter:

I would like to know whether you have the same data for the Jewish population, if you have the same data for the Italian population, ... or have you followed those populations with the same eagerness, have you followed those populations with the same scientific strength that you seem to demonstrate when it comes to Haitian studies? (*Blood Products Advisory Committee, 1990, 35–36*)

This AIDS exclusion echoed two other double standards in blood donor practices: in the 1980s, Haitians with hepatitis B were prohibited from blood donation, while homosexual men, with a higher prevalence rate of hepatitis B, were allowed to donate (IOM, 1985, 111, 122). And in the 1940s, the American Red Cross (ARC) had rejected Black blood donors. When ARC met resistance to this discriminatory practice, it accepted Blacks as donors but then for a time segregated Black and White blood for transfusion purposes (*Love, 1996: 141*).<sup>6</sup>

Added to these ‘othering’ practices, or perhaps because of them, was a common confusion about the nature of ‘risk’. In public health terms, risk factors are ‘various conditions that can put people at risk of getting a disease’ (*Altman, 1983b: 2*). Yet some believed that Haitians themselves were a condition that put other people at risk of AIDS. In other words, some understood Haitians to be as a risk factor for AIDS—and risk factors are, of course, to be avoided (*Altman, 1983b*).

The CDC recognized this misunderstanding:

... the classification of certain groups as being more closely associated with the disease has been misconstrued by some to mean that these groups are likely to transmit the disease through non-intimate interactions. This view is not justified by available data. Nonetheless, it has been used

unfairly as a basis for social and economic discrimination. (*Centers for Disease Control, 1983b*)

Yet CDC officials reinforced this perception when they spoke confidently that something ‘different’ was going on among Haitians, despite their stated lack of understanding of how Haitians were being infected. Said one CDC official,

Sure we can’t get all the information.... Sure there is going to be some concealment. Sure, having a white non-Haitian interviewer versus a black and Haitian patient creates certain cultural and other strains that are going to prevent you from getting all the information. However, even given all that, there remains *something different* about the subgroup. (*Altman, 1983b: 2; emphasis added*)

CDC Director, William Foege, agreed: ‘The fact is that the rate of AIDS in Haitians in the United States far exceeds what we see for non-Haitians, and we have to come up with some explanation for that’ (*Altman, 1983b: 2*).

Within a year after its creation of the Haitian risk category, and without explanation, the CDC began to refrain from naming Haitians as a risk group in its reports. A September 1983 report grouped Haitians with ‘others whose risk and exposure factors are under investigation’ and did not identify them as a distinct risk group (*Centers for Disease Control, 1983b*). It did the same in subsequent updates (*Centers for Disease Control, 1984a,b*), noting in late 1984 that ‘the rate of increase among Haitian AIDS patients is significantly less ( $P < 0.001$ ) than among the remaining groups’ (*Centers for Disease Control, 1984c*).

Health officials’ confidence that Haitians were ‘different’ was inevitably influenced by widely held attitudes and beliefs about Haitians, or as Farmer described it, a ‘symbolic network’ of meanings characterized by racism and exoticism (*1992: 220–228*). Albert’s 1980’s assessment of US media coverage of the AIDS epidemic found that,

... Haitian-Americans present preexisting characteristics of *an already non-normative character*. They are black, tend to be poor, are recent immigrants, and the association of Haiti with cultural-religious practices fuels the current tendency to see deviance in groups at-risk for AIDS. (Albert in *Farmer, 1992: 221; emphasis added*)

As Farmer observed, ‘... the Haitian cases fit the already established script: the incidence of AIDS in Haitians served to *reinforce* the stigma experienced by those with AIDS’ (*1992: 221*).<sup>7</sup>

Testimony at the 1990 BPAC meeting revealed powerful examples of how the FDA policy reinforced existing racial stereotypes and stigma. As one psychiatrist described it,

If you are a Haitian living in Florida, you would probably be referred to as a boat person. You would probably be referred to as those people that they get on the high seas and turn away because you cannot have political ground to make a demand for asylum. Also, you are the people who are not educated...and now with the FDA policy, you are the people that are carrying that deadly virus, HIV. (*Blood Products Advisory Committee, 1990: 101*)

Another BPAC presenter observed,

What people would infer, looking at such a policy, would be that Haitians are by birth genetically disease-ridden citizens, and therefore are threatening to contaminate our blood supply in the U.S.

Another deduction would be that Haitians are more sexually promiscuous than citizens born in other places, ... and therefore are more likely to spread AIDS heterosexually. (*Blood Products Advisory Committee, 1990: 94–95*)

Similarly, the President of the Haitian-American Nurses Coalition of Florida reported, ‘...a general attitude [exists] which the FDA position aggravates, that places Haitians in a somehow distinct and maybe dangerous biological category simply because of their national origin’ (*Blood Products Advisory Committee, 1990: 131*).

An NAACP representative highlighted one consequence of such stigma:

...by including Haiti and sub-Saharan Africa on the exclusion list of the FDA, this gives support to the belief of many people on this country that AIDS is a problem of “other people.” If it is a black problem, most people need not be concerned. If it is a problem of hemophiliacs, most people need not be concerned. Most people find refuge in believing that this is a problem of the unwanted, the unwelcome, and the undesirable. Unfortunately, the FDA policy gives comfort to this position. (*Blood Products Advisory Committee, 1990: 151*)

In short, the FDA policy labeled Haitians an at-risk group by virtue of their national origin and excluded them from blood donation. Widespread cultural ignorance and racial stereotypes about Haitian immigrants helped to justify this exclusion. The FDA exclusion of

Haitians as blood donors both reflected and added to the existing stigma and discrimination that Haitians experienced. When national origin became an increasingly unacceptable justification for donor exclusion, policy-makers shifted ‘the mark’ and the heterosexuality of Haitians became the vehicle of their exclusion.

### Haitians as Risky Heterosexuals—National Origin Obscured

In May 1985, the CDC officially *declassified* Haitians as a distinct group at risk for AIDS:

The previous separate listing for Haitian-born patients has been discontinued in light of current epidemiological information that suggests both heterosexual contact and exposure to contaminated needles (not associated with intravenous (IV) drug abuse) play a role in disease transmission. (*Centers for Disease Control, 1985*)

As Haitian national origin ceased to be a CDC classification for persons with AIDS, Haitians diagnosed with AIDS who were not homosexual or using IV drugs were now assigned to the ‘other/unknown’ group for reporting purposes.

But in a contrary move, the CDC declared that Haitians would continue to be deferred as blood donors, citing a report that 5 per cent of Haitians carried antibodies to the AIDS virus: ‘While this seroprevalence is lower than that found in other patient groups, it is several times higher than that seen in random blood donors’ (*Centers for Disease Control, 1985*). Thus for blood donation purposes, Haitians continued to be excluded as donors.<sup>8</sup>

But several years later during the 1990 BPAC review of the policy, the FDA offered a different explanation for its continued deferral of Haitian donors:

In 1986 it was recognized that countries of Central Africa as well as Haiti had a distinct pattern of spread of HIV in which heterosexual transmission was the predominant factor in the spread of the epidemic. Because, for the vast majority of potential donors, risk from heterosexual conduct is more difficult to identify than risk from homosexual behavior or IV drug use, it was decided to defer immigrants from Central Africa and *continue to defer immigrants from Haiti on that basis*. (*Blood Products Advisory Committee, 1990: 24; emphasis added*)

In other words, after 1986, Haitians were deferred because the FDA understood them to transmit AIDS primarily heterosexually, which was different than perceived dominant patterns of transmission in the USA then, which were sex between men and IV drug use.

The relatively high heterosexual transmission rates in Haiti and central Africa, combined with the belief of US health officials that heterosexual risks for HIV were hard to identify and screen for, meant that, in effect, Haitians were still deferred by national origin though now under the cloak of heterosexual risk. Not all heterosexuals were deferred, only those from Haiti and certain other countries.

Cultural ignorance and racial stereotyping contributed to Haitians' relative absence in the making of this policy. Extensive analyses of the policies and politics of 1980's AIDS reveal contested debates between medical/public health officials, gay rights, AIDS activists and hemophiliacs, with little mention of Haitians (Shilts, 1987: 220–224; Bayer, 1999; Institute of Medicine, 1995).<sup>9</sup> For example, a 1995 Institute of Medicine (IOM) report provides the most comprehensive analysis of blood policy-making from 1983 through 1985. It offers no evidence of Haitian participation in policy-making, and its few references to Haitians serve primarily to track them as AIDS cases in CDC reports (Institute of Medicine, 1995). Written accounts of the legendary January 1983, CDC-sponsored public meeting, which brought together a wide range of blood policy stakeholders, do not mention a Haitian presence, nor do they note their absence (Institute of Medicine, 1995; Shilts, 1987).

One consequence of this lack of Haitian involvement in policy deliberations was that its harmful effects went largely unnoticed. Testimony at the 1990 BPAC meeting described in painful detail the policy's many stigma-generated harms: Haitians lost jobs, life and health insurance, and homes (Blood Products Advisory Committee, 1990: 77–78, 152); school children perceived as having AIDS were attacked (152), and all had to deal with the psychological effects of discrimination (123, 152–153). Stigma became an obstacle to AIDS education (103), and some Haitians came to distrust even Haitian health care workers (131), thus in tragic irony, generating a climate for the spread of AIDS (117, 126, 145).

### BPAC 1990: The Policy's Undoing

By the 1990 BPAC meeting, the FDA was hard pressed to justify both its original deferral policy and its later policy expansion to all Haitians in the USA. FDA presentations at the meeting reflected a conflicted attempt both to defend current policy and to justify a potential change to it. On the one hand, after the CDC de-designated Haitians as a risk group, Curran (of the CDC) held that the deferral of Haitians nonetheless provided 'additional protection' to the blood supply (Blood Products Advisory Committee, 1990: 15). Similarly Epstein

(of the FDA) asserted that the 'exclusion of Haitian donors contributes some increment of safety to the blood supply' (30) and offered a detailed calculation of the increased risk of AIDS to the blood supply if Haitians were allowed to donate blood (26–29).<sup>10</sup>

On the other hand, public health officials acknowledged the significant problems with the data underlying the policy. The CDC revealed that it did not have HIV prevalence data on Haitian blood donors (48, 55) or on the Haitian-American population in the USA (30, 42)—data necessary for an accurate calculation of blood supply risk. Nor was it collecting such data: '...we do not have any ongoing studies specifically directed at Haitians at this time' (54). An FDA official conceded that '[w]e by and large work with available published literature and expert opinion that we can get from consulting scientists' and that data on Haitian blood donors would be difficult to obtain in any case since the FDA had excluded Haitians as blood donors since 1983 (56). The FDA acknowledged that HIV prevalence rates and risk factors were 'as high in some US communities as they are in immigrants from certain countries' and that high rates of heterosexual transmission were found in many countries, not just those few excluded in blood deferral policy (26). Furthermore Epstein revealed,

Neither the FDA nor the larger PHS has taken a position on the level of prevalence in a population that constitutes a greater than acceptable risk to either the blood center or the transfusion recipient. Indeed, there may not be any such definable level (29).

Ultimately this confusing set of policy rationales became moot with the FDA's admission that its 1990 policy expansion excluding all Haitians 'was not subjected to close scientific scrutiny at the time that the change was made' (56–57). Epstein explained that given the pressure on the FDA to streamline donor exclusions, the policy expansion was,

... an effort to make the exclusion consistent for the Africans and Haitians... but it was not a change which was based on any new scientific data ....

.....

It was simply an effort to make the system work smoothly and at the same time be conservative [about blood safety] ... (57).

While this rationale of convenience explained rather than justified the 1990 policy expansion to all Haitians, it neither explained nor justified the original deferral of Haitians. In the end, the FDA simply ended the policy.

It would be another 20 years before definitive surveillance data and trends regarding Haitians with AIDS in this period would be published (Marc *et al.*, 2010).

## Multiple Meanings of Justice

The 1990 BPAC meeting revealed not only injustice, understood here as cultural imperialism, but also four related understandings of justice as described by Haitian participants: legal justice, human rights, restorative justice and participatory justice.

A legal sense of justice was evident in Haitian invocations of the US Constitution:

... the US Constitution requires equal treatment under the law for each of its citizens. The government ... cannot discriminate against persons based on certain different grounds like national origin or race, for instance, unless they both have a compelling reason and there is no alternative but to use the characteristic of the [sic] national origin as the basis of that discrimination.

This requirement is not met in this case. Even if protecting the blood supply is a compelling reason, there is an alternative to discrimination based on national origin, which is the HIV antibody test. ...There is no justification for using national origin as the basis for exclusion of blood. Such a policy is repugnant to the principles of the letter of the US Constitution. (*Blood Products Advisory Committee, 1990: 92*)

Another witness called for due process and claimed that the policy was ‘a mistake . . . pregnant with civil rights violations’ (88). These calls for equal treatment and due process clearly challenged the FDA’s assumption of national origin as justification for exclusion.

The second sense of justice pointed to the FDA’s responsibility to make policy ‘consistent with human rights principles’ (154). ‘All human beings deserve respect and preservation of their dignity in interaction with other human beings. Haitians, Africans, are not exempt. The fact that the FDA sets up such regulations without scientific data is an example of discrimination and disrespect in human treatment of Haitians.’ (91)

Both these human rights and legal understandings of justice asserted that national origin was not a legitimate moral or legal basis for differential treatment and required that Haitians be judged according to the same criteria as non-Haitians. Actual risk behaviors, they asserted, not national identity, should determine eligibility for blood donation, and scientific evidence should be required to that demonstrate that risk. In practical

terms, both legal justice and the human rights perspective required that the FDA end this policy.

Restorative justice called for government action beyond simply ending the policy, such as a public apology to Haitians (92, 137). One BPAC participant asked for ‘widespread media diffusion’ of the regulation’s end (147); another, for a ‘strong message from the FDA’, a ‘forceful statement of clarification from government’ (154). A Haitian Coalition representative called on the FDA ‘to actively and aggressively inform the medical community of the reason why it chose to drop them [Haitians], so there are no innuendos that any political pressure was brought to bear that caused the changes and the revision’ (129).

Finally, calls for participatory justice went beyond the demands that the Haitian community be treated equally, that the policy be ended, and that a government apology be issued. Participatory justice required that Haitians be included in the making of policy that affected their lives. It is this sense of participatory justice that most fully responds to the cultural imperialism of the policy. The National Haitian-American Commission representative was eloquent in describing this desired inclusivity:

We are asking today that the Haitian community, which is quite concerned about this decision which affects every aspect of their lives, that we be consulted as other groups are being constantly consulted in the US. We want to be a part, and we are – and I repeat – we are as concerned as anybody else about the safety of blood in the US (86–87).

Specifically they wanted to improve AIDS research by offering to design ‘culturally sensitive instruments’ for identifying risk factors (102). Said one Haitian Coalition speaker, ‘...we want you to work, as we proposed six years ago, with the Haitian community to assist it to do the educational work that needs to be done....’ (129)

‘We are all at risk’ reminded one BPAC presenter (135); asserted another, ‘This is not a Haitian problem nor an African problem; it is a problem of all America’ (148).

## Precedent

Haitian immigrants were one of several groups designated at increased risk for AIDS by the 1983 FDA policy and thus deferred, but they are the only of these groups that has been reinstated as eligible blood donors. A current donor policy controversy involves the FDA’s

lifetime deferral of men who have had sex with a man even once since 1977 (MSM), a risk group that has notable commonalities with the former Haitian risk group. MSM too were stigmatized before the FDA policy as a sexual minority group represented by a symbolic network of dominant group norms woven with sexual stereotypes and discrimination. And the ‘marking’ nature of the current policy both reflects and reinforces this stigma. MSM today have a more significant voice in FDA policy discussions than Haitians did in the 1980s, but the data associated with the current MSM exclusion are similarly problematic. Furthermore we still have no agreement on what constitutes acceptable risk in the blood supply (Galarneau, 2010).

This narrative and analysis of the FDA blood donor policy regarding Haitians remind us that there is precedent for public FDA reconsideration of the scientific data undergirding blood donation policy as well as precedent for policy change. It also demonstrates that health officials did not undertake this change without considerable pressure from the group most affected and their allies. Finally, we do well to understand how Haitians in the USA have been subject to the injustices of past public health policy, including the cultural imperialism of FDA blood policy, to better avoid such injustices today and in the future.

## Notes

1. The CDC is responsible for HIV/AIDS surveillance while the FDA has regulatory authority for blood policy. Here I follow the then conventional use of the term ‘Haitians’ to include Haitians citizens in the US as well as US citizens of Haitian origin.
2. Few in the mainstream media noted this policy opposition or questioned the policy. One who did was Robert Bazell, Science Correspondent for NBC News who, in an August 1983 *New Republic* article, criticized the labeling of Haitians as at increased risk for AIDS as well as the notion that AIDS had originated in Haiti (Bazell, 1983).
3. The exception was the National Hemophilia Foundation, which supported the FDA policy because it believed that a policy change would increase the AIDS risk to blood recipients (*Blood Products Advisory Committee, 1990: 110–115*).
4. BPAC also recommended that the FDA (i) develop donor screening questions related to heterosexual HIV risk and (ii) consider the pre-screening of first-time blood donors (*Blood Products Advisory Committee, 1990: 31*).

5. In the rest of the article, in-text references containing only page numbers refer to the transcript of the April 1990 BPAC meeting (*Blood Products Advisory Committee, 1990*).
6. Such discriminatory blood collection practices have not been limited to the US. In 1996, the Israeli blood-collection agency acknowledged dumping the donated blood of Ethiopian immigrants and explained that its actions were due to the relatively high HIV rate among these donors (Schmemann, 1996).
7. Also reinforcing the ‘already established script’ were suggestions that the AIDS virus originated in Haiti (Vieira *et al.*, 1983: 128; Simons, 1983; Fournier and Herlihy, 2006).
8. Notably the New York City Health Commissioner, David Sencer, had taken Haitians off the City’s list of AIDS risk groups two years earlier based on his data that Haitians represented 3.5 per cent of the City’s AIDS cases and on his understanding that many of those cases involved homosexual activity or IV drug use. Sencer also recognized the harm generated by such designations: ‘There is no reason to continue to stigmatize Haitians at a time when they already face considerable job and housing discrimination’ (Sullivan, 1983).
9. Farmer (1992: 208–228) is a notable exception. For more general attention to Haitians and AIDS, see Altman (1986) and Sabatier (1988).
10. Days after the BPAC meeting, the New York Times editorialized, ‘Any extra risk to the blood supply is unacceptable.’ (New York Times, 1990).

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