

Informed Refusal: Toward a Justice- based Bioethics

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Abstract

“Informed consent” implicitly links the transmission of information to the granting of permission on the part of patients, tissue donors, and research subjects. But what of the corollary, *informed refusal*? Drawing together insights from three moments of refusal, this article explores the rights and obligations of biological citizenship from the vantage point of *biodefectors*—those who attempt to resist technoscientific conscription. Taken together, the cases expose the limits of individual autonomy as one of the bedrocks of bioethics and suggest the need for a justice-oriented approach to science, medicine, and technology that reclaims the epistemological and political value of refusal.

Keywords

ethics, justice, inequality, protest, politics, power, governance, other, engagement, intervention

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In this article, I investigate the contours of biological citizenship from the vantage point of the *biodefector*—a way of conceptualizing those who resist biologically based citizenship. Biocitizenship is part of a family of concepts that sets out to understand the rights and responsibilities that accompany enhanced techniques for intervening in life itself (Benjamin 2013; Petryna 2002; Nelson 2011; Pollock 2015; Rabinow 1999; Roberts 2012; Rose and Novas 2005).¹ As such, biodeflection offers a lens through which to critically examine the stigma and penalties that may result from opting out, a conceptual corollary to the language of citizenship, which trains the analyst's attention on the various forms of exclusion and resistance that arise in biomedical and technoscientific settings. For example, biocitizenship may be enacted by those screened for the breast cancer genetic mutation, parents who bank a child's cord blood for a future stem cell transplant, or customers who sign up for the genetic ancestry testing company 23andMe's community portal—23andWe—through which the company connects customers to people who share their genetic traits.

This notion of biodeflection builds upon Montoya's notion of "bioethnic conscription" (2007) and Rapp's work (2000) highlighting the fraught process of speaking back to scientific authority, in which she refers to those on the biomedical front lines as moral pioneers: "at once conscripts to technoscientific regimes of quality control and normalization, and explorers of the ethical territory [that biotechnology's] presence produces" (p. 307).² In their confrontation with biomedical uncertainty, research participants must weigh, situate, resist, and integrate new facts *and* new ignorance in a vulnerable context. For Rapp, these moral pioneers are not only those who avail themselves of biotechnologies but also those whom she refers to as "refusers" and "draft resisters." Both recruits and resisters alike engage in a "philosophy of the limit," wherein they enact personal choices within a context of social limits beyond which they are unwilling or unable to tread. She explains that these limitations on choice are mediated by gender, race-ethnicity, class, and religion, so that people engage with biotechnologies through a complex interplay of their past experiences (real and imagined), present circumstances, and future hopes and fears.

On the most basic level, biodeflection may take the form of refusing to participate in or consume the available choices in these various contexts. But this form of agency may also extend beyond individual modes of opting out to collective forms of conscientious objection. In contexts shaped more by structural violence than consumer choice, a different model of biodeflection is likely to be enacted. For example, neighborhood residents may work together to prevent the building of a Biosafety level-4 laboratory that houses

research on the world's most dangerous microbes, as occurred in Roxbury, Massachusetts (Beamish and Luebbers 2009). Or an indigenous community may repatriate blood samples after it is found out that geneticists were conducting research that was not specified in the informed consent agreement (Garrison 2013). In the latter case, a Havasupai delegation wearing white lab coats, singing, praying, and crying collected their relatives' blood from the Arizona State University lab, offering a particularly poignant illustration of biodeflection (Bracken 2014). Community members donated samples with the hope and understanding that geneticists would identify why they had experienced a deadly spike in diabetes. The fact that scientists carried out research that was not specified in the consent forms *and* that they had failed to advance knowledge that was of particular value to the community set off a chain of events that led members to reclaim the samples (Reardon and TallBear 2012). As such, this and other moments of refusal discussed below should not be conflated with "antiscience" sentiment, but rather situated within a spectrum of agency in which talking back to scientific authority offers a prism on to a much larger terrain of action and negotiation.

The work of indigenous scholars Simpson (2007) and TallBear (2013) informs this discussion, as both conceptualize forms of sovereignty that fieldwork informants exercise and they both refuse to represent indigenous communities in particular ways for ethnographic consumption. Simpson describes these as simultaneously methodological and political choices, explaining "how refusal worked in everyday encounters to enunciate repeatedly to ourselves and to outsiders that 'this is who we are, this who you are, these are my rights'" (p. 73). Elsewhere she notes that "In listening and shutting off the tape recorder, in situating each subject within their own shifting historical context of the present, these refusals speak volumes, because they tell us when to stop. Whether or not we wish to share that is a matter of ethnography that can both *refuse* and also take up *refusal* in generative ways" (2006, 78). TallBear, in turn, explains how "The concept of refusal helps frame the silences . . . as not only against the ethnographic grain but as *productive* and *supportive* of indigenous self-determination" (2013, 17; emphasis added) and the self-determination of subordinated social groups more broadly.

The challenge of respecting the silences of research participants that these indigenous scholars reveal resonates with my own experience as an African American sociologist studying a cord-blood banking program for sickle cell anemia patients. Early on in my doctoral fieldwork, I found it difficult to refuse the urging of the program director to serve as a kind of

spokesperson for the cord-blood procedure. In one instance, and on very short notice, he convinced me to make a presentation at a national biomedical conference highlighting the benefits of adult stem cell transplants for sickle cell patients. After the fact, I reflected on how I was *enrolled to encourage enrollment* of “hard to reach” populations—what sociologist Steven Epstein calls “recruitmentology” (2008), in which culturally specific outreach practices and protocols are developed to target a diverse study sample. A key strategy is to use in-group members as spokespersons for research initiatives in order to mitigate distrust and appear more “culturally competent.” For example, Epstein recounts how one young African American physician was “invited to be a co-investigator on a study, only to conclude that what the senior investigator really sought was a ‘black face’ to display at community forums for purposes of reassuring potential participants” (2008, 816). While this kind of racialized pragmatism was not exactly my experience in the stem cell arena, the whirlwind manner in which I went from studying a program to temporarily becoming its spokesperson with very little room to maneuver (lest my access as a participant–observer be placed in jeopardy), spurs my current concern with how power and status distort biomedical encounters, regardless of the intentions of individual researchers. It has led to my own epistemological refusal of “distrust” as an ever-ready cultural trope used to explain why racialized communities are “hard to reach” and to my shift in focus to the relative trustworthiness of biomedical initiatives and institutions (Benjamin 2014). In short, the role of the in-group social scientist—as cultural translator *cum* ventriloquist—is one of many features of colonial modes of knowledge production that require critical attention and resistance.

The potential of refusal not only to negate colonial forms of knowledge production but also to create new, more equitable relationships between researchers, subjects, and the state is vital for conceptualizing a postcolonial feminist bioethics. An informed refusal, in other words, is seeded with a vision of what can and should be, and not only a critique of what is. The following sections provide brief glimpses of three moments of refusal in the context of sickle cell disease treatment in the United States, genomics research in South Africa, and genetic ancestry testing in the United Kingdom. In addition to geographic heterogeneity, the different institutional contexts—a national border agency, a regional teaching hospital, and a national biobanking initiative—necessarily create the conditions of possibility for distinct forms of authority and resistance to take shape. While it is not within the scope of this article to offer in-depth analysis of these differing institutional contexts, one difference is

important to highlight: in the first two cases, we hear the voices of patients and prospective research subjects, whereas in the third case, the penalty for refusal is so severe (i.e., deportation) that we hear “second-hand refusals” of those speaking on behalf of asylum seekers. The latter case underscores the need to institutionalize informed refusal rather than leave it to already vulnerable individuals to question those in authority.³ In this way, the following discussion lays the groundwork for situating refusal within a more comprehensive spectrum of human agency vis-à-vis technoscience, in which institutions are called upon to consider how their own norms and practices, as well as existing social hierarchies, place pressure on people to defer to authority.

Taken together, then, the prism of informed refusal sets out to explore the capacity for resisting and reimagining the rights, obligations, and capacities that inhere in biological citizenship, without at once romanticizing or valorizing resistance as an inherent “good.” In particular, it should be noted that the capacity to refuse rests upon a prior condition of possibility—that one has been offered something in the first place. Such offering, in turn, implicitly sets one apart from those who have been altogether neglected and excluded, so as not even to have the chance to refuse. That said, a key feature of social marginalization in the context of biomedicine is that subordinate ethnoracial groups are typically situated at the deadly intersection of medical abandonment and overexposure or, in the words of Alondra Nelson, a “dialectic of neglect and surveillance” (2011, 164). As such, exercising agency is not simply a matter of taking an “antimedicine” or “antiscience” position, but rather attempting to negotiate the terms of one’s engagement, an “ambivalence-in-action” (Benjamin 2011), in which refusing the terms set by those who exercise authority in a given context is only the first (and at times privileged) gesture in a longer chain of agency that not everyone can access. Although the following vignettes are partial in their illustrations of different forms of resistance, they offer a starting point for recouping a set of subaltern capacities to challenge status quo configurations of social power and technoscience.

Refusing Therapy: “We’re Not Takin’ That Stuff”

In 2005, I shadowed staff in a cord-blood banking program and adjacent sickle cell clinic, as part of research that sought to understand why black sickle cell patient families were not registering for the cord-blood program or undergoing stem cell transplants at the same rate as the predominantly

Asian American thalassemia families. Voiced from the perspective of the research director, “why were African Americans refusing to participate in this lifesaving intervention?” Next door to the cord-blood program similar concerns about “patient compliance” and “trust” abounded in relation to more mundane clinical procedures, which is where the following vignette picks up: the Harts are a family who had been coming to the sickle cell clinic for fifteen years and had developed a keen sense of the various facets of patient care. At the time of my fieldwork, a 55-year-old grandmother Sethe Hart was the primary caregiver of 15-year-old Destiny. On one particular day, Destiny was being checked by a pulmonary specialist, who went on to tell Ms. Hart that Destiny would benefit from an inhaler. Hearing that, Sethe Hart proceeded to ask the specialist a battery of questions, and a few weeks later, when I was visiting the Harts at home, Sethe explained:

Speaking of asthma, we’re challenging the test that we’re supposed to be in right now. We’re not taking that stuff. We’re walking [that is, exercising]. So when we go back in a month, they’re gonna say, “Oh! It’s the results.” Check this out. We fixing to make a fool out of them. We’re gonna walk every day, build up that breathing, whatever it is they’re looking for with them lines on that machine, and we just gonna make a fool out of them. Don’t believe everything you hear from man, ‘cause if you do you’ll be in bad shape, ‘cause there’re side effects to everything, there’re side effects to all medications⁴

In other words, Ms. Hart predicted that Destiny’s improved breathing would be falsely attributed to the inhaler. And like anthropologist Ian Whitmarsh’s 2008 “potential asthmatics” who were prescribed medicines as part of the diagnostic process, Ms. Hart was skeptical about what she perceived to be a tendency to overprescribe. Whitmarsh’s respondents described pharmacists who would take out the printed insert that described the serious side effects of the medication before giving them to caregivers, “suggestive of a dangerous secrecy” (2008, 127)—in his words—to induce compliance. Likewise, I observed Ms. Hart’s informed refusal when she was confronted with the experimental protocols routinely proposed to her in the sickle cell clinic. She explained,

Ever since Destiny was born, they have always tried to get me to OK tests, you know, with different medicines. Every time we come to an appointment they want to introduce me and Destiny into a study, and I tell them “No!” every time. Don’t even waste your time! ‘Cause I don’t want them.

When Destiny was young, they wanted to do a study to see if she was going to have a heart attack! They were going to inject stuff, give her medicines, and once we leave the hospital, I'm the one who has to give her all the medicines and stuff. And I said, "No way! I'm not gonna do that," because she was still young, and her body was pure, and clean.⁵

Sethe Hart's seeming sabotage of Destiny's prescribed treatment, and her rejection of Destiny's participation in medical studies, grows out of multiple experiences inside and outside of the clinic, including her experience as a caretaker and observer of other children's run-down conditions, which she attributes to their participation in clinical procedures of uncertain therapeutic efficacy. These multiple layers of observation and subjection recall anthropologist Audra Simpson's articulation of refusal (2007):

There seemed rather to be a tripleness, a quadrupleness, to consciousness and an endless play, and it went something like this: "I am me, I am what you think I am and I am who this person to the right of me thinks I am and you are all full of shit and then maybe I will tell you to your face." (p. 74)

When I questioned Ms. Hart about the conflict between her frustration with both routine and experimental treatments and her relative support for stem cell research, she answered that while she thinks it's fine for taxpayers' money to be used for research that may cure sickle cell disease, she doesn't believe they will ever find a cure, because scientists don't acknowledge the ultimate spiritual source of cures; by seeing themselves as the source of cures, researchers sabotage their own success. Here, Ms. Hart appeared to identify scientists as the biomedical saboteurs, pointing to their lack of confidence in spiritual intervention—and not to her own lack of confidence in experimental protocols—as the reason why stem cell treatments may not succeed.

What might be regarded as her "distrust" of medical studies, in other words, could be understood otherwise as her trust in something other than an experimental method. And lest her religiosity appear misguided or even dangerous, consider the growing body of epidemiological findings that show a "protective religious effect on both morbidity and mortality," especially for African Americans, and most notably among sickle cell patients (Levin, Chatters, and Taylor 2005). It is important to distinguish the use of religion here: not necessarily to contradict scientific claims (as in climate denial discourse) but to question the authority and power that inheres in the figure of "the scientist" as the only one who can purportedly produce

legitimate knowledge. In the next section, I return to this question of how religious knowledge may be used to unsettle the implicit forms of certainty and universality that inhere in technoscientific initiatives.

Refusing Translation: “Doctors Are Killing Us, Not Treating Us”

In 2010, the academic journal *Nature* published an article titled “Complete Khoisan and Bantu Genomes from Southern Africa” (Schuster et al. 2010). The investigators, who were based in the United States and Australia, reported the genetic structure of four Khoisan individuals as well as Archbishop Desmond Tutu. According to the article, “. . . until now, fully sequenced human genomes have been limited to recently diverged populations. . . . In terms of nucleotide substitutions, the Bushmen seem to be, on average, more different from each other than, for example, a European and an Asian . . .” (Schuster et al. 2010, 943). One of the headlines following the article’s publication was that Tutu was found to have San ancestry that he didn’t know about, which is illustrative of the wider phenomena of *diagnosing identity*—the use of genomics to assess who belongs, or not, to a particular group.

Also important to note is that ethical review boards at Pennsylvania State University, University of Limpopo Ethics Committee, and University of New South Wales, Australia, approved the *Nature* study. Readers are told that “all participants consented either in writing or via video-recorded verbal consent, and that the collection of human DNA in Namibia was conducted under a permit by the Ministry of Health and Social Services of the Namibian Government” (Schuster et al. 2010, 947). Alongside the publication, the *Nature* researchers hosted a public forum in Windhoek, Namibia, to present their findings. At the meeting, a member of the San community asked the researchers “why they had bypassed the community councils in the consent and sampling process?” In response, a representative of the research team stated that they had followed established informed consent protocol. As a result of this series of events, concerned South African researchers, ethicists, and lawyers decided to convene a series of workshops in which elected council members from Namibia, Botswana, and South Africa came together to discuss issues they had with the *Nature* article and genomics research more broadly.

In September 2013, I attended the first such workshop in Kimberley—a historic mining town located 478 km southwest of Johannesburg. As Roger Chennells, former legal advisor to the San and participant in the Kimberley

workshop, explained, one of the reasons that the San leaders were frustrated with the *Nature* article was an issue of labeling: researchers referred to the community as “hunter-gatherers”—a label that brings associated stigma and discrimination (2014). Connected to this issue of representation is the fact that the researchers did not seek approval from the councils beforehand; instead, “uneducated community members had provided informed consent on this complex project without assistance, each participant being described in the paper as the oldest member of his tribe” (Chennells 2014, 188). A letter addressed to the editor of *Nature* by San leader Mathambo Ngakaeaja explains,

We were truly shocked when the article was published. None of the official San structures in Namibia had been approached in the customary and expected manner. The Namibian San Council has representatives of all the language groups, and such a project was clearly far too complex to be explained to simple rural San, particularly “tribal elders” in the words of the article, who were unlikely to have any form of education whatsoever. I can only conclude that no effort was made to contact the community leaders in the haste or alternative secrecy that drove the researchers. (Chennells 2014, 188)

Given the serious breach of trust, the director of the South African Genome program hoped to begin a long-term partnership with the councils to establish best practices in the consultation, collection, reporting, and benefit-sharing stages of the program, assuming the councils were willing to engage. And while a number of important issues were raised during the workshop, I will highlight three recurring themes:

The first issue was around *benefit-sharing*, and in particular, capacity building emerged as very valuable to several members of the San council who asked whether members of the community would have an opportunity to be trained at the university to contribute to and raise questions about genomics research. An interesting tension arose between science in the public domain and accountability to the community: the genomicists explained that they had to make the information derived from San samples available to the global research community and that after a benefit sharing arrangement was established, the contract would not apply to other researchers who might make use of the information. So a considerable amount of time was spent discussing whether it would be possible to build in protocols whereby other researchers would have to reconsult the San about additional uses of the information and adhere to benefit-sharing

norms. The genomicists seemed skeptical about whether this would be possible, saying once information was in the public domain what happens is out of their hands, which troubled council members a great deal.

A second theme that emerged was the possible *stigma* associated with medical genomics. For example, council members wanted to know whether researchers were obligated to make it public, if they found that a certain percentage of the San were affected by HIV. And would they necessarily tell the individuals affected? A discussion ensued about whether people want this information. Researchers assured council members that people can decide beforehand what, if anything, they wish to learn from medical genomics tests. The San, like other socially subordinate groups, have a fraught relationship with biomedicine. As one council member explained, the clinic they go to gives out medicine that often makes individuals feel worse: “doctors are killing us not treating us,” he said. Interestingly enough, this experience became the grounds for both researchers and council members to recognize the value of genomics and its promise of individualized treatments. That is, there was a tentative agreement among the participants that the medicine was often harmful because the doctors lacked genomic information about the San.

Finally, a third theme arose around the *efficacy of ancestry tests* to “diagnose indigeneity” (Benjamin 2015). This refers to the query raised by council members a number of times about whether genomics could tell us if someone was truly San or not. After all, if, as the researchers said countless times, there is something “special” about the San DNA that makes it valuable to the South African Genome program, then surely the scientists could tell them who has this special DNA and who does not. It is worth noting here that the stakes for diagnosing indigeneity are getting higher. In the wake of relatively new government recognition and rights, following a long history of marginalization, the South African council members, in particular, were wary about San coming out of the woodwork who had never identified as such before. So, the possibility that a genetic test could tell them who is an authentic San sounded appealing. It was initially hard to grasp researchers’ response that in fact no such diagnosis of identity was possible, since medical genomics was presented as effectively predicting illness: why couldn’t the same techniques be used to diagnose identity?⁶

Amid these themes that were the explicit focus of deliberation, another important current ran through the Kimberley workshop—the inclusion of prayers and songs on the part of council members. Starting about midway through the first full day, one of the younger council members interjected that

an older council member would begin the proceedings with a prayer. Immediately after the prayer, when one of the researchers asked if the prayer could be translated from Tswana for the rest of the group, the younger council member—following a quick back and forth with the elder—responded that “just as the majority of the deliberations held in English were not translated neither would the prayer be.” Up until that point, individuals who required translation from English to Afrikaans or Tswana relied on someone willing to sit and whisper next to them. Translation, in other words, was happening in a piecemeal fashion. The refusal to translate the prayer for everyone was, in a sense, a way to insist on reciprocity.

Later that evening, in an informal context, the same elder who shared the prayer took the lead in singing a number of songs accompanied by a traditional string instrument that he played. In this setting under the veranda, he welcomed translation of the lyrics by other council members—many of which were funny and mischievous—for those of us who were enjoying but unable to understand the songs. During the session, the following day he also opened the workshop by singing; so what began as an informal exchange in the evening became an official part of the proceedings. Taken together, and whether intentionally or not, the increasing centrality of prayers and songs that were not originally on the workshop agenda began to shift the balance of authority and expertise on display. This dynamic recalls a point made by Herbert Marcuse in *One Dimensional Man* (1964):

Whether ritualized or not, art contains the rationality of negation. In its advanced positions, it is the Great Refusal—the protest against that which is. The modes in which man and things are made to appear, to sing and sound and speak, are modes of refuting, breaking, and recreating their factual existence. But these modes of negation pay tribute to the antagonistic society to which they are linked. (p. 63)

Technoscientific initiatives often presuppose a set of relationships and exchanges between experts and lay people, in which the latter are poised to gain knowledge and skills that will be beneficial in “their factual existence.” But by introducing prayers and songs to scientific proceedings, forms of expertise that underlie the facts of existence are potentially troubled. Religious, cultural, and linguistic knowledge is called forth, enacted, performed, *and* withheld, offering no easy transmission of cultural competency from the San to the non-San.

In this way, the interventions challenge a model of engagement in which clinicians and researchers are often taught to master a finite body of

knowledge (e.g., laundry lists of cultural traits) in order to relate effectively to patients and potential research participants. For this reason, Tervalon and Murray-Garcia (1998) argue that “cultural humility,” not competency, is a more desirable quality:

Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations. (p. 117)

They reject the deficit model of expert–lay relationships, because it demeans the competency of so-called laypeople, while ignoring the subjectivity and biases of experts. Too often, biomedical and scientific culture and Euro-American values of autonomy and free choice elude interrogation, while the cultures of “diverse” patient populations are regarded as exotic or problematic. Likewise, Tervalon’s notion of cultural humility shares important features with Jasanoff’s call for “technologies of humility” that “compel us to reflect on the sources of ambiguity, indeterminacy and complexity” (2007, 33):

Science fixes our attention on the knowable, leading to an over-dependence on fact-finding. Even when scientists recognize the limits of their own inquiries, as they often do, the policy world, implicitly encouraged by scientists, asks for more research. For most complex problems, the pursuit of perfect knowledge is asymptotic. Uncertainty, ignorance and indeterminacy are always present. (Jasanoff 2007, 33)

Indeed, by incorporating prayers and songs *without* translation into the workshop proceedings, San council members give voice to that which is unknowable and thereby signal the limits of scientific knowledge claims. This, in turn, has the effect of destabilizing existing status and power relationships that presume the San are there to learn from the experts. It is worth pointing out that—in *what* they said and *how* they said it—the genomicists sought to create a reciprocal learning environment for all involved. However, it was my impression that only after the inclusion of prayers and songs did the tenor of deliberations begin to reflect the desired reciprocity. In other words, what matters is not only who is in the room and the intentions of those gathered, but also the structures of participation,

modes of inclusion, and assumptions about what forms of knowledge and expression are valid and relevant.

Developing *technologies of humility*—that is, “disciplined methods to accommodate the partiality of scientific knowledge and to act under irredeemable uncertainty” (Jasanoff 2007, 33)—redirects our attention to the ethical and normative dimensions of scientific knowledge and governance. Such technologies compel us to begin redressing inequality before setting out to produce (which often means in practice simply *reproducing*) information about why subordinate groups remain elusive to researchers. If we understand trust and distrust not simply as individual or cultural predispositions that are “held” by some and not by others, but rather as outgrowths of social relationships that are produced through the allocation of material resources and symbolic power, then we see that techniques for cultivating relationships hinge on redistributing and refashioning those, respectively.

Refusing Refugees: “It’s Peoples’ Lives We’re Dealing With”

In 2009, the UK Border Agency (UKBA) initiated the Human Provenance Pilot Project (HPPP), with the aim of using genetic ancestry testing and isotope analysis to vet asylum claims.⁷ If, over the course of a standard interview, a caseworker grew suspicious of an applicant’s story, they would request samples of saliva, nails, and hair. The primary targets of the project were East Africans. Somali applicants escaping persecution were eligible for asylum so if the tests indicated someone was from Kenya—a phenomenon dubbed “nationality swapping”—they were scheduled for deportation. The entire process was, technically, a policy experiment. Yet over the course of the project, actual cases were vetted using these methods. A letter from the deputy director of the project, Phil Douglas, states that “all samples will be provided voluntarily,”⁸ but caseworkers are encouraged to regard *refusal to submit samples* with suspicion. The official protocol instructs,

If an asylum applicant refused to provide samples for the isotope analysis and DNA testing the case owner could draw a negative inference as to the applicant’s credibility . . . There must be other compelling evidence which also clearly demonstrates that the applicant has attempted to conceal information or mislead the UK Border Agency, it must not be stated within the RFRL in isolation and must certainly not be stated as a primary reason for refusing the applicant’s asylum claim.⁹

First through the protests of refugee advocates and the work of journalist John Travis, and not through any regulatory or oversight governing body, the project came under public scrutiny. In the process, academic scientists expressed shock and disgust, insisting that the techniques could not be used to diagnose nationality in the way the project assumed. David Balding, a population geneticist at Imperial College London, noted that “genes don’t respect national borders, as many legitimate citizens are migrants or direct descendants of migrants, and many national borders split ethnic groups” (2009).

Mark Thomas, a geneticist of University College London, who called the HPPP “horrifying,” contended that even determining a person’s ancestry—as distinct from nationality—is more problematic than many believe. “[Mitochondrial] DNA will never have the resolution to specify a country of origin. Many DNA ancestry testing companies have sprung up over the last ten years, often based on mtDNA, but what they are selling is little better than genetic astrology,” he said. “Dense genomic SNP data does have some resolution . . . but not at a very local scale and with considerable errors.” Likewise, Alec Jeffries, one of the pioneers of human DNA fingerprinting, wrote that:

The Borders Agency is clearly making huge and unwarranted assumptions about population structure in Africa; the extensive research needed to determine population structure and the ability or otherwise of DNA to pinpoint ethnic origin in this region simply has not been done. Even if it did work (which I doubt), assigning a person to a population does not establish nationality—people move! The whole proposal is naive and scientifically flawed. (Travis 2009)

As it relates to isotope testing, an isotope specialist at Durham University, Janet Montgomery, explained that “Unless the border between Somalia and Kenya represented some major geological or hydrological division, I cannot see how isotopes will discriminate between people living there let alone living at/on the border.” As Montgomery specified: “Isotopes do not respect national borders or convey some inherent national attribute. They are not passports” (Travis 2009; cf. Silverstein 2011).

Despite such severe criticism from the scientific community, the HPPP did not initially shut down or rule out the possibility that it would reintroduce a similar initiative in the future. In their own defense, representatives of the Border Agency insisted that only asylum-seekers who had already failed linguistic tests (another contested method of determining nationality)

would be asked to provide mouth swabs, hair, and nail samples.¹⁰ It also released the following written response to scientific criticisms:

Ancestral DNA testing will not be used alone but will combine with language analysis, investigative interviewing techniques and other recognized forensic disciplines. The results of the combination of these procedures may indicate a person's possible origin and enable the UKBA to make further enquiries leading to the return of those intending on abusing the U.K.'s asylum system. This project is *working with a number of leading scientists in this field* who have studied differences in the genetic backgrounds of various population groups. (Travis 2009; my emphasis)

Given the swift response from prominent academic scientists criticizing the project, several of those interviewed say they suspect that private labs that come under much less regulatory oversight were involved. And while the UKBA has since tried to downplay the significance of the project, in the words of Pearson, "it's peoples' lives we're dealing with."¹¹ The purported voluntariness of the HPPP conceals the threat of guilt if an applicant does not consent to testing. It is coercive to say one has a choice, when one of those choices is automatically penalized, and yet this presumption was built in to the protocol. As Tutton, Hauskeller, and Sturdy (2014) explain, "In the UK, official and popular attitudes to those who request sanctuary have become dominated by a hermeneutic of suspicion. Public and policy discourses portray asylum seekers as mostly 'bogus' refugees seeking admission to the country for economic, not humanitarian reasons" (p. 739) as if the distinction were so clear-out.

The quest for scientific tools to determine ancestry and arbitrate group membership continues apace toward a variety of political and biomedical ends. The near uniform criticism on the part of academic researchers toward the UK project serves to highlight a key feature of the underlying science—its refusal to adhere to "terms of use" insofar as the UKBA was unwilling to completely shut down the project. Likewise, when the same methods are used in ways that purportedly help subordinate groups—especially (but not only) in health research—researchers often rally in defense of the field and overstate the conclusiveness of such findings. Furthermore, essential for this discussion is that such technologies are not objective arbiters of identity claims. "They actually redefine the social categories of identity on which immigration and asylum decisions are based," further disempowering those who are already oppressed by current configurations of power and authority (Tutton, Hauskeller, and Sturdy 2014, 749).

But due to the dexterity of the field, supporting as it does competing ideas about personhood and belonging, it has also been enrolled in initiatives that seek to empower groups that have been historically dispossessed. The latter, as I argue, should attract as much careful analysis as the HPPP, because of the way that the authority of genomics may displace other forms of group-making and mobilization. What is more important for our purposes is that, if applicants refused the test, protocol demanded that border agents regard them with added suspicion, increasing their chances of deportation. In the UK case and beyond, rebuffing the authority of the state as exercised through technoscience causes individuals to experience the underside (or outside) of biological citizenship . . . a form of biodeflection in which refusal is always, already guilty.

A final point is worth emphasizing: unlike the previous cases where the perspectives of biodeflectors are foregrounded, analysis of the UK case relies on “secondhand refusals.” This, in part, reflects the precarious legal status of those targeted by border testing and underscores the need to institutionalize informed refusal rather than leaving it to already vulnerable individuals to question scientific and state authority. Whereas the United States and South African contexts illustrated the ability and willingness of people to do just that, the UK case shows us the limits of *individual* agency as the mode through which bioethical autonomy is exercised. If institutional structures do not actively and genuinely support the choice to refuse participation in genetic testing, then individuals who inhabit precarious social locations—those whom such principles were created to protect in the first place—are required to risk the fallout from acting autonomously (e.g., deportation). If refugee advocates and academic scientists had not voiced dissent on behalf of asylum seekers, it is likely that the project would have continued apace, despite the scientific and ethical problems outlined above. So rather than rely on “secondhand refusals” by public advocates, watchdogs, and whistle-blowers, it is vital to cultivate norms and develop mechanisms that allow those who are targeted by a particular initiative to voice dissent on their own terms.

Reclaiming Refusal

Moving toward a feminist postcolonial bioethics, I suggest we attend to “informed refusal” as a necessary corollary to informed consent—one that extends the bioethical parameters of the latter in to a broader social field concerned not only with *what is right*, but also with the political and social *rights* of those who engage technoscience as research subjects and tissue

donors. Science and Technology Studies (STS), feminist science studies, and postcolonial studies scholars have long wrestled with questions of power, knowledge, representation, and sovereignty. Anthropologist Cori Hayden suggests that scientific knowledge “does not simply represent (in the sense of depict) ‘nature,’ but it also represents (in the political sense) the ‘social interests’ of the people and institutions that have become wrapped up in its production” (2003, 21). Political scientist Michael Saward’s work on representative claims-making rightly conceives “representation as a creative process that spills beyond legislatures,” so that representatives are not simply those who have been elected, but anyone who seeks to speak on behalf of others. For Michel Callon, “to speak for others is to first silence those in whose name we speak,” even as “the groups or populations in whose name spokesmen speak are elusive” (1986, 78).

In the context of genetic ancestry testing, for example, we observe how scientists not only represent but also produce the legitimate boundaries of populations. This is the creative dimension of spokespersonship Saward refers to when he asserts that the “central aspect of political representation—the active making of symbols or images of what is to be represented” is a more accurate point of departure than a “fixed, knowable set of interests” which spokespeople either do or do not adequately represent (2006, 15, 17). His observation suggests that there is an element of “ventriloquism” in representative practices, wherein spokespeople both represent and fashion the biosocial world—through symbols, language, and in the current discussion, bioinformatics. So that *speaking back* to dominant representations can be understood as a form of political and epistemological hacking: if, as anthropologist Christopher Kelty argues, programming is a variant of “free speech and free assembly” (2008, 212), then moments like the Kimberley genomics workshop—where council members insisted that something akin to an “informed refusal” goes hand in hand with an informed consent and that scientists must commit to capacity building so that San can contribute to *and* critique genomics—offer a kind of hacking space: “creating new things, new practices, and new forms of life” (Kelty 2008, x). This, in sum, is the radical capacity to understand “a system well enough to control it and to make it do something it wasn’t meant to do, not just de-mystify it” (2010, 1-2).¹²

Rather than simply acknowledge that “refusers” are justified in their distrust of the medical and scientific establishment, a substantive approach to enacting justice requires a reorientation away from the purported traits and dispositions of “problem people,” to paraphrase Du Bois (1903), toward the relative trustworthiness of institutions. The

notion of “informed consent”—although developed to protect the rights and autonomy of individuals to accept *or refuse* participation in research—implicitly links the transmission of information to the granting of permission. As Corrigan (2003) argues with reference to a number of previous studies, “the *request to consent* can be interpreted as *guidance to consent*” (782; emphasis added).¹³ The juxtaposition of “informed” and “refusal,” by contrast, links the transmission of information with an expectation that individuals may very well decline participation.

In a *Science, Technology, & Human Values* special issue on “Entanglements of Science, Ethics, and Justice” (2013), Mamo and Fishman compare STS treatments of ethics and justice, saying,

Justice is a public matter focused on common human interests, equitable distribution of social goods, resources, and opportunities, and a commitment to fostering empowered political participation. Yet, unlike ethics, justice has not been as explicit an object of STS inquiry. (p. 161)

Building on their insight, “informed refusal” may be considered one part of a larger justice-oriented approach to science and technology. How might it change the terms of engagement if subjects’ refusal to participate were more fully institutionalized, beyond the assurance that patients, tissue donors, and human research subjects can “opt out” at any time? For starters, greater onus would be placed on institutions to incorporate the concerns and insights of prospective research subjects and tissue donors *upstream*, far in advance of recruitment.

The homograph *ref-yoos*, that is, something discarded as worthless and *ri-fyooz*, that is, the act of declining a request, offers a discursive starting point for rethinking standard bioethics. The purposeful conflation aims to reclaim refusal as a way to construct more reciprocal relationships between institutions and individuals—one in which biodeflection is not stigmatized but rather stands as a necessary critique of the assumptions and excesses of forms of belonging that rest so heavily on biological claims.

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Notes

1. See Pollock (2015) for a useful overview of the different models of biological citizenship: “The Petryna model of biological citizenship is helpful for understanding situations of scarcity and deprivation, the Rose model is helpful for understanding situations of consumerist creativity, and Nguyen’s therapeutic citizenship captures situations of abandonment by the state. I argue that these models must be combined in order to understand the biopolitics around the Scott Sisters case, and the role of mass incarceration in constituting biological citizenship in the United States more broadly. Indeed, the tensions between racialized exclusions, the promise of consumerist freedom, and the lack of expectations of the state are foundational to a distinctly American biological citizenship” (p. 16).
2. Montoya (2007) offers an in-depth analysis of “bioethnic conscription” of Mexican Americans for genetic epidemiology research on type 2 diabetes.
3. Other features of the different biopolitical projects that would benefit from more in-depth analysis include a closer look at the three consent procedures—one of which is aimed at preventing the entry of people of “questionable” origin (United Kingdom), one of which is aimed at a therapeutic intervention (United States), and one of which is aimed at collecting samples for a biobanking initiative (in South Africa).
4. Personal interview. December 7, 2005. Sethe Hart, interviewed by Ruha Benjamin.
5. Ibid Sethe Hart, interviewed by Ruha Benjamin on December 7, 2005.

6. To begin to understand the particular stakes for diagnosing “San-ness,” one must appreciate several features of the broader political landscape: the first is that official data on the number of Khoisan people currently living in South Africa are nonexistent because they “are not constitutionally recognized as Indigenous communities. The current legal institutions continue to classify them as ‘Coloreds’ just like the apartheid regime did” (Le Fleur and Jansen 2013, 1). The second and related point is that, whereas the constitution contains stipulations pertaining to traditional authorities, offering designated groups legal protections and rights, the Khoisan are not eligible as a distinct ethnic community. They “have been in ongoing discussion with government for the last 18 years to address this recognition of their indigenous leadership” (p. 3). In this context, one can appreciate the appeal of population genomics to legitimate San self-identity; when political redress hinges on the ability to claim a unique experience of discrimination and dispossession, distinguishing indigenous from Colored ancestry becomes vital.

The stakes for laying claim to a scientifically validated indigenous status have been heightened further in the wake of recent statements by President Jacob Zuma about the country’s land restitution policy; he implied that his administration was willing to consider “historical claims for land lost before the 1913 cut-off date,” a change that would benefit the San (p. 4). In fact, five months before the genomics workshop described above, a two-day meeting with Khoi and San leaders attended by the Minister of Rural Development and Land Reform was held in Kimberley on April 16, 2013.

In the context of affirmative action policy in South Africa, as it pertains to land, employment, and educational equity, the ability for the San to distinguish themselves from Coloreds is of great practical importance. So, if researchers could confidently use genomic tools to understand disease predisposition, as was described throughout the genomics workshop in Kimberley, then perhaps it would be possible to distinguish San from Coloreds, that is, to diagnosis San-ness.

7. “While genetic ancestry testing concentrates on tracing the genes of ancestors in contemporary human bodies, isotope testing is based on the ways the different environments in which an individual lives may leave distinctive traces in her or his body. The proportions of different isotopes of various chemical elements present in the environment vary from one locality to another. These elements are ingested in food and drinking water and are incorporated over time into body tissues. Consequently, assuming that a person consumes local food, water and air, the proportions of different isotopes present in her or his tissues will mirror those in the place where s/he lives. Moreover, because different tissues are laid down at different times in a person’s life, they embody a record of the person’s diet, and her or his movements over time” (Tutton, Hauskeller, and Sturdy 2014, 744).

8. Letter dated September 9, 2011, provided by journalist John Travis.
9. “Nationality Swapping - Isotope Analysis and DNA Testing” government protocol (Annex A), Accessed June 14, 2016. <https://48822435ff65f9423681428795927e1499ecbbf7.googleusercontent.com/host/0B1arYAWdEZhkbnJjcEt2NlY4RTg/nationality-swapping-DNA-testing.pdf>
10. Ibid.
11. Ibid.
12. What comes of this and similar interventions is yet to be seen: will the researchers follow through on the training program? Will the web of accountability that is woven through benefit-sharing contracts be severed due to public domain norms? Will genomic notions of San ancestry reify collective identity despite the scientists’ disclaimers? Will knowledge gained through medical genomics translate in to tangible clinical benefits? in short, can the subaltern genome code?
13. “Bamberg and Budwig (1992), who conducted a discourse analysis study, found that ‘the voice of research is most likely to be interpreted by the patient/research subject within the framework of curing’ (1992, 165) In another study (Bevan et al. 1993), 38 percent of patients who had consented to participation in clinical trials stated that their motivation for doing so was to comply with the doctor’s request. Furthermore, assumptions are often made by those involved in clinical research—physicians, nurses and prospective patients alike—that the intervention being studied is the best treatment option (King 2000)” (cf. Corrigan 2003, 782).

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