THE BIOCOLONIAL NARRATIVE:
MEDICAL GENETICS AND
THE DIVERSITY OF THE HUMAN GENOME
IN A POLITICAL AND POST-COLONIAL WORLD

A thesis
submitted in fulfillment
of the requirements for the degree
of
Master of Arts in Political Science
in the
University of Canterbury
by
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University of Canterbury
2005
Acknowledgements

I would first of all like to thank my family, for their support and most of all their trust in my judgment to pursue my university education to the point I find myself today. To the M.A ‘Veterans’ of the Political Science and Communications department, I thank Tim, Nic, Ben and James in particular for being inspirational and shining examples (sic) of how to best do a Masters thesis. I hope I have done justice to your proud tradition. To My friends, as varied as they are, my deepest thanks for putting up with periodical fits of stress and long maligned periods of inertia, and the concomitant psychological intrigues that comes with them.

Of course, many thanks to Jill Dolby, for years of simply getting things done around the department and being a fair and frank source of advice, and when necessary, procrastination. I still marvel at your cryptic crossword abilities. My gratitude goes to the offensively uncomfortable Fukushima winter and the surprising quality of Japanese 7-11 o-bento meals, which in the last month of writing colluded to ensure that I finished on time without suffering the effects of scurvy.

My sincerest regards to all the staff in the University of Canterbury Political Science department for their help over many years and in many different ways. More specifically thanks to Jim Ockey for reading over the initial stages of this thesis, and last but by no means least, my sincerest thanks, and for that matter deepest apologies to Amy Fletcher who I fear I have subjected to five years of cruel and unusual academic torture. Your patience has been a virtue, and your willingness to allow me to delve into a somewhat unique area of political science, irrespective of the resultant quality, made this thesis more interesting of an a experience than it might have otherwise been.
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Abstract

As interesting as current research into medical genetics is for many people in the Western world, not all groups share the same excitement in regards to such research and innovation. Many of those, whose history reflects embedded ambivalence towards Western medical interaction, especially if this interaction was an important facet of previous colonial influence, tend to view research on diversity in particular with a great deal more apprehension. This thesis tries to detail aspects of this historical memory and show how narratives of colonial exploitation, past, present and future, influence the political debate surrounding these issues.

Using a secondary narrative analysis, this overarching narrative of colonial exploitation in medicine is further broken down into four interrelated components, which are argued to shape the political terrain where debate over genetic diversity in the modern era takes place. Tracking this narrative from the time of early colonial intervention, through pre-World War II bacteriology research, to post-World War II infectious disease research and finally to contemporary population genetics research, it is seen through a perceived consistency of exploitation in medical research, why many groups still suffering from various forms of disadvantage are not assuaged of their concerns by promises of modern genetic beneficence.

The politics of biotechnological resistance, best exemplified in the case study of the Human Genome Diversity Project, utilizes these narratives to question the moral, scientific, political and economic integrity of the research, and thus the motivations of scientists themselves. However, it important to understand this resistance as more than just cynical politics but as the embedded emotive means of legitimate resistance in an era of large scale scientific innovation where the concerns of these groups are underrepresented. Furthermore of interest is the development of a new style of politics which takes advantage of the opportunities presented by globalization, particularly telecommunications, in which to build coalitions that augment local politics. Ultimately it is argued that unless genetic researchers engage with the populations they wish to study in a more comprehensive way, the will fail to lift themselves out of the narrative trap they currently find themselves in , and thus will not attain the trust required to conduct research in emboldened but lamentably not empowered, post-colonial contexts.
Introduction: The Spectre of Colonialism in a Genetic World

"I ascribe a basic importance to the phenomenon of language. To speak means to be in a position to use a certain syntax, to grasp the morphology of this or that language, but it means above all to assume a culture, to support the weight of a civilization." – Frantz Fanon

With the end of slavery in many parts of the world, the end of colonialism, the comprehensive denouncement of Nazi eugenics, and even the termination of apartheid in South Africa, it might seem like a less than obvious time to reinstitute a debate about issues like colonialism, racism and genetics. However, with the seeming successes of genomic research programs like the Human Genome Project\(^2\) and the pervasive march of globalization in its many forms, a variety of forces and interests have come into both collusion and conflict in a way that has created a new terrain for political debate about old themes. This thesis therefore is intensely interested in how discussion of these topics is anything but passé.

The motivation behind this thesis is to try and demonstrate that in order to move beyond what were mistakenly thought to be outdated concerns, an honest engagement with the legacies of the past must be undertaken, if a potentially explosive situation is to be avoided. With this in mind, the guiding question of this thesis is “how should genetic science proceed in controversy prone contexts where issues of ethnicity and accusations of colonialism are politically salient?” The argument that will therefore be advanced is that not only do scientists and research organizations need to become more politically aware and astute in regards to interacting with groups who identify with the ‘post-


colonial' condition, but they must also be prepared to make some concessions regarding way research design itself is implemented in relation to these groups. The precise content of this argument will be articulated through the course of the thesis.

**Rationale**

Before proceeding any further it is important to explain why one should at all be interested in such a topic. The topic, briefly described is one of many intrigues. In the modern era, genetics research into ethnicity, or the more neutral sounding 'population genetics' has been assailed by a network of activists who insist that such science is the latest attempt in a long history of exploitation. This continuing saga relates tales of imposition, biased objectification, commodification of life, and the ultimately, the denial of, post-colonial, minority and indigenous people's importance and their societal worth. However, these attacks are not merely haphazard accusations but derive from a comprehensive narrativisation by activists of western scientific interaction in post-colonial contexts of health.

This 'biocolonial' narrative has roots in both contemporary culture and historical memory. Early European imperialist powers in their desire to acquire land in the most far-flung parts of the world in the interests of power politics imposed certain types of social organizations onto many different types of ethnic groups throughout the world. This included the structuring of health systems in these societies, and combined with the adverse political-economic consequences suffered under colonialism, medical research and treatment is said to have ultimately worsened health outcomes for these groups. Even after colonial authority somewhat violently receded from the colonies after WWII, critics of the infectious disease research paradigm have suggested unwillingness to compromise
the domination of political, economic, and scientific priorities of the hegemonic 'West' in the interest of post-colonial people's health is reflective of a reinvigorated 'neo-colonial' impulse.

The 'biocolonial' narrative of the 'genetics age', sensitive to the symbolic and political-economic plight of post-colonial peoples past and present, takes this neo-colonial logic and infuses it with an even more dramatic image. The image portrayed is one of attempts to subjugate and take ownership of one of the fundamental aspects of human existence: the human genome. This thesis strives to understand the reasons for the existence of such a narrative and its implications for scientific research.

Thus, the rationale for the relevance of this topic is encompassed in many dimensions of interest. From a purely Political Science point of view, major points of interest include how groups utilize available rhetorical, communicative and human resources to achieve overt and covert political ends, and the relative failure and success of these attempts. From a Sociological and Anthropological point of view, there is great interest in how the protestation of genetic research into the basis of ethnicity is not only the result of political mobilization, but also the construction of new types of communities and cultural forms, particularly in a globalizing age. Also, from this perspective, how both sides understand and represent their own culture and the culture of the 'other' in circumscribing the parameters of debate is of interest. Lastly, from a science policy point of view, this topic is interesting because it poses challenges to previously accepted ways of research design creation and science policy making. However, with challenges there also comes opportunities, and thus how science and scientists engage with perceptions of their own agency is important in dictating how science reconfigures the notion of
expertise and its relationship to society in general to suit modern decision making processes.

**Terminology**

Before advancing on to a description of this thesis’s methodology, an explanation on the use of terminology is appropriate. The major concept employed throughout the course of the thesis is of course “Biocolonialism”. Biocolonialism, in its simplest form is an observation about a new stage of colonialism developing wherein “the bodies of the colonized are the land and capital”\(^3\) for exploitation and extraction. However, for the purposes of this thesis, Biocolonialism is actually a much broader concept. While the image of genetic slavery is indeed a simple, emotive and compelling one, Biocolonialism actually encompasses a wider range of exploitative issues that are every bit as pressing as concerns over genetics and ownership as implied above. As will be explained in depth later in the thesis, the ‘Biocolonial’ narrative circumscribed in political debates regarding population genetics, describes ethical, scientific, economic and political possibilities for exploitation. In other words, the processes of imposition and control and how they underpin hegemonic interests in genetic research, is the major concern of the biocolonial narrative.

Of course, the ‘biocolonial’ narrative owes a lot to postcolonial theory that came before it. While the theories and discourses of postcolonialism are many and varied, for the purposes of this thesis a more practical vision of postcolonialism is used. Postcolonialism, as a theory is interested in the experiences of politically independent cultures who have historically been subjected to colonial or imperial influence. How

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colonial domination has influenced these cultures and continues to shape interactions between hegemonic and marginalized discourses is an important concern of postcolonial theory and postcolonial criticism.\textsuperscript{4} It is concerned with the discursive struggle between cultural particularity and the universalizing assumptions of Western developmental discourse. However, for the purposes of this thesis, the concern is mainly with how constructive and empowering health interactions ‘after’ colonialism has ‘officially’ ended, or in the case of indigenous people in Western nations, after some sense of the legitimacy of cultural rights was first politically and institutionally recognized, are still thwarted by many of the same developmental problems. How this in turn shapes the politics as it relates to discordance on biotechnological issues is thus of interest.

This post-colonial image of ongoing exploitation serves as the basis for describing the category of people being studied in this thesis in terms of their narrative pronouncements. Rather than it being an imposed category, ‘post-colonial people’ is a reference to a self-asserted identification with, and opposition to, structures of domination. When interpreting the relationship of the identity group making claims about dominant interests supposedly demarcating the political-economic and ethical-epistemological terrain, if the invocation of colonialism as an explanation for continued exploitation is used by these groups, then this is the basis for their inclusion under this admittedly wide ranging category.

The problem is that within the many fields of social science and science itself, the use of different ways of categorizing people causes confusion. Indeed, race, ethnicity, or ‘population’ can all be used to describe the biological features of a group, as will be

explained later. Indeed, there is a problem with categorizing people at all in regards to medical research in particular, due to either biological or social realism that often precludes the meaningful use of discrete groups of classification in this research. Thus, this is why a more fluid conception of human difference has been chosen, wherein the political content of the discourse is of primary importance, rather than necessarily ‘who’ the groups are. The only time a more specific reference is made to a category of people is in the section on genetics, where a case study, the Human Genome Diversity Project is used to give a grounded perspective on the exact dimensions of narrative development. Here, the notion of an “indigenous person” is referred to, simply because this group, while not exclusively the interest of population geneticists, has been singled out by the project. However, how to define indigeneity is in itself problematic, and again, it is the specific content of the political message, one of counter-hegemonic resistance by reference to colonial narratives, that is of importance.

Lastly, the two major fields of research referred to in this thesis are the ‘infectious diseases paradigm’ and ‘population genetics’. Population genetics, as will be restated in chapter V, is interested in detailing the scope and frequency of genetic variation as it relates to discrete human groups, otherwise known as “populations”. While this is very neutral sounding, a variety of different research interests, and a lack of agreement on what is considered a population and the appropriate use of terminology, has meant that this field of research comes across rather awkwardly in political debate and thus ripe for being attacked as something more sinister.

The infectious disease paradigm on the other hand, is interested in how infectious disease can be identified, studied and ultimately removed from scourging human societies.
However, as it is interpreted in post-colonial contexts, this paradigm is actually both epidemiologically and politically problematic, as it neither appropriately describes the causes of disease in many developing post-colonial countries, nor recognises the impacts on societies of stigmatisation or narrow treatment regimes. While many other terms are used during the course of the thesis, these are the ones that are most important, or at least deserve the greatest amount of clarification in regards to their usage.

**Methodology**

Initially, the major method used in this thesis is a secondary narrative analysis technique. Essentially, ‘secondary analysis’ is ‘the reanalysis of data that was originally compiled by another researcher for purposes other than the one the present researcher intends to use it for’. In a qualitative sense, it means taking advantage of analysis already provided in many diverse fields of research in regards to the issues posed, which contributes both factual and analytical content to the research development. In the case of this thesis, the secondary analysis is sensitive to linguistic and logical overlap in the analysis of many different and sometimes competing strands of analysis. The purpose is to construct a more comprehensive picture of political dialogue, wherein the ‘black box’ semantic references of some authors are given explicit detail by reference to the logic and research of another author. Thus, the analysis is also taking on an explicit narrative focus, because many of the both academic and non-academic articles written on this topic

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5 O’Connor, T., *Qualitative Social Science Research Methodology* <http://faculty.newc.edu/tconnor/308/308Lect09.htm> accessed on February 20<sup>th</sup> 2005.


That is the assumed “given facts” that are often made in research and analysis, especially as it pertains to “scientific” knowledge.
involve scientists, anthropologists, activists and representatives of many diverse groups who are actively involved in defining the parameters of the debate.

Without wanting to describe the overall research focus of this thesis as a "poststructuralist" project, the general academic tradition that methodological insights are derived from is most definitely one concerned with "the importance of discourses and narratives for the construction of political reality". Like Gottweis, this thesis is sensitive to the "constructed nature of actors in politics and society, and the phenomenon of competing, conflicting, and often contradictory structures of meaning and expression in social and political life" and seeks to detail more specifically both the content and the political implications of the politics of language surrounding population genetics in particular in the modern era.

Therefore, a word that will be a frequent feature of the thesis is "representation". A focus on how "articulations of science and technology" are "the outcomes of complicated processes of inscription" is the basis on which this thesis discusses the influence of colonial narratives, particularly the 'biocolonial' narrative on political debate. Representations of facts are paid particular attention to, as well as the motivations attributed to political 'otherness' in terms of moral and political conceptualisations of responsibility for health developments, both preceding and during the debate over the influence of colonialism in genetic science. This "narrativist turn" is relevant to political outcomes because narratives "bring elements of clarity, stability, and order into what usually tends to be the complicated and contradictory world of politics". Thus narratives are fundamentally important to how major protagonists influence the "problematisation"

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7 Gottweis, p.11
8 Gottweis, p.21
9 Gottweis, p.31-2
of the political concern, “enrolment” in terms of how certain actors take on roles in articulating the concern, and eventually “mobilisation” of other actors in service of political interests and beliefs.\textsuperscript{10}

While at first the analysis is quite general, mainly for the purpose of articulating the narrative frames of reference, it will eventually be specifically grounded in what is a more substantive exposition of the major themes of this thesis. The case study is the “Human Genome Diversity Project”\textsuperscript{11} where controversies regarding the proposal and attempted implication of research goals became a destabilising issue. The HGDP was chosen as case study not only because it expresses many of the issues which are of rhetorically and political importance, but on a practical level, because of its global visibility, it functioned as a lightning rod for various forms of activism to congregate around in protesting not only an anti-population genetics agenda, but a broader anti-biotechnological one. It also demonstrates that the development of a new type of politics which is not only more trenchant in its desire to protest injustice on a global scale, but one that allows new kinds of social and political coalitions to be built and new methods of communication to be utilised. In this sense, the language used in both the affirmation and disputation of the projects moral and political legitimacy is quite revealing.

This is where an astute reader will recognise a slight departure from an overt narrative focus to a more action orientated focus in terms of discussing the implications of the research. Description of the narrativisation of HGDP politics in particular is therefore utilised to essentially underscore the pressing need to engage in different types of policy, or in this case, research justification discourses that give rise to different types

\textsuperscript{10} Gottweis, p.32
\textsuperscript{11} Morrison Institute, Human Genome Diversity Project
<http://www.stanford.edu/group/morrinit/hgdp.html> accessed on February 20\textsuperscript{th} 2005.
of political engagements. This involves moving on slightly from the language component of the debate of this thesis to taking on a sensitivity, to borrow from the research vocabulary of Hajer\textsuperscript{12}, to the implications for "policy making in a network society". How language and narratives shape the political terrain and thus affect policy outcomes, or in this case the research direction and viability of the HGDP, is thus of major interest. Hajer argues that the way that policy discourses develop and express relations of power depend on three major factors of interaction. The first, the "process of mutual positioning", specifies how "actors intersubjectively create and transform political conflicts using language".\textsuperscript{13} Hajer also discusses for the importance of "discourse coalitions" and how the lending of rhetorical and authoritative resources between policy domains can influence the debate. Lastly, how "institutional practices" are important in shaping the nature of discourses and the outcomes of discourse is an important variable in discourse development.

In terms of this thesis, debate is centred on research design and acceptance of innovation and technology rather than explicit broad-based policy making by government institutions. Nevertheless, many of the same insights are valuable, and the debate around population genetics in particular is mature enough to be representative of likely policy discourses were governments prescient enough to become actively interested in the issue. If it is not a de-facto policy discourse, the debate over population genetics is clearly a precursor to future policy debate, should any government or public organisation have the political courage to tackle these issues.


\textsuperscript{13} Hajer, p.95-98
In this respect, the process of “mutual positioning” is concerned with how both sides of the debate rhetorically define both their own positions as well as the position of the others in terms of moral authority and political intent. Related to this, the activation of discourse coalitions are relevant particularly in regards to the way that academic, activist and localised politics colluded to rhetorically define and protest the actions of another perceived confluence of interests, which is, the relationship between modern genetic science and the economic imperatives of corporations and aggressive governments. Thirdly, institutional practices are important in the way that institutional authority of scientists both defined the initial policy discourse in a way that created the conditions for its eventual failure, and still continue to do so. Of particular importance is how institutional scientific authority defined in a narrow and technical sense, and understandings of what is considered to be “expertise” on such issues, fails to recognise the importance of the need for more ‘enlightened’ engagement and thus fails to meet the challenges that assails it.

Ultimately, this is why the methodology in this thesis cannot be fully described as a language analysis. While the eventual recommendations in this thesis lamentably lack precise detail, some attempt is made to take the lessons implied in the literature and relate it to general perspectives on science and society interactions. Furthermore, an argument for the need to diversify the nature of research by coming to a deeper understanding of how colonial narratives shape political discourse on scientific research and innovation is made and how they also necessitate the need for different methods of political engagement to be employed in these contexts. This will clearly be a challenge to a field
in which issues like race and ethnicity identity politics are traditionally not the concern of somewhat European focused “participatory policy” research paradigm.

**Structure of this Thesis**

Part I, consisting of Chapter I and II, is an analysis of the research on interactions between colonized people and their colonizers dating from the 1800’s to 1945. Aside from detailing the analytical history of the colonial era, these chapters also function as expositions of the major components of the ‘colonial’ health narrative that will eventually evolve into the ‘biocolonial’ narrative. The rationale for splitting into two chapters is that one aspect of the colonial narrative deals with more ethereal themes such as ethical and epistemological discordance, while the other deals with more the more ‘wordly’ concerns associated with economic and political exploitation.

Part II, consisting of Chapter III and IV is an exploration of infectious disease research with a view to seeing how the interaction between Western scientists and peoples in post-colonial contexts is complicated by a colonial narrative that borrows from the past and reconfigures these images of exploitative intent to suit modern political and economic realities. Here a discussion of the emerging diseases paradigm is entertained followed by what is the rationale for including this section in the thesis other than for chronological and narrative interest; to show the way that epidemiological research in the area of infectious disease, while making many of the same political mistakes as the population genetics field, have attempted in some notable cases to engage with some post-colonial groups in a more constructive fashion. This will demonstrate that research
into 'best practice' methods in regards to genetics research could also be potentially profitable.

Part III takes the "colonial" narrative developed in previous health discourses and shows how it applies to population genetics research in the contemporary age by grounding the narrative in a specific case study. The Human Genome Diversity Project, an attempt to map the full diversity of human life was a conceived of as being a compliment to the Human Genome Project by seeking to map the genomes of people who might otherwise not be adequately genetically represented by such a project due to 'unique' biological isolation. Thus indigenous people became the stated target of such a project, and it was not long before many of these groups decided that such a project was not going to be implemented quite as smoothly as the scientists and organizers intended. The invocation of 'biocolonialism' became commonplace and so did attempts to delegitimize the project by reference to its dubious moral, epistemological, economic and political character. The development of this biocolonial narrative in relation to population genetics is thus elucidated in Chapters V and VI.

Part IV, the concluding section of the thesis, takes the narrative analysis previously articulated and discusses it in relation to both primary sources of political mobilization and secondary sources discussing the nature and meaning of political mobilization and representation in the modern era. Chapter VII is a discussion of political mobilization by indigenous groups and post-colonial groups and those claiming to represent the interests of these groups in contesting the merits of the HGDP in particular and population genetics and biotechnology in general. Here not only will some needed
analysis of primary materials be provided but also a discussion of the types of rhetorical strategies used by such groups and how they simplify political reality is given.

Chapter VIII will discuss the meaning of biocolonial politics by reference to notions of risk and trust. Not only with this impart a better understanding of how and why representation of political ‘otherness’ shapes the discursive debate, but it also provides balance to a purely cognitively based mobilizational perspective. This is important because any attempt to understand the debate and create innovative policy or research designs that attempt to solve the problem, will need to take account of more than just overt political statements and interests, but also the embedded politics of identity and representation that derive from these post-colonial contexts.

Before concluding the thesis, Chapter VIII will briefly discuss what qualities types of participatory methodologies must possess to have a chance of succeeding in many of these contexts. Furthermore, arguments will be provided as to why engaging in this type of rethinking of socio-political interaction is needed. Then in conclusion, a summary of the thesis followed by the restatement of the essential argument of this thesis, this argument being highly suggestive of other avenues for research in the future.
Chapter I: Ideological, Ethical and Scientific Arguments

Relating to Colonial Medical Exploitation

The first and second chapters will provide a generalized account of the interaction between medical research, colonial policy, and socially disadvantaged ethnic groups in the late colonial period as detailed by the social scientific and historical literature on this topic. The years under consideration are from approximately 1800 to about 1945. The intention is to provide historical background to contemporary discourses and controversies regarding medical scientific practices in situations where notions of ethnic and racial identity are politically salient. This in turn will elicit an understanding of why historical narratives are an important factor in considering how apparently benign scientific innovation governed by seemingly strict and clear rational principles can generate controversies which threaten the viability of intended medical interventions. One of the key analytical interests guiding the direction of this thesis is how historical experiences and perceptions of exploitation impact upon postcolonial political discourses on human biomedical science. With this in mind, the guiding question of the first two chapters is “What are perceived to be the important historical experiences of colonial ethnic groups in regards to colonial biomedical science?”

Clearly, to condense the whole of historical experience of many diverse and distinct cultural groups into one overriding narrative would be a vast oversimplification if the goal was to analyse the precise details of every ethnic groups' experience at the hands of colonial powers. Indeed, one of the key lessons drawn from the colonial period relates the dangers of treating different groups in a similar manner. It is also important to note that the specifics in terms of behaviour and
actions of different colonial powers themselves was not always identical, although it appears that in medical practice the differences were mainly competitive and nationalistic, rather than philosophical. However, there are some key and telling patterns that emerge from even a general examination of the impacts of medical science on third world, indigenous and minority groups, many of these groups to this day still identify with the ‘colonial’ or ‘post-colonial’ condition.

However, my major concern is not so much with what “actually was”, which would be a very difficult task considering the proliferation of postcolonial revisionist histories, but instead with how these patterns and narratives are utilised in political discourses in later periods to question both the objectivity and the social impact of medical science in an increasingly ‘globalized’ world. This will be discussed in later chapters by way of reference to rhetorical mobilisation, risk, trust and empowerment, and ultimately the implications of these issues for policy and research design.

Initially, however, it is necessary to summarise the main themes that arise when reviewing the literature on colonial medical science in this period. These ‘exploitative’ narratives take a variety of different forms and include both ideological-epistemological narratives, which are discussed in chapter I, and political economic narratives discussed in chapter II. Ideological-epistemological concerns include the “ethical justification for intervention and control” and the “compromised neutrality” narratives. Included in the discussion of political economic narratives are concerns with commodification and commercialisation of knowledge and persons in medical contexts, and also issues surrounding political contexts of exploitation. Also of interest is how medical science fails to adequately address health outcomes and equity

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2 Although the historical facts regarding some of the interventions outlined forthwith will be revealing.
through the ignorance of important socio-economic and socio-cultural effects on health.

These four narratives are related to commonly occurring themes that are outlined in colonial histories of medicine and their concomitant interventions. These four narratives, representative of modes of colonial power establishment were spatially, physically, philosophically and chronologically important. They are indicative of both how colonial discourses, particularly scientific ones, comprehended the existence and behaviours of other cultures in contexts where colonial agents were intimately linked to their modes of sociability, and of how they exercised and executed certain prescribed political, economic and ideological interests in lands that they had at least partial dominion over. The nature of this influence is at the very least revealing of the subjective experiences of some non-western groups, and possibly the machinations of power in extending social control through medical and scientific practices and discourses, both of which may still hold some import when considering the issues involved in medical genetics and ethnicity in the modern era.

**Narrative One: The Ethical Justification for Intervention and Control and the "Civilising Mission"**

While colonial powers had sufficient military strength to conquer most lands without necessarily needing to justify their actions, there was often an attempt to at least superficially articulate rational reasons for intervening in foreign territory and culture in this period. This may well have been related to the need for sensitivity to moral sensibilities in domestic politics and also recognition that while military power alone might secure the initial victory, it may not always ensure the pacification of a
population. Thus the concept of a “civilising mission” was often employed to this end.3

The “civilising process”4 is the gradual development over time of social mores and institutions which usually emphasise the importance of more ordered, restrained and “rational” behaviour. This “process” often circumscribes the basis of morality and behaviour more formally and usually accelerates when societies become larger and socially diverse.5 It is a reaction to the challenges of increasingly massified societies where the necessity of limitation becomes apparent to individuals and groups due to the reality of diverse and competing interests. Thus not only is the rationalisation of interpersonal interactions a component of the civilising process, but also the development of social and political institutions that attempt to provide a certain degree of order in society, and also place limitations on the exercise of power for the “common” benefit of all. The “civilising mission” is a more active and often self-referential attempt at imposing some of these formal systems of morality and behaviour on to other people who usually do not share the same sense of ‘civil society’, usually those who are recognisably different in many facets. While they were conceived of as being benign and potentially beneficent, “civilising mission” justifications that were usually invoked to legitimate intervention in foreign societies during the period under question were usually based on biased and self-selected world views that also often underpinned certain rational interest that colonial powers had invested in distant lands.6

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6 Elias, p.43
On the one hand these justifications would allow differing European moral world views (both secular and religious) to support these ventures, as they could all ethically invest in the stated goals of intervention, which as will be seen, are usually related to the need to give philosophical, intellectual and spiritual enlightenment\(^7\) to those unfortunate enough to be deprived of such capacities and to implement “physical” improvements in the social life of the colonised. The provision of medical services was one of the clearest ways in which colonial powers could both educate and ameliorate what they saw to be the insufferable and ignorant plight of the colonised populations.

The notion of a ‘civilising mission’ would thus contribute to justifying the intervention of these powers into foreign lands by providing a symbol of beneficence\(^8\) to local populations, who would eventually submit to the self-evidentiality of the ethical and social value of medicine as a form of science. In that sense, being able to provide greater health benefits to the colonised would seemingly convince them of the good intent of these powers and demonstrate to them that there was much to be gained by listening and submitting to the will of the conquerors, and thus confer upon their intervention and eventual administration a greater sense of legitimacy.\(^9\) While it should be remembered that some benefits did accrue to the populations in question, both the justifications and the actions of colonial administrators and medical personnel were at times quite problematic. The moral worth of the concept of the “civilising mission” is questionable on two levels. One level of analysis brings into disrepute the concept of the “civilising mission” in terms of its moral and

\(^9\) Arnold, p.3-4, 17-18
philosophical consistency. Another level of analysis questions the narrative in terms of the actual practical intent of such seemingly munificent justifications.

In terms its practical medical component, the intention of bringing benefits to foreign and sometimes hostile lands as a primary motivation is doubtful. One common feature of the colonial medical enterprise was its close relationship with the military, with the French medical corps being one of the best examples of this. The presence of medical personnel in colonised contexts was at least initially conceived of as a way to maintain troop health while fighting, and then after victory, as a way to insulate military and administrative personnel from the diseased and downtrodden natives. Only once these primary objectives were executed would the indigenous populations be brought into the healing fold, and often even here this would be seen an opportunity to garner interesting information and facts regarding disease and health, or to maintain the health of those who laboured under colonial economic enterprises, both of which will be discussed in greater depth later in chapter II.

The relationship between medicine, the institution of the military and imperialism had engendered a great deal of suspicion, and in one sense, perhaps undermines the stated social benefits of the medical enterprise. Indeed, their interests were often interrelated and local populations were not totally ignorant of these relationships. Seen as “vigilant sentinels of truth” and “representatives of scientific democracy” it was not unusual for medical personnel to merge medicine and

12 Lorcin, p.654
13 Lorcin, p.658
politics, whether it be for personal or scientific gain or to consolidate their ideologically and politically privileged position.\textsuperscript{14}

Military and political administrators also found this relationship convenient, not only for the purposes of maintaining the health of their respective countrymen, but because doctors were often one of the most valuable sources of information (social, political and scientific) due to their often more intimate relationship with local populations.\textsuperscript{15} While medical surveillance was indeed quite important in at least attempting to control local populations, it also served to reinforce conceptions regarding local populations and their culture; and in many cases erroneously.\textsuperscript{16} This is where one can question the concept of the civilising mission in terms of its moral and philosophical consistency.

The medical profession in colonial contexts often served a very important function for consolidating the consistency and persuasiveness of the “civilising” justification for intervention. The study of local populations was not merely confined to disease aetiology, rather, also involved the supply of information regarding social and cultural mores\textsuperscript{17}. Often, this involved the emphasis of social, cultural\textsuperscript{18} and sometimes biological\textsuperscript{19} inferiority by reference to medical and social hygiene\textsuperscript{20} and beliefs about moral capabilities of studied populations.\textsuperscript{21} This allowed certain

\begin{footnotesize}
\begin{enumerate}
\item[14] Lorcin, p.654, Otis, p.88
\item[15] Lorcin, p.671
\item[16] Vaughn, p.138
\item[17] Lorcin, p.654
\item[18] Lorcin, p.662, Arnold, p.7
\item[19] Vaughn, p.111
\item[21] Vaughn, p.101-115
\end{enumerate}
\end{footnotesize}
measures of value to be utilised which would underline cultural dissimilarity and make clear differentials in "civilisation", which in turn would allow colonial powers to represent and justify their presence in certain foreign lands as "progressive inevitability".

These representations are problematic for two major reasons. They are clearly humiliating and disparaging to the populations in question, and thus a source of consternation and ambivalence towards cultural and medical interaction. Furthermore, in many cases they have been shown to be inaccurate and as self-reinforcing means to justify initial intervention and the conduct of administrative, military and medical personnel post-intervention.

The preceding discussion has attempted to make clear the relative importance of medical practices and discourses that helped justify initial colonial intervention. Medical science could well have indeed been one of the more benevolent "gifts" that Western civilisation could impart to others. However, often it practical effect was weakened by misunderstandings regarding local cultures, and furthermore, medical personnel were often inextricably tied into the interests of colonial and military administrators, which prevented constructive utilisation of their capabilities in a way that was appropriate to the interests of the local populations. That the medical profession also through the articulation of certain types of discourses helped construct disparaging narratives regarding social, cultural and biological life of "native" peoples, is seen to be another example of how colonial medical science betrayed its claims to authority and helped to undermine its pretensions to compassion, truth and

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22 Lorcin, p.661
23 Lorcin, p.668-670, Arnold, p.7
"Progressive Inevitability" as a concept basically means that there is a hierarchical conception of development that is articulated by reference to what is considered to be natural (and therefore, moral) order.
24 Fanon, p.230
efficacy. The next section will therefore seek to expand more specifically the content of some of these representations, and how they contributed to the further consolidation of imperial power in colonised lands.

**Narrative Two: Compromised Neutrality? Representations of “Otherness” and the Convolution and Conflation of Scientific and Social metaphors in Colonial Medical Research**

The aforementioned “civilising mission” narrative was justified by reference to two signifying and problematic concepts. First of all, it was justified on the basis of practical legitimacy, or the notion of beneficence. Secondly, through the ‘ethical’ articulation of theoretical legitimacy, whether it be a culturally or biological justified prerogative to rule or the seemingly compelling need to bring truth and order to others less fortunate, the “civilising mission” was seen to be a worthwhile cause. Medicine and science helped greatly in establishing both of these justifications, by giving them both empirical and theoretical coherency. Another common theme during this period, and related to the discussion above, is the convolution of cultural with medical metaphors and concepts that impacted upon the identity and identification of “others”. Like the “civilising narrative”, this narrative has multiple components, and it is important to outline the different facets so to demonstrate through examples, the means and ways in which politics and medicine can blend.

The convolution of cultural and medical metaphors and contestation over the meaning and interpretation of scientific knowledge took place not just in the colonised lands themselves, but were also heavily influenced by domestic political dynamics in

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25 Arnold, p.8, Vaughn, p.138
the home nations. With Darwinian theories on natural selection gaining traction in the late 19th century, new perspectives on biological and cultural inter-relationships evolved. Indeed, the two most controversial debates of the times, that is, the religious-secular and Left-Right divides, often utilised scientific and biological "data" and theories to augment the explanatory power and therefore political relevancy of each of their respective theories on society.²⁷

At a time when previously predominant conceptions of human nature were being challenged, and "practical" problems were being encountered in a climate of heightened cultural and class interaction that arose in the late colonial period, science became all the more important to give meaning and interpretively convey a sense of order in a rapidly changing world. These dynamics were indeed being played out in Europe; however, they also had a great impact in the colonies, where both the insecurities and interests of colonial nations were most saliently expressed and often made reference to medical knowledge and theories in articulating certain conceptions of moral, biological and social relationships as will be seen.

Developments in domestic politics interacted with the interests of colonial powers to create specific types of representations of "otherness". One of the most pervasive metaphors in administrative, medical and literary discourses at the time was the concept of "tropicality". This basically refers to the process where tropical or foreign lands, (non-European) were constructed as being inherently sick, unhealthy and dangerous. This geo-medical construct expressed a certain degree of ambivalence towards the colonies, as on the one hand they represented a fearful reservoir of new and exotic diseases as well as other dangers, but also presented an opportunity to

²⁶ Fanon, p.230
study interesting and novel people and diseases. The "facts" regarding tropical nations were often conflated with the mystique of these places, where dual reactions of fascination and disgust where often invoked; as such the medical construction of "Africa" was one of the most pervasive and "entertaining" of these tropical narratives. It must also be noted that is was not necessarily an association of disease with a geographical construct that was problematic, rather, it was also an association of a land with a people, who in turn were inseparably linked to the origins and spread of disease.

The development of the science of Bacteriology and some of its political manifestations are testament to this. The science of Bacteriology developed very quickly during the late 19th century due to the outstanding contributions of Robert Koch and Louis Pasteur, who contributed to the science by outlining the bacterial elements and dynamics of infection of specific diseases. The theories of Bacteriology, along with advances in technology, allowed scientists and doctors to increasingly and more precisely isolate important contributing components of disease. The very real concept of "bacteria" however came to dominate not just medical concerns with health, but the metaphor eventually was developed and utilised in expressing the dynamics of social and political life, and interactions with the colonial 'other' in this period.

The discovery of the importance of bacteria in explaining disease was lauded both domestically and in the colonies. In Europe however, there was much debate at the time as to whether environmental factors contributed to disease causation, by undermining the both the biological and social "immunity" that would sustain

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29 Vaughn, p.155-180
30 Otis, p.26-31
community health; or if bacteria were the fundamental threat to human health, thereby making preventative measures mostly irrelevant. This was very much the case in Germany, where the works of great doctors such as Rudolf Virchow and Robert Koch were used for the purposes of trying to procure funds and support for certain types of medical policy; for example, Virchow was a proponent of sanitation systems and concerned with the impact of poverty, while Koch on the other hand thought that immobilising and eradicating the bacteria would have the greatest impact on health outcomes.  

Despite, this over time the "Bacteriology" school of thought gained ascendancy in these political contests, perhaps because it required less political will to execute the programs, this being an important consideration at a time when many European countries and societies were undergoing political and social turmoil and reform. It probably also appealed to a prevailing sense of order and a certain type of worldview that allowed the explanation and location of responsibility of disease to be isolated easily, and elsewhere other than the innate human or socio-political body. At a time when previously held conceptions of identity, human nature and morality were being challenged by cultural change, a more structured ideological paradigm would allow those that engaged in these cultural interactions to maintain a somewhat more coherent identity disposition and allow their behaviour to be justified by reference to a consistent worldview, that would still allow them to act in line with their prescribed interests.

Therefore, conceptions of the colonial relationship to "otherness" were developed in line with this scientifically prescribed Euro-centric worldview, and led to a variety of problematic disease conceptions and explanations. The language of

31 Otis, p.8-36
32 Otis, p.27-35
Bacteriology provided a convenient metaphorical language for the articulation of cultural difference, and the fears and insecurities that it engendered. First of all, the prevalence of bacteria and disease was inherently linked to the different indigenous societies they encountered. Most commonly, it was linked to certain types of cultural behaviours that often served as not only explanation for the prevalence of disease, but also as evidence for previously justified and naturalised inferiority. That the colonisers often misread or misunderstood cultural behaviour, attributed disease to the wrong types of behaviours, or ignored other explanations for disease prevalence (such as socio-economic factors, or the impact of the colonisers themselves) was not often considered.

These aforementioned fears also often served to justify segregationist policies in the colonies. Again using the language of medicine and biology, there was a metaphorical equation of difference with disease that was often expressed widely in society, not just in medical discourses. Fear of what close interaction of colonial actors with indigenous individuals and communities often compelled colonial administrators to pursue certain courses of action that would alienate the respective populations. Of course, with the exception of perhaps South Africa, where medical segregation preceded political and social segregation, cultural and physical interaction

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33 Arnold, p.7-8
Deacon, H., "Racism and Medical Science in South Africa's Cape Colony in the Mid- to Late Nineteenth Century" in Osiris Bruges: St. Catherine Press, number 15, 2000. p.204-205


36 Deacon 2000, p.204
37 Marks & Andersson, p.259, Arnold, p.8
was inevitable. However, attempts to manipulate populations in this manner have left
enduring impacts, of which will discussed later.\textsuperscript{38}

Another interesting way that the language of medicine influenced the colonial enterprise was the use of its language to valourise certain cult figures and social roles that were important in executing colonial medical and political interests. Robert Koch is one of these cultural “heroes”, in this case, a “microbe hunter” galvanised by the spirit of the conquering pioneer, who through superior knowledge, was bringing order to disorderly places.\textsuperscript{39} Koch performed a variety of services for the German, and at times other European governments, and was rewarded appropriately.\textsuperscript{40} Indeed it may well have been that Koch himself was more interested in the scientific knowledge and applications that could be gained by such adventures rather than necessarily any material or cultural rewards, however, it is clear that European doctors were represented as being analogous to medical soldiers who bravely strived to bring health to inherently plagued and pestilent societies, as well as maintaining good health in their own.\textsuperscript{41}

They were also considered to be performing a defensive function, insulating their own people from the well known menaces already uncovered and indeterminable dangers lurking outside then current comprehension. This “Imperial immune system”\textsuperscript{42} relied heavily on the vigilance, rigour and stoicism of medical personnel, who through their knowledge and expertise would detect potential threats and allay fears of contamination. These medical conceptions of disease and threat however also became synonymous with broader cultural concerns regarding the perils of increased

\textsuperscript{39} Otis, p.28-36
\textsuperscript{40} Bynum, p.145, 152
\textsuperscript{41} Otis, p.28
cultural, political and social interaction. Indeed the success of the colonial enterprise probably heavily relied upon the pursuit of knowledge in general. Scientific surveillance, of which medicine is a key component, may well have allowed both the consolidation of imperial identities and the execution of political economic interests while facing the challenges that European societies were undergoing due to the globalisation of both disease and culture that was a feature of the 19th and early 20th centuries.

Scientific idioms other than Bacteriology were also utilised to explain social, cultural and biological difference in some colonies. While Darwin himself was somewhat more specific and precise in terms of the interpretations that could be drawn from his work, the metaphors implied in his work provided useful frameworks of analysis that could be employed for the ends of colonial powers. In that sense medical psychiatry utilised notions of natural selection and adaptability to reinforce representations of superiority and legitimacy in regards to their interactions with indigenous groups. This hierarchical arrogance probably preceded the advent of the popularity of Darwin’s theories, however, notions of self-evident supremacy were clarified by reference to theories of natural selection and in turn, by linking these ideas to the “empirical” studies of “native” psychology. Many of these studies revealed what turn out to be self-serving beliefs about “otherness” and psychological and moral capability, which allowed a certain degree of devaluation of indigenous identity, which would in turn justify greater scope for medical intervention and colonial intervention in general without necessarily referring to the interests of the

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42 Otis, p.110
43 Arnold, p.8
people directly affected by these intrusions, of which will be discussed in the following section.

Within these frameworks of reference, the colonised were often represented as being of "primitive mind"\textsuperscript{45} and not "self-aware", thus implying a lack of moral and social capability, and ill-disposed to living in a civilised way.\textsuperscript{46} Furthermore, many of these psychiatric discourses were highly sexualised,\textsuperscript{47} and this further reinforced pretensions of moral and cultural superiority in comparison with the perceived savage and uncontrolled social behaviour of the colonised.\textsuperscript{48}

Relatively, intelligence was also represented within a natural selectionist framework that further underpinned notions of superiority. For example in South Africa, poor scores in IQ tests by Blacks were attributed to immutable inheritance,\textsuperscript{49} while poor scores by Whites were often seen to be the result of environmental factors. This differential understanding of the explanations for intellectual development reveals quite vividly the way that medical discourses tried to impose self-serving beliefs about the "other" on to these cultures, and thus contribute to justifications for political, social and scientific dominion over these cultures.

To avoid being remiss, it is also pertinent to point out that many of these representations did not only apply to race. Women and those of poor class background also had similar aspersions cast upon their psychiatric and intellectual dispositions.\textsuperscript{50} They were often seen to be uncontrolled and morally incapable, as well as having less

\textsuperscript{45} Deacon 1999, p.101
\textsuperscript{46} Vaughn, p.108-109
\textsuperscript{48} Vaughn 1991, p.131, 138
\textsuperscript{49} Indeed, Europeans and other cultures supposedly had different types of "madness", and often non-European madness involved symbolic savagery, whereby metaphors of jungle life would exemplify in the minds of the psychiatrists, an inherently debased disposition.
\textsuperscript{50} Dubow, p.148-149
\textsuperscript{50} Vaughn 1991, p.20
intelligence. Medical discourses while seen to derive from the spirit of scientific liberalism, often served, whether intentionally or otherwise, to strengthen authoritarian control and centralised regulation, and thus particularly useful at a time when nationalism in Europe and beyond was becoming an increasingly disruptive problem and competition for resources in the colonies was intensifying. Indeed the development of eugenics movements in both the settler colonies and Europe later on in the twentieth century have their origins in the medical discourses that evolved during the period under analysis here. In this case they were even more inextricably tied to powerful interests, although this time "national" interests, both in European nations and settler colonies, became of paramount importance due to more precise articulation of political, economic, cultural and territorial boundaries, and concomitant interests.\(^5^1\) Thus notions of national strength were constructed around the identification of science with culture, but a culture narrowly conceived upon notions of self-evident superiority which pathologized social difference.

In summary, while the "civilising mission" narrative, which helped justify domestically colonial actions in foreign lands, is closely related in terms of the methods employed in representing "otherness", this compromising of scientific neutrality in terms of scientific representations of difference is argued to have helped in extending the influence of colonial powers over the lands themselves after initial justification of intervention. This is because the convolution and conflation of scientific with political metaphors was important in the establishment of a colonial intellectual space in the colonies, which helped at least as far as the sometimes myopic colonialists could see, fortify legitimacy of dominion over larger and larger social spaces.

These conceptions of otherness also helped maintain in the minds of the colonial powers a sense of order, righteousness, and coherency in terms of their actions and perceived self-identity. This became particularly important at a time when the realisation of cultural difference and also the globalisation of disease could potentially undermine both the articulation and execution of embedded interests of colonial powers. Thus on the backs of these concerns, medical discourses practices evolved during this period from being the concern of a select few domestically, to an important part of service to the imperial state. The increasingly technological usefulness of medicine meant that not only could it help in dealing with perplexing problems encountered in intervention, but it could also justify by reference to superior utilitarian outcomes, greater centralised control over society, both home and abroad. Furthermore, it also helped justify through the devaluation of difference, continued research into scientific, medical and often perceived “social” problems, which will be elaborated on further in the next chapter, which discusses the relevance of political and economic narratives of claimed historical exploitation.
Chapter II: Political and Economic Arguments Relating to

Colonial Medical Exploitation

The previous chapter discussed how colonial subjects came to be represented in a certain self-serving way by medical and colonial discourses as somehow being inferior. One outcome of the devaluation of “other” identities, is that it allowed the devaluation of life in general, as certain peoples are seen to not have full “human” capabilities, and thus neither worthy of great consideration if such consideration would be contrary to the pre-existing interests of the dominant powers, or seen to have the capacity to make decisions regarding their own respective interests. This stigmatisation is in itself sufficient to cause concern, however, it takes on greater import when we consider how such constructions provided an intellectual foundation for political-economic forms of exploitation, which first of all, relied upon the categorisation of “otherness” in a way amenable to the scientific and economic interests, and secondly, the obfuscation of epidemiological causation and responsibility which might imply remedies that were contrary to the interests of colonial administrators and medical personnel, each being discussed in turn.

Narrative Three: The Commodification and Categorisation of

Knowledge, Colonised Bodies and Culture for Scientific, Economic and Political purposes

This particular section discusses how the commodification and categorisation of medical knowledge, bodies and culture served certain political, economic and medical interests. It will become clear that not only did medical discourses and
practices play an important part in ideologically justifying certain interventions and actions taken during the course of the colonial enterprise, but that they also served certain material interests, which to some degree relied upon the previously described referential frameworks of dehumanisation and assertions of multi-faceted superiority.

Science in general found the colonial enterprise most profitable. Anthropology, Botany, Geography, Geology and a variety of other disciplines found the opportunities presented to them by access to previously unknown lands of great benefit to the development of their respective professions.\(^1\) Museums greatly increased in prestige and interests at the time,\(^2\) both home and abroad, and were triumphant markers of the power that science had to illuminate and inform on what was previously considered bizarre and unknown, through systems of classification. The wider ranging and more exotic the display on offer, the greater the prestige accruing to the museum or country that exhibited certain collected artefacts would be. However, the eventual collection of scientific information was to have implications not just for national or civic pride, but also material outcomes became important, this being particularly true of medicine.

People and communities provided useful subjects for investigation for medical practitioners.\(^3\) The aetiology of disease could be studied outside of the domestic sphere where a more remote and “scientific” approach to disease causation and its spread could be applied. Despite pretensions to the contrary, practitioners were seldom interested in the health of the “natives” themselves, rather, only in what they could learn from their experiences. The gathering of medical information which in turn could be applied back to maintaining the health of their own troops and thus

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allow further “exploration” of colonised lands was a more important concern. Medical findings and the development of certain related technologies that allowed the amelioration of disease was indeed quite important in allowing the physical settlement of colonial territories. While great losses were still suffered by the colonisers, many more deaths were prevented because of certain innovations. In this sense, the development of quinine, and the findings of Koch and Pasteur were some of the most important developments for the expansion of the colonial enterprise.\(^4\)

Unfortunately many of these innovations and new findings were only selectively applied to indigenous health. Usually, it was only if the threat of cross infection with settler communities would the treatment of locals become a priority, and even then only if segregation was not considered an option.\(^5\) Another reason why the native population might gain access to health care is if it served certain economic interests of the colonial powers. Often a large labour force was maintained for the purposes of extraction of economic resources. Thus, while the workers themselves did not earn a great deal, they were considered of some value. Many of the insights gained by studying local populations were never really benefited those populations until much later,\(^6\) and thus, an example of how medical categorisation and research supported certain interests of the colonisers.\(^7\)

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6 Arnold, p.15


7 Furthermore, the ways that medical services were delivered were often not appropriate to the social structures and conditions of the time. Medicine was usually administered in a way that was doctor orientated, hospital centred and urban based, which drastically reduced its effectiveness.

There were many other ways in which medicine and scientific study served to uphold the interests of colonial powers. First of all, there is the previously mentioned way in which systems of classification helped in defining differential identities that would serve the ideological and psychological interests of the colonisers. Secondly, the prominence of medical findings was an important source of national and colonial pride, and was often touted as an example of cultural superiority within Europe itself.\(^8\)

Thirdly, in the previous section it was mentioned that sex, sexuality and concomitant concerns with reproduction were ways in which colonial cultures differentiated themselves from “others”; however sex was also quite often considered to be an important commodity. Where there was a great imbalance in gender ratios, prostitution was often a common resort for colonial men.\(^9\) Furthermore, there are examples where the moral and legal pretensions were dropped when it served certain purposes.\(^10\) Despite the representations of hypersexuality attributed particularly to Africans by colonists, there were indeed times when colonial administrators became acutely concerned that certain populations were not breeding quick enough to maintain productive labour populations. Medical and colonial officials then went from disparaging sexuality in these lands to promoting it.\(^11\)

Fourthly, medically promoted hygiene methods were eventually mildly successful in reconfiguring social identifications in those newly emerging indigenous populations who had considerable experience of life under colonial auspices. This meant that new markets for the health and medical products existed and thus a new

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\(^9\) Vaughn 1991, p.202, Arnold, p.3-8


source of profit was uncovered. This is one example of how the impact of colonial interventions impacted upon local populations and thus altered, and not always as expected, local social structures. Indeed, medicine was often only a facet, albeit an important one, of broader attempts at "social engineering" that were undertaken by the colonists in some areas. In some situations, administrations consciously endeavoured to reconstruct colonial life to suit certain purposes, such as easier political administration, economic accessibility and social coherency. However, while they thought they were acting in the best interests of their subjects, often these types of programs created unforeseen impacts, many of which will discussed in the next section.

Lastly, although they were thankfully quite rare, there were some examples of direct medical experimentation being conducted upon local populations, usually taking place in labour camps, where doctors were on hand to try and maintain the health of workers, but in some cases where the opportunity was present, use them as test cases to further understanding about "disease" aetiology. Similar types of experimentation on African-Americans both before and after the emancipation of slaves in the United States, is also encountered, with one of them, the Tuskegee experiment, continuing on into the late twentieth century, still serves as a notorious point of reference to resistance against medical interventions not only in the African-

11 Vaughn 1991, p.141-143
12 Vaughn 1991, p.198
American community in the US, but by other groups already suspicious of the 'racial' intent of modern medicine.\textsuperscript{16}

At the time the demarcation between political administrators, medical practitioners, military personnel and corporate interests was less clear than it might be in the current era, where a certain degree more transparency in terms of conflicts of interests is apparent. This is one explanation as to why certain interests became so intertwined and led to a variety of adverse outcomes. The consequence is that perceived shared links between colonial agents came to be represented as an exemplar of how colonial powers and medical practitioners were preoccupied with commercially orientated interests. It is also highly suggestive of why certain priorities were put in the forefront ahead of others that might have been important if a consistent ethical and scientific approach to intervention was applied. Indeed, from a purely social point of view, the intimate relationships between many of these social actors did engender a degree of suspicion on behalf of the local populations.\textsuperscript{17} This of course undermined the sense of trust so important in doctor-patient relationships, and while many of the indigenous societies did directly protest colonial intervention, many choose to resist more passively by being recalcitrant in terms of the adoption of medical practices and specific cultural behaviours.\textsuperscript{18}

Most importantly however, is how these perceived collusive interests are a feature of representations of colonial exploitation in the future also. Political, economic, military and medical interests are all seen to be benefit from the commodification of people and disease. Firstly, scientific intervention and eventually

innovation is seen to augment both scientific and national ‘prestige’ for both individuals and organisations. Secondly, medical intervention is seen to more easily allow the competition for resources extraction, the potential for trade opportunities, and inexpensive labour utilisation by cleansing the environments that colonial agents operate within. Thirdly, medical science itself benefited from investigation, research and experimentation in colonies which allowed the extraction of greater medical knowledge without necessarily with comprehensively reapplying the fruits of that knowledge to colonial societies. While many of the exact modern methods of exploitation are clearly different the colonial period, the commodification narrative, by reference to examples of how colonial medical discourse and activities were solely concerned with self-interest, tries to demonstrate that claims of beneficence by medical agents in service of justifying medical research and policy agendas are probably another thinly veiled ruse designed to exploit ‘post-colonial’ people.

The first two sections emphasised how medical superiority was initially circumscribed in “hygienic, moral or social terms”\(^{19}\) This latest section argued that the development and centralisation of colonial influence in the colonies also relied upon medicine both providing information and the means for further extension of control in a physical sense so to allow resource extraction and inexpensive labour utilisation, as well as upholding and redefining colonial “intellectual spaces”\(^{20}\) through the refinement of knowledge and the use of novel but powerful technologies for fighting disease. Once intellectual spaces based on the logic of civilising and medical constructs were well established, and a degree of social control was exercised over the local populations, they had a salient impact upon social dynamics in the areas


\(^{19}\) Lorcin, p.678
concerned. This next section discusses how some of these impacts in terms of disease causation and aetiology were either ignored or explained by reference to other rationalisations that suited the interests of the colonial powers.

**Narrative Four: The Marginalisation of Socio-Economic and Socio-Cultural Explanations for Health Outcomes, and the Impact of Science on Colonial Societies**

Colonial interventions dramatically altered health outcomes in the societies themselves. Once colonial administrations and social units had become somewhat entrenched or institutionalised in many of these societies, they would eventually have an impact upon them by helping in generating evolving conceptions of culture and socio-morality, socio-economic change, and also alter physical population and ecological structures. From a medical health point of view, these changes are possible sources of disease causation that should have been duly considered. However, we often see biased behavioural interpretations or a dramatically narrow focus on hygiene and microbial exposure in many of these historical accounts which leads to the deployment of misleading explanations which at best ignore other complementary ways of dealing with disease, or at worse, actually exacerbate the problem through destructive types of intervention.

To be sure there were some notable examples of medical personnel who did protest these narrow conceptions of medicine and medical activities. Rudolf Virchow, while not necessarily dismissive of the popular field of “bacteriology” led by the likes of Koch and Pasteur, thought that the denial of the importance of social conditions.

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20 Lorcin, p.670
would cripple biomedical effectiveness. While he did have some success with getting government approved sanitation systems put in place in some areas in German cities, he on the whole started to lose the “cultural” battle for support between environmental and bacterial focused methods for medical intervention that seemed to nicely dovetail with the liberal-authoritarian dynamics prevalent in German politics at the time. However, while Liberals in Europe were not always on the winning side in these cultural wars, they did at least have some ability to vigorously contest attempted imposition at what they thought was bad social policy. The colonial context does not seem to reflect the same sort of active defiance to imposed narrowly defined medical discourses; at least not until the anti-colonial struggles that develop closer to middle of the Twentieth Century.

Therefore it will be of great informative value to provide a brief account of the ways in which many colonial interventions, both medical and social, contributed to disease outcomes or placed misleading emphasis on explanations that may have given a more comprehensive account of sufferance. The most obvious example of how colonisers affected their subjects by way of health is related to the simple act of their arrival. Much in the same way that colonials suffered from novel forms of disease when encountering new types of people, the colonised also suffered from new types of disease bought with them from Europe that indigenous immune systems did not have any defence for. This, in some places more than others, killed millions of people

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even by the simplest acts of interaction, and thus in itself dramatically altered societies and obviously, health outcomes in those societies.\textsuperscript{23}

Once somewhat more entrenched, colonial administrations altered and not always intentionally, socio-structural dynamics. Urbanisation is one obvious example of how different ways of living affected disease outcomes. Many consequences of urbanisation would eventually contribute to subsequent health problems. First of all there is the simple fact that people live closer together and much more contact is experienced. Secondly, urban centres tend not to be as ethnically and culturally homogenous, meaning support networks for the afflicted were not always available. This is on top of the fact that many different types of people who would not always interact come together, again presenting the problem of novel disease transmission. Disconnection from socially embedded forms of health care and traditional healing practices, whatever their efficacy is also seen as a potential problem here. Lastly, the problem of poverty, which will be discussed in more detail later in this section, became a particularly acute problem in urban centres and exacerbated the ability for the previously mentioned problems of urbanisation to create adverse health outcomes.

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Work camps were also contributed to the development of disease reservoirs. Much of the same problems apply here as one would expect to find in the urban centres, however, they were probably even more problematic due to the onerous working conditions that many of the workers suffered under. That they were an even more artificial type of social unit made the aforementioned problems with urbanisation and health change more severe, and those that worked within these

camps were more even more dependant on Western medical treatment than elsewhere with the issues of limited access and selective treatment, and even some examples of exploitation and experimentation also prevalent.25

The increased social mobility that many colonised societies experienced during the period under question is also relevant. Technological innovation made physical mobility much easier than it had been in the past. With different economic dynamics and opportunities possible also, there was also the motivation for transmission of peoples from one place to another that ultimately resulted in a vastly changed social structures. On top of the presence and mobility of the colonisers themselves, the result was the undermining of local ecological balance between populations and disease, meaning epidemics became more likely and usually of high intensity.26

A particularly important problem, whose legacy will be discussed in more detail in later chapters, was the change in the sex industry in many colonial societies. Prostitution while clearly pre-existing any colonial encounters, underwent dynamic change during the colonial period. The aforementioned problems of urbanisation and increased social mobility along with changes in socio-economic fortunes and socio-cultural morality, also resulted in higher levels of interaction between prostitutes, local populations and those from societies further away, whether they be from colonising or colonised societies. Both explicitly sexually transmitted diseases and other disease were spread through such intimate contact, thus the supply and demand of prostitution created by social change that was either intentionally intended or at best naively triggered by colonial powers, was and still is a particularly tragic

25 Marcovich, p.112
problem. Except of course where the sex trade could be a useful commodity or serve some interest, prostitution was often condemned as a problem of morality, and often used as an example of the debased nature of non-western cultural behaviour, further contributing to the undermining of a positive sense of non-western identity. This is instead of viewing the problem within a broader and more reflective social analysis framework.

A related problem was the fact of changing sexual norms governing behaviour during the period under question that occurred in many of these colonial societies. This in itself would have somewhat contributed to the spread of disease and augmented the transmission potential already suggested by prostitution. However, even with sexually transmitted disease, the focus on sex itself as the primary determinant of disease is perhaps somewhat misleading. Often disease was misdiagnosed as being of sexual nature but turned out to not be the one under investigation, or was an endemic non-sexual variant of that disease. Furthermore, socio-economic factors, such as access to medical resources, information, and nutrition also exacerbated the problem, and sometimes lead to the misdiagnoses of disease outcomes, sexual or otherwise. It would obviously be imprudent to blame the whole of disease causation on social change alone, however, it is also obvious that not taking account of these factors would undermine treatment effectiveness or promote

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26 Lyons, p.243
27 Bryder, p.812-815, 821-822
Furthermore, when blaming prostitutes for venereal disease, it was often circumscribed in both medical and moral terms. This is in spite of the fact that colonial men often engaged in the use of prostitutes, even at the same time they condemned the practice. This selectivity of emphasis was not terribly helpful in dealing with the issue of venereal disease, and furthermore the problem of prostitution that colonial actors at least partially contributed to by encouraging a market for the dispensation of such services. Colonial authorities were often "squeamish" in dealing with issues of sex and sexuality (other than in a negative sense) and this morally bounded lack of concern would come to have enduring impacts in many parts of the world.
28 Arnold, p.8, Vaughn 1991, p.138
possibly harmful interpretations of problems encountered, leading to stigmatisation of local populations.

Even in the field of medical psychiatry socio-economic and socio-cultural explanations for sufferance could be applied. There was a great emphasis in the later period in psychiatric discourses regarding the malaise and manifestations of psychological illness suffered by colonised peoples. Earlier discourses as mentioned focused a lot on the "native" or "primate" mind in terms of its capability to deal with civilizational and social change. While in many cases the content of these discourses improved over time, they still reflected a certain bias towards this mindset, even if they recognised that it was culturally rather than biologically determined. The culturally determined reaction to modernity that colonial psychiatry propounded placed a lot of emphasis on "deculturation" as primary explanation of colonial social illness, implying that colonised people often lacked the capacity to focus adequately in 'civilised' society.29

Clearly afflictions of "identity" were a particularly important problem at a time of heightened social change, for both colonised and coloniser. However, even singularly focused cultural explanations, which were often still biased by implied reference to the problematic dichotomy of individual (Western) and collective (non-Western) identity manifestations leading to implied differential reactions to social transformation, could ignore very important socio-structural and socio-economic explanations for mental illness. The more "mundane" day-to-day stresses of poverty, movement, familial disruptions, morbidity and mortality experienced at the time probably accounted for as much mental illness as those more existential problems such as identity disturbance.30 The inadequacy of colonial management of social

30 Vaughn 1991, p.119
change in regards to many of these problems is as much an explanation for the presence of varying types of disease as is bacteria, behaviour and culture.

Of course disease existed in colonial nations and was a legitimate problem of its own before colonial influence became a factor. However, the processes involved in colonisation did accelerate the incidence of morbid outcomes by altering structural and ecological components that are important factors in understanding disease aetiology. The impacts of colonialism itself added to the selective and often narrow biological or biased behavioural explanations for health outcomes ventured by many medical discourses would have complicated more constructive attempts at dealing with health problems by simply not acknowledging other plausible insights and explanations, or by discrediting them by reference to the self-righteous and seemingly 'self-evident' authority of western scientific and policy formulations.

It was previously mentioned that one reason that more narrow explanations were employed was related to certain cultural filters that were of importance in domestic Europe. Changing conceptions of identity and the challenging of privileged conceptions of morality meant that the comprehension of societal dilemmas was somewhat less coherent than previous, and science and medicine provided a new and potentially exciting way of coming to understanding the world. Order, logic and systematic access to the truth were key metaphorical components of the scientific enterprise and appealed greatly to both the psychology and interests of domestic elites in Europe, and in this sense, they were even more reassuring when applied in colonial contexts.

However, giving a purely psychological explanation for the importance and popularity of scientific investigation would probably not explain the full story. At the same time many colonial powers were expanding, they were suffering from a variety
of social problems back home. Aside from the increasing moral and ideological diversity previously mentioned, the problems of industrialisation were becoming apparent, leading to a great deal of socio-structural change, and of course, poverty.\textsuperscript{31}

The development of more mass scaled societies was indeed an important consideration, and science and medicine in particular were extremely important for both the amelioration and identification of social ills. Technocratic supervision became increasingly legitimised by such demands on societal management, and medical and scientific ideas and innovations became all the more important in both allowing and legitimising the expansion of centralised control.\textsuperscript{32} The fact that increasing competition between first of all colonial administrations abroad, and then between domestic European powers at home, meant that the centralisation of control and the development of scientific technology and expertise became all the more imperative.

However, while enlarged medical surveillance and healing capability was a specific and probably necessary adaptation to the evolution of larger types of societies, and the types of societal and security dilemmas experienced at the time, it is clear that the narrow focus, whether or not it could be avoided, probably reduced the biomedical effectiveness of many medical interventions. There may have been times that addressing issues of poverty, nutrition, social policy and planning may have produced greater health outcomes for those concerned. This was eventually acknowledged, but not until after the period under question.\textsuperscript{33} Indeed, a particular problem at the time was the confluence of interests involved in the centralisation of control, and whether or not their concerns were with superior health outcomes may be

\textsuperscript{31} Arnold, p.18
questionable. This is particularly true in colonial contexts where we see an even more insular and tight relationship between important elites, whether they be political, medical, military or economic.\textsuperscript{34}

Whether the use of certain types of narratives justifying intervention as seen in the previous sections, or the adoption of certain types of explanations for adverse health outcomes was due to a conscious and contrived self-interest, to a general and genuine ignorance of social dynamics, or a mixture of both, the impacts and legacies of colonial intervention on health outcomes in the places under due consideration, are not unimportant. The eventual anti-colonial struggles that arose during the middle of the 20\textsuperscript{th} century often questioned both the effectiveness and the moral legitimacy of the West in influencing the societies they came to have some dominion over.\textsuperscript{35} Medicine, while providing some benefits to the populations under question, was one of those Western systems or institutions that could potentially be a source of exploitation. The combination of humiliating representations of “otherness” plus a lack of true medical effectiveness due to selective prioritisation of prescribed interests and narrow conceptions of social and medical policy, meant that the power of medicine as explanation and solution was by no means unquestioned during these anti-colonial struggles, and in varying degrees, anti-colonial agents were consciously aware of this perceived lack of beneficence.

The next section expands more on this theme by summarising the interrelation of the aforementioned narratives, and suggests that the legacy of these narratives are important in considering contemporary developments in the context of non-western health. It will also outline the development and structure of the rest of the thesis, and suggest ways in which the insights outlined in this chapter may be of some relevance

\textsuperscript{33} Arnold, p.20
\textsuperscript{34} Lorcin, p.658, 673, 678.
when considering modern health outcomes in an ethnically diverse world, or even potential future developments, such as the rise of medical genetics that is currently under scrutiny.

Why develop a narrative framework to interpret history?

First of all, it must be restated that the development of the narratives given here is a generalised account of the literature on historical events as they relate to the interaction between medical discourses and institutions, and non-Western people in the period from 1800-1945. The purpose was not to establish a comprehensive and unequivocal perspective on the history of such interactions that could be applied to all contexts. Indeed, there are slight differences in the institutional mechanisms and strategies each colonial power developed in intervening in foreign lands, differences in the particular types of experiences “native” people endured at the hands of the colonisers and not all these narratives were present in the purest manifestations presented here.

However, medicine as a form of social or public practice was “internationalised” in Europe from around the nineteenth century onwards, and there was a gradual development of a community of interests which regularly meet to discuss pressing issues in medical practice. Since many of the perspectives on medical intervention discussed in this chapter were reaffirmed in regular meetings that involved trans-national delegates,36 we can see why critics in particular would see the actors of the medical communities in a more homogenising light. This in combination with the perceived confluent interests of governments, military, economic and

medical communities is why such an overarching narrative is articulated in much of
the literature, where mutual interests are transformed into actively contrived interests.

Furthermore, while there were a variety of divergent opinions regarding what
was considered the most effective means of treating populations medically, best
exemplified by the debate between Robert Koch and Rudolf Virchow mentioned
previously, the colonial or exported version of medical science was somewhat more
emphatic and coherent in so far that it reflected the material and political interests of
increasingly centralising states. What this is meant to imply, is that while many of
the case histories merit study on their own, it is also not without merit generalising
about their impact on the populations under question, especially if these generalised
accounts are recycled for use in modern debates about imperialism and medicine.
Understanding these generalised categories, if nothing else, helps us understand
important reference points of resistance in regards to medical practice, and an
understanding of these reference points, as will be argued later on in this thesis, has
great practical import.

However, it would be remiss to not mention that even medical and general
revisionist histories on the time period under consideration here have also questioned
whether or not colonial relations were as simple as top-down imposition of values and
institutions that is often argued. In these historical texts, while it is clear that

37 Bynum, p.145-146, 152
Those interests including but not limited to being able to both import and export valuable economic
resources, which in turn was related to the perceived competitive interests of many of the imperial
powers. Also being able to uphold a technically sophisticated but politically simple social policy in
regards to the colonies was very much in line with these interests.
Ernst, W., “Introduction: Contemporary Perspectives on Race, Science and Medicine” in Ernst, W.,
and Harris, B., (eds) Race, Science and Medicine, 1700-1960 London: Routledge, 1999
Elena, A., and Ordonez, J., “Science, Technology and the Spanish Colonial Experience in the
Elena and Ordonez, p. 85 also warn that while colonies might have been initially profitable, during the
later stages of the Nineteenth century it is less than clear that aside from Britain, whether colonies were
sources of prosperity for imperial nations, even if these very nations believed that they were.
Western colonial powers were still dominant and exercised a large degree of influence over foreign customs and spaces, the reactions by indigenous or colonial peoples to medical interventions were not always as accepting as is sometimes portrayed. Rather than being a weakness in the argument being made this insight is actually fundamentally important to the overall argument and direction of this thesis. While the narrative history presented here is by no means the final word on medical colonial history, it is an exposition of a certain type of “accessible” history that became important in anti-colonial struggles, and as we shall see later, in more contemporary reactions to scientific and medical developments. The processes by which history and logic threads are extracted and then reconfigured to suit political interests and purposes is a key theme that will be developed in subsequent chapters, and thus, the four narratives here will be instructive regarding the nature of both similarities and differences in Western and non-Western medical relations in the modern world.

However, these varying narratives do have an interrelated logic that suggests that they are somewhat interdependent. First of all, in the concept of the “civilising mission”, we have an “establishing” narrative, whereby those with sufficient military, economic and political power attempt to justify, both home and abroad, initial intervention in lands of interest. Here cultural and moral metaphors regarding superiority of one group over another are employed to demonstrate a right to intervene, regardless of whether or not this intervention is desired. Medical discourses played a particularly important part in rendering these perceptions “true” in the minds of important colonial elites.

Secondly, there is a "reinforcing" narrative in the form of the "representation of otherness" account of colonial interactions. Not only did this rearticulate and develop the previously discussed superiority assertions, but also tried to make obvious the self-evident need for medical intervention particularly, by reference to both biological or cultural notions of "savage" or "primitive" inferiority, of colonised peoples. The language and metaphors of medicine and science are particularly important to acknowledge in terms of how some of these representations gain popular saliency by reinforcing collective understanding of changing global interrelations and interactions, changing senses of identity and morality, and furthermore, provide examples of how science and medicine could be useful in studying and exposing the truth about novel, exotic and potentially dangerous peoples and worlds that were being discovered.

The commodification of body and culture could well be seen as an "extending" narrative. In so far that some degree of control and power was established then reinforced in colonial lands, the commodification of body and culture helped in physically expanding the dominion of power for the purposes of serving certain material, political, economic and scientific interests. Indeed, as the power of science and medicine increased not only in terms of its institutional capacity, but also in terms of its technological ability to alter the world around it, colonial lands became important sources of information as well as a reservoir of resources that could now be better exploited due to medical advances in controlling diseases such as malaria, tuberculosis and others. In this case, medicine became both the means and ends of further advancement and entrenchment in these societies, and its selective application in terms of its healing potential only reflects the pre-eminence of prescribed interest in the minds of the powerful.
Lastly, we see an “obscuring” narrative in terms of the selective interpretations used to explain continuing adverse outcomes in colonial contexts. While the focus on narrowly defined biological or behavioural explanations was being challenged in European discourses\(^{41}\) on social policy, with a few notable exceptions,\(^ {42}\) such challenges were not able to be mounted in colonial contexts due to less established and effective contrary political movements. The narrow focus on, for example, microbes or cultural hygiene as explanations for disease outcomes suggest that colonial powers where either ignorant or intentionally oblivious to the socio-structural dynamics that also contributed to the spread of disease during this period. It also reflects a desire or preference to further employ technical means for understanding and altering societies, both in Europe and overseas. The implication is that if colonial and medical interests reflected more appropriately on the causes of disease, a broader consideration of the causes of disease could undermine moral justifications of beneficence and colonial conceptions of pre-eminent authority in colonies.

In this sense, these four narratives not only relate to each other in terms of performing a different function that underpinned certain interests, they also reflect the changing nature of European society itself during this period.\(^ {43}\) Moving from a more morally and culturally prescribed sense of superiority to a more technocratic imposition of values is quite complementary with social developments in Europe, and certain challenging dilemmas that were being faced at the time. Medical surveillance

\(^{41}\) Otis, p. 11-12
\(^ {43}\) Ranger 1988, p.180-186

Again, this does not imply that colonial influence was accepted without reservations, more that there were few effective “indigenous” institutions that allowed the capacity for sustained resistance until the anti-colonial movements that began later on in the twentieth century. Indeed, Ranger provides an example of how African spiritual churches filled an important desire to understand the etiology of disease when Western medical policy and explanations had failed to offer suitable solutions to the influenza pandemics of the early twentieth century in Southern Rhodesia.

\(^{43}\) Arnold, p.18, Lorcin, p.678-679
and solutions became increasingly more important in social policy, and while to some degree this may have been necessary, it was by no means a remote, apolitical and objective process of societal evolution.

Indeed, with the development of Eugenics movements, both in Europe, and the settler colonies like the United States and Australia, and with its most tragic aberration manifesting itself in Nazi Germany, the institutional, moral and technological power of medicine emboldened nations and powerful interests to speculate on the utility of the ultimate social policy; that of altering the biological makeup of populations to serve national security, by way of ‘scientific’ evaluation. The Nazi eugenic ‘model’ shows how medical practitioners and biomedical discourse were politically mobilised for the purposes of condemning and persecuting certain class and racial elements that were considered detrimental to “national health”. While Eugenics became quite unpopular after the war due to Nazi excesses, it does demonstrate that given the right social context, science and medical discourses can be easily appropriated for obviously political ends, even erroneously so, as was the case with the Eugenics movement. Later chapters will outline how many people on behalf of disadvantaged ‘post-colonial’ groups in subsequent eras are concerned that similar developments in hegemonic culture in the genetic age could lead to a eugenic resurgence, to the detriment of these very same historically afflicted groups.

It is troubling to note that many of the discourses or narratives that were utilised in early twentieth century Eugenics movements either had their origins in, or


were "trialled" in colonial contexts. That is, the initial development of conceptions of superiority by way of contrasting certain cultural reference points with "otherness", combined with the increasing power of technical explanations of disease at times of great social tension, made the jump between the exercise of objective institutional knowledge and the clearly flawed and selective use of scientific information in favour of certain political ends, all the more easier. However, the legacy of medical and colonial intervention is clearly not just a problem in how it was applied in the European context, but also left an enduring impact on the colonial societies themselves. Whether it be disturbing representations of otherness, both biological and cultural, inadequate social policy, or the simple economic, political or military (and disease) impact on the societies themselves hastened by intervention of colonial powers, it is by no means clear that this was an innocently isolated period in history with no persisting manifestations.

The insights gained in the previous two chapters will be important for understanding a few important contemporary developments. First of all, the manner in which medical and general colonial influence was utilised in identity politics as examples of exploitation and thus contributed to the delegitimization of Western institutions, both in initial anti-colonial struggles, and ongoing protests against the perceived abuses of hegemonic 'bio-power' in the world, will be of great interest. Secondly, how past medical abuses, both psychological and biological have undermined medical mobilisation (with education being an important aspect of this) itself, and how continued ignorance of the importance of understanding structural conditions persists to complicate health resolutions is another notable legacy outcome. Lastly, the impact of colonialism itself on socio-economic and social structures of many societies is a recurrent theme in many contemporary discourses. While it is not
the author's intention to blame one group or another for modern developments, it is important to note that the manifestation of change in many of these societies was at the very least initiated and often influenced by colonial interventions, and that this not only impacts upon considerations of identity politics and medical mobilisation, but is an important factor in understanding modern health outcomes for 'post-colonial' people.

Therefore, the following chapters will attempt to elaborate on the three considerations mentioned above, by relating them to a variety of post-colonial health contexts. In Part II, chapters III and IV will discuss post-colonial developments in health as it relates to the “Emerging Diseases” worldview, where HIV/AIDS research provides a particularly resonate example of residual relations of exploitative disadvantage between hegemonic biomedical practices and constructs, and peoples and communities in non-Western health contexts. What is of particular interest is how these notions of colonial dominance are incorporated within critical health discourses which then level accusations of “neo-colonialism” against the activities of Western medical and economic institutions and interests in the post-colonial, or what is often known as the “developing” world.

In Part III, a discussion of the meaning of historical and contemporary developments in health outcomes, and the political importance of the narratives employed by both non-Western and Western health interests will be entered into for the purposes of outlining the potential problems that might be encountered when applying medical genetics to the study of ethnicity, where it appears that colonial and “neo-colonial” relations of discursive and political economic disadvantage are reproduced in biomedical discourses surrounding population and medical genetics research. Again, how critical health expression find resolve in the articulation of a
“bio-colonial” narrative that reflects previous analyses of the exploitation of social otherness is pertinent in chapters V and VI. Indeed, if nothing else, this chapter has articulated a narrative framework in which to evaluate contemporary and possible future developments in regards to the interaction between medical practices, discourses and institutions, and the socially contingent dynamics of ethnicity that problematize medical investigation and intervention into the concomitant issues surrounding social difference in the modern world.
Chapter III: Ideological, Ethical and Scientific Arguments

Relating to Perceived Colonial Influence in Infectious Disease Research

Part II serves three purposes and like Part I, is split into two chapters detailing the narrative constructions of health. First of all it attempts to provide some chronological continuity between the first two chapters, which were concerned with medical developments and exploitation in colonies up until 1945, and the fourth and fifth chapters which is concerned with controversies regarding genetics research in regards to ethnicity from around 1990 onwards. Secondly, Part II also provides some analytical continuity, as it is both prefaces and parallels the debate on issues surrounding genetics research into ethnic difference, and also provides evidence of residual characteristics of ‘colonial’ relations, which are also reflective of the narratives developed in chapter I and II. Thirdly, it is also demonstrates how lessons have been learnt from misapplied health interventions, which will hopefully be of some instructive value when addressing the mobilisational issues raised in Parts III and IV. However, the immediate concern is with health developments in colonial nations after colonisation, and the developments that eventually lead to a belief in a ‘reinvigorated’ colonialism in this period.

The immediate post-colonial period (used in its practical rather than ideological sense) represents a period of mobilisation and optimism, in which newly independent nation-states were able to mobilise their populations for the purposes of achieving certain goals in a way that colonial powers, even with coercive power,
could not. Concerns with health were seen as a very important aspect of national health and well being in general, and indeed health outcomes were seen to be an important signifier of state legitimacy in this period, whether or not the political system was democratic, communist, socialist or otherwise. The combination of political, economic and medical mobilisation initially yielded good results in terms of both economic and health development in the immediate post-colonial period, and Western medical aid and knowledge and its use by post-colonial developmental regimes was viewed positively to some degree in terms of its ameliorative health potential.

These initial advancements however started to slow and eventually a regression in health well being is seen in many developing countries, thus betraying the initial optimism and expectations of achieving Western levels of health outcomes. What is interesting in terms of this thesis is how this decline is related in critical health discourses to a continuing sense of ‘colonial’ relations, in which the legacy of colonialism is seen to permeate and complicate health outcomes both internally and externally in many post-colonial societies. Residual institutional, cultural and medical practices left over from colonial times are said to have a detrimental effect on the ability of nation-states to organise effective health programs internally, due to their political and economic instability, as well as inappropriate and ineffective

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medical interventions. Externally, perceived unfair political and economic relations, as well as the hegemonic dominance of Western medical knowledge and practice are seen to collude in a way that upholds internal instability and inequities in terms of health outcomes, and thus sets the scene for reinvigorated accusations of colonialism, or "neo-colonialism". 6 'Western' medicine and science as it is seen to be applied in these post-colonial contexts, takes on the role of both being a cause and consolidator of health inequities and the perceived interests of Western institutions and their agents, are seen in this neo-colonial narrative as being both ends in themselves, as well as means to other ends.

These themes are developed during the course of this chapter, aided by looking at these 'neo-colonial' relations through lens of the "Emerging Diseases" worldview. More specifically, the controversies over Western institutional and ideological involvement and intervention over perhaps one of most hyped and threatening diseases in human history, that of Acquired Immune Deficiency Syndrome or AIDS is covered. The "Emerging Diseases" worldview is characterized by three developments of importance. First of all is the observation that an "unprecedented" number of new diseases have been discovered since the 1970's when health started to wane in developing nations. Secondly, pre-existing or "re-emerging" diseases are defying their previously 'controlled' designations in the third world, and lastly, mutation and microbial resistance are becoming an increasingly vexing problem for concerned medical and scientific experts. 8 HIV/AIDS is relevant on all three accounts, because not only is it a 'new' disease that is also susceptible to

6 Kanji et al, p.986
mutation, but it also has been found to hasten the re-emergence of other diseases which were thought to be under control.\textsuperscript{9}

Why this is important to this thesis is because there are further concerns with emerging diseases such as HIV/AIDS because on the one hand, it has lead to a more proactive investment of medical knowledge and resources in trying to investigate and mitigate the worst outcomes of such diseases in developing countries;\textsuperscript{10} and on the other, concerns over the globalisation of both economics and disease, and the relationship between the two in terms of health security and wellbeing of both developed and developing nations alike are relevant.\textsuperscript{11} These two aspects of concern are argued as being contributors to biased outcomes where poor health is both cause and consequence of hegemonic institutional relations between the developed and developing world, these institutional relations being politically, economically, ideologically and medically inspired in nature. In line with the previous two chapters, the presentations of these concerns will be constructed in terms of the four overriding aspects of the 'colonial' narrative with concerns over medical imperialism being discussed first.

**Narrative One: The Ethical Justification for Intervention and Control**

While the notion of the “civilising mission” became relatively unpopular after World War II for both practical and moral reasons, there is a belief that a more subtle type of ethical superiority is still circumscribed by health discourses in the post-colonial era. As in chapter I, this superiority is articulated in terms of the humanitarian

\textsuperscript{10} King, p.768
\textsuperscript{11} King, p.767
potential of the provision of medical services and the assertion of objective superiority in terms of mediating conflicts over ethical conundrums. 12 While clearly watered down in terms of the scope of such arguments as compared to the past, accusations of ethical imperialism are prevalent in areas associated with the ethical evaluation of research, cultural appropriateness and informed consent, cost and benefit decision making, and lastly but importantly, over the nature of research collaboration in post-colonial contexts. These are discussed in turn with reference to such issues in terms of HIV/AIDS and other infectious disease research.

_Ethical Evaluation, Cultural Appropriateness and Research Imposition_

The clearest example of the way that much post-colonial medical research represents a certain type of ethical arrogance is in how the controversy over the ethical merit of research into HIV/AIDS vaccines is discussed almost entirely within the medical community itself. Recent controversy over vaccine research derives from a concern with proposals to lessen the need to meet medical and ethical standards in conducting such vaccine research in developing nations, such as the requirements of "duty to care" and "informed consent". 13 Arguments for abrogating such standards include the idea that because of high rates of infection, such research is scientifically more expedient, and furthermore that it is justified by reference to an assumed need for such research due to the extra burdening of suffering imposed upon many developing nations, especially in regards to HIV/AIDS. 14 Proposals to abrogate the need for informed consent in some contexts is most contentious as it seems to tacitly

12 King p.779-80
13 De Zulueta, P., “Randomised Placebo-Controlled Trials and HIV-Infected Pregnant Women in Developing Countries. Ethical Imperialism or Unethical Exploitation?” in Bioethics Oxford: Blackwell Publishers, Volume 15, Number 4, 2001.p.298-300. This includes requirements in terms of the "duty to care" and informed consent, which is discussed below.
imply a diminished sense of individual worth based on references to a scientifically justified sense of futility, which suggest such infected lives do not deserve equal consideration. This type of justification looks particularly suspicious when placed next to expediency justifications for such research that would probably otherwise not happen.  

Indeed, the lessening of ethical standards in the name of “compassion” is particularly interesting as while it is possible that it may well be more ethical to conduct vaccine or drug trials in nations or communities with a high HIV/AIDS prevalence, the problem is that the relevant communities themselves are not making this decision. Furthermore such ethical paternalism often ignores the less immediate impacts on such individuals or communities, such as the expectation of therapy and eventual derived benefits, the potential for stigmatisation, or the potential for such guidelines to be manipulated by researchers who do not have such a “compassionate” disposition. These are all factors which could contribute to a politically explosive situation where historical injustices have been experienced in a similar manner if the plight of research subjects were not to improve or even worsened.

Controversies over informed consent are particularly problematic as it may not be practically or culturally possible to fulfil sincerely the requirements of informed consent as would be expected in Western contexts. Issues in linguistic and cross-cultural communication are potentially problematic, as are issues in terms of cultural

De Zulueta, p.301. This is especially true when the use of placebos is advocated, which while a necessity of “rigorous” science, can be quite controversial when they are used in certain communities who have more immediate health needs.  
De Zulueta, p.305  
De Zulueta, p.302
appropriateness of an individually articulated notion of consent.\textsuperscript{20} Furthermore, there may also be a coercive factor involved in some of these medical ‘transactions’ where the expectations of cures or other rewards which may never be fulfilled are used as an enticement by researchers or some sort of other incentive to participate, or merely that the intimidating presence a medical researcher may cast over such interaction, both issues which may potentially contravene the principle of ‘voluntariness’ which is important to the effective ethical exercise of informed consent.\textsuperscript{21}

Issues of cultural appropriateness are also relevant not only in terms of consent, but in terms of symbolism associated with blood and body.\textsuperscript{22} While potentially culturally and spiritually important on its own, the issues take on greater meaning when suspicion is abound due to scepticism over the motives of the researchers in contexts where ‘colonial’ relations or past medical abuses have been apparent. The impact that research may have on intra-community relations is also an important but often ignored ethical issue, as is the potential for stigma arising from a positive diagnosis, misunderstanding of the nature of the research, the breaching of confidentiality, or the potential for researchers to create jealousies or beliefs in biased or unfair treatment, all issues of significant import.\textsuperscript{23} The ignorance of such issues seems to underpin claims of ethical imperialism through the ‘imposition’ of ethics and research on to certain communities which may otherwise be uncomfortable with it.

\textsuperscript{22} Mitchell et al, p.1089-90
\textsuperscript{23} Mitchell et al, p.1084-6, 88-9, Baylies, C., “Community-Based Research on AIDS in the Context of Global Inequalities- Making a Virtue of Necessity?” in Kalipeni, E., Craddock, S., Oppong, J., and
Beneficence, Benefits and Partnerships

While such research may have practical and moral impacts that an ‘objective’ medical appraisal of ethics may ignore, the very notion of beneficence that is also used to justify the investigative and eventual intervention agendas in HIV/AIDS research have been questioned. There is a concern that while such research may yield practically useful results, it is unlikely that the research will be re-applied to the communities that have been subjected to sometimes risky research. This may be because that while medical innovations are developed through “testing” on developing populations; selective political and economic priorities in developed nations prevent the redistribution of such benefits back to the societies that helped in their innovation.24

This is particularly relevant where there the distribution of such medical resources has been commercialised, further ensuring that many persons in developing countries are disadvantaged due to problems of access, or the funding of priorities that may not be considered crucial to the health needs of communities in developing nations.25 These political and economic aspects are developed in more depth later in chapter IV; however, the immediate concern is with the ethical appropriateness of allowing persons to participate in risky medical research that might not benefit them in the long term on the very thing that makes their suffering useful to medical researchers.

24 Patton, p.89
25 Craddock, p.250-251
The arguments surrounding ethics are quite complex and this rudimentary treatment of the issue only touches on this complexity briefly. Indeed, some of the arguments for ethical imperialism can go two ways, for example the necessitation of equal ethical standards or the differential relaxation of these same standards have both been portrayed as examples of ethical imperialism.26 This is also pertinent to ethical discussions regarding whether or not benefits should be expected from such research.

The essential problem therefore, is that whatever the ethical dilemmas involved in research into AIDS or disease causation in general, the “ownership” of the problem by medical institutions and researchers as articulated in medical and health discourses is seen to be a significant cause of both practically and ethically perverse medical outcomes, and thus the lack of problem “ownership” is accorded significance when considering accusations of ethical imperialism.27 Where problem ownership is an issue of contestation, debate over responsibility for adverse outcomes becomes an issue of moral significance, and thus where ownership is seen to be held in the hands of one (normally socio-economically and politically predominant) “group”, then the reconciliation of these adverse outcomes with beliefs about exploitation is made all the more easier.

Comprehensive and equitable partnerships between communities and researchers are seen to be beneficial to both the communities and researchers because first of all, it somewhat alleviates some of the controversy over issues of moral responsibility, and secondly, it allows the acquisition of “contextualised” knowledge that may augment the utility of the data, and might even mitigate potentially perverse medical or ethical outcomes by better understanding the needs and culturally

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26 De Zulueta, p.289
27 King, p.776
significant nuances that would otherwise complicate such research interventions. Furthermore, and this is particularly relevant for HIV/AIDS research interventions, participation in projects may increase if more appropriate means of working within contexts of political, economic or health disadvantage are employed, as trust is considered an important motivator of research participation. Many of these themes will be elaborated on further in the final chapter, however, for now it is important to understand that as long as ethical and epistemological control is asserted over research projects by Western health experts and institutions, then accusations of ethical imperialism are likely to persist. Some authors believe that this is not only a matter of ignorance, but sometimes related to subtle bias on behalf of scientists and medical researchers, where the ability of non-scientists, particularly non-western lay persons, to comprehend important medical and ethical concerns is doubted.

Clearly the manner of understanding the nature of disease in the developing world will not be expressed in the same manner as medical discourses do, however, this should not imply that input by those affected by such research is unnecessary or without value. Where researchers fail to adequate address many of the above problems, it should be expected that other inadequacies will be bought to light, often in order to further uphold the accusations of ‘neo-colonialism’ that are directed at mostly ‘Western’ medical researchers and institutions. Often raised as a signifier of further bias are aspects of infectious disease and HIV/AIDS research that do not always appear to be totally scientific, neutral and objective and thus are suggestive of

30 Palca, p.200
31 Patton, p.82
social influences affecting scientific judgement, issues which are discussed in greater
detail in the next section.

**Narrative Two: Compromised Neutrality? Questioning the objective use of concepts, metaphors and methodologies in Infectious Disease Research**

This section discusses how that even within medical and public health discourses surrounding HIV/AIDS in particular, the focus on a narrow range of explanatory phenomenon is considered to be a reflection of certain pre-existing bias' or interests that prevent a more appropriate appraisal of the medical relevant determinants of health. This section is therefore concerned with how narrowly explained disease aetiology can lead to disease exoticization and stigmatization which helps in the construction of differential categories of medical affliction, which in the 'neo-colonial narrative' are seen to underpin certain political and economic interests.

**Disease Aetiology and Biomedical Explanatory Focus**

Chapter I discussed the relevance of the medical controversy between the "Bacteriology" focus on disease causation and "Cellular Pathology" in the colonial era. There is also a parallel in infectious disease research in that the fields of "virology" and "immunology" study biomedical phenomenon in a way that often leads to different explanations and thus interventionist outcomes. Virological research was the main focus of AIDS research in particular for quite some time, where a focus on the virus itself was seen as the appropriate research focus, and thus the eradication and control of the virus itself became the only valid response to the HIV/AIDS
epidemic. This however was at the expense of "immunological" research which focused more on susceptibility and the biological environment that the virus interacts within, thus the initial HIV/AIDS research focus was quite narrow.

This is important because such a simplistic medical focus could potentially undermine public health interventions and the "management" of HIV/AIDS by focusing on "magic bullet" solutions, which rely on a high level of technological expertise, and are solely concerned with its eradication at a viral level. One such example is the initial ignorance of broader explanations for HIV/AIDS transmission, where simple exposure by fluid transmission to the virus is not often as powerful an indicator of disease contraction as the viral load of the individual and the co-infection with other (treatable) diseases. Pre-existing immunosuppression also complicates the analysis, as one is more likely to contract HIV/AIDS if the immune system is already compromised through malnutrition or co-infection. Furthermore, the scientifically validity of HIV/AIDS detection has also been questioned particularly in nations which have inadequate medical resources. The problem of "false positives" was prevalent in early research in particular as diseases such as Malaria could result in the expression of symptoms that were very much in line with those that would be exhibited if the person had contracted HIV/AIDS, and in general the standards of diagnosis is less than in the West.

32 Patton, p.63
33 Patton, p.64-5
35 Patton, p.83, 87-8, Murphy, p.40, 45
Obviously in situations where access to medical resources (to treat other types of diseases) and nutritional requirements are limited, HIV/AIDS is likely to prosper. While a focus on the virus and its transmission is important, the nature of HIV/AIDS itself is complicated both in terms of its contraction, and its progression post-infection. HIV/AIDS is very much a “syndrome” in that while the disease is a virus that is spread through fluid transmission, the nature of its transmission, detection and infection progression are very much socially constructed in terms of how they are respectively understood. Indeed it has been argued that the construction of the disease in biomedical and behavioural discourses often emphasise the distribution of the virus as it relates to its geographic origins and manner of sexual transmission, and seem to also portray an undervaluation of quality of life post-infection at the expense of a more ‘ecological’ understanding of disease sufferance and the implied solutions, all aspects which have come to be controversial when applied to post-colonial situations where such bias can cause offence and resistance.

**Disease Exoticization, the Politics of Blame, and Stigmatization**

The appearance of HIV/AIDS in the USA in the 1980’s initially caused a great deal of confusion in biomedical discourses over the nature and the cause of the disease. It was initially believed that the disease was a homosexual orientated disease, and then eventually, it was believed to be a Haitian specific disease. Eventually it origins were located in the African continent, however, it is the way the disease was initially represented in relation to its location that represents a clear bias in terms of HIV/AIDS research at least in the initial period of its research.

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37 Shapiro, p.2189
The sexualisation of disease transmission was the first way that social bias came into research agendas and biomedical discourse. First of all, the location of transmission in the sexual acts of homosexuals, Haitians, and eventually Africans was prominent in this research. Furthermore, it was expressed in way that seemed to exoticize the cultural behaviours (often falsely) of certain groups of people, and often the response to the disease was thus conceived solely in terms of behavioural alteration, which often had a moralizing tone to it and naively expected that ‘information’ dissemination was enough to change ‘risky’ behaviours. The situation of the disease in areas of the world traditionally associated with unclean practices and disease infection was also prominent in much of the early biomedical literature to the point it could be deemed political rather than scientifically relevant. Subsequently, the focus on sexuality as a determinant of disease infection of generalized risk groups, which just happened to fit in nicely with prevailing societal discrimination against and social beliefs about such groups, has been found to not be as relevant as it was thought, especially since this research on sexuality is very much bound up in stereotypes and beliefs that were found to be erroneous anyhow.

Furthermore, the controversy over culpability was not as simple as was made out in biomedical discourses. For example, the initial association of strange acts of a

38 Shapiro, p.2189
39 Gaussen, p.510-11
41 Patton, p.69,
42 Poku, p.533, Sharpiro, p.2190, Otis, p.171
sexual nature with HIV/AIDS in Haitian communities and their subsequent immigration to the USA has been questioned because it is quite likely that the popularity of sexual tourism with Westerners in Haiti is also an explanation of the origin of the disease.\textsuperscript{43} However, more important than this “politics of blame” is how the characterization of the disease as such has had enduring impacts and thus while it is now recognised in many quarters that HIV/AIDS is more than simply a biomedical and behavioural problem,\textsuperscript{44} the early construction of risk groups by reference to their sexualised and unsanitary predisposition has lead to the social stigmatization of the virus, which now complicates other HIV/AIDS health initiatives, both in the developed world and in post-colonial contexts.\textsuperscript{45}

However, it has been argued that the narrow interpretive breadth of HIV/AIDS aetiology and the construction of categories of affliction that emphasise biomedical and behavioural rather than social solutions to the problem, actually serves a variety of ‘neo-colonial’ interests, rather than being an example of plain ignorance. First of all, the medicalization of the problem ensures that the power of explanation and definition and thus eventual intervention remains in the hands of medical institutions and researchers. Secondly, when categories of affliction are constructed in a simple and often biased biomedical and behavioural way, it allows the objectification and medicalization of suffering and the association of disease with stigmatizing categories such as has happened also leads to a devaluation of life experience. This can lead to

\textsuperscript{43} Barrett et al, p.258
\textsuperscript{45} Patton, p.55-57, Merrill Singer, p.1321-3
the justifying of research interventions by reference to the "exotic", "dangerous" and "inherently" diseased nature of many developing geographic "spaces", which justifies a somewhat self-serving justification of the need for intervention, often based either on contrived 'ethical' or 'security' considerations. This therefore, makes developing nations and post-colonial communities a site for 'valuable' research, but of course, also resembles, even if in a less obvious way, previous colonial discourses on disease, culture, behaviour and location.

The biomedical objectification of HIV/AIDS research in the way that has happened is also argued to relate to the interests of biomedical commerce and political economic realities. Clearly if biomedical and simplistic behavioural solutions to problems are upheld exclusively through funding priorities as the best manner in which to treat disease in general, this of course ties these interventions and research agendas into the interests of those who develop and manufacture medical products and lend their expertise to developing nations. Furthermore, the narrow technically orientated focus also seems to suit the political-economic interests of commerce in general, as an explicitly biomedical and behavioural centred health focus denies the health focus of political and economic considerations of health and well being, which if duly considered, could challenge these commercial and political interests. This aspect of the “neo-colonial” narrative as representative of unfair relations in the political economy of exchange where information is opportunistically extracted and only reapplied when profitable is developed in more depth in the next chapter.

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46 King, p.774-7, Farmer, p.4-51
47 Patton, p.83-6, King, p.769-775, Barrett et al, p.257-8
Chapter IV: Political and Economic Arguments Relating to Perceived Colonial Influence in Infectious Disease Research

This section is primarily concerned with arguments regarding how medical research both contributes to the consolidation of inequality and also profits from it. Here considerations of the legacy of colonialism and the continuation of inequality and inequity under ‘Western’ models of development are primarily important to understanding the context in which medical research is conducted and how it can be represented as part of a ‘neo-colonial’ impulse by being seen to tacitly uphold relations of disadvantage.

**Narrative Three: Commodification and Commercialisation of Health and the Political Economy of Inequality in Infectious Disease Research**

**The Legacy of Colonialism**

Immediately after the end of colonial rule after World War II there was much anticipation that in the developing world the inequalities suffered under such rule would be slowly transformed over time into prosperity. However, as discussed previously expectations were not met, and this is particularly true in the area of health. Part of the problem was situated in the enduring impact of colonial influenced social organisational and institutional structures in preventing such inequalities from being addressed. This is because many new states were only interested in rhetorically supporting claims for greater health and economic equity,¹ and in fact often set about

¹ Andersson and Marks, p.525
exploiting the inequalities created under colonial regimes for the benefit of the power holders who inherited or took power from such regimes. The problems of inadequate state formation such as is seen in Africa, and experimentations by post-colonial states with similar types of “authoritarian social engineering” as was practiced under colonial rule, only added to the consolidation of inequality within these nations.

Furthermore, the utilisation of medical knowledge was based on colonial ideals of development which were biased towards curative, physician centred and urban centred models which often disparaged rural life and indigenous customs as well as accentuating the inequality between rural and urban life, and furthermore, often provided access mainly to elites, making the idealisation of health for all as illusory in some nations as it was previously. While there was initial improvement in terms of many health indicators, post-colonial states were not sufficiently organised enough to sustain health development, and furthermore, were overly dependent on Western medical aid and research, which while initially very helpful, past a certain point became less effective in combating the problems of infectious disease.

Part of the problem is that most nations, with the possible exceptions of non-Western countries such as China and Cuba, were not able to create independent indigenous health capabilities, which would have allowed more specifically catered medical intervention to be utilised in the fight against disease. Thus medical research by Western experts and institutions was for the most part accepted in the developing

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2 Ogoh Alubu, p.642  
3 Ogoh Alubu, p.639  
6 Ogoh Alubu, p.642  
7 Barrett et al, p.256  
8 Sung Lee, p.37  
9 Sung Lee, p.25
world, even if it continued to be institutionally and epistemologically paternal.\textsuperscript{10} However, such research got caught up in both contemporary and past narratives of exploitation as medical research was represented as the consolidation of old inequalities under neo-colonial relations of disadvantage, and thus the activities of medical institutions and corporate interests in the modern era are seen to uphold these pre-created relations of inequality through an unfair political economy of exchange.\textsuperscript{11}

\textit{Commodification, Commercialisation and Information Exploitation}

More recent developments within the emerging infectious diseases worldview, emphasise that the developing world is a potentially profitable source of medical knowledge, both because of the lack of restrictive legal and ethical limitations that would normalise jeopardise such research in the developed world,\textsuperscript{12} and because the rate of disease is high, thus making research it a “cost-effective” laboratory.\textsuperscript{13} This is particularly relevant to HIV/AIDS research as the development of pharmaceuticals and attempts at developing a vaccine are often tested in many developing nations as discussed previously.\textsuperscript{14}

While such research is justified ethically in humanitarian terms, often the reapplication of such technology only comes about in very selective cases, and often only if a price is paid, thus calling into question beneficent pretensions. The inequity implied in the commercialisation of biomedical knowledge and technology is a recurring theme in much of the literature and obviously in a free market orientated global system of exchange that started taking shape from the 1980’s onwards clearly

\textsuperscript{10} Sung Lee, p.28
\textsuperscript{11} Kanji et al, p.986
\textsuperscript{12} Benatar, p.337
\textsuperscript{13} King, p.775, Palca, p.200
\textsuperscript{14} Dahir, p.100-102
disadvantages many of these countries who cannot compete for the acquisition of such technology.¹⁵

A good example of this from the HIV/AIDS literature is the problem of access to pharmaceutical associated with the control of HIV/AIDS such as AZT.¹⁶ While the drugs are unaffordable for many nations, many of these nations have run into trouble with supra-national organisations such as the WTO when they tried to manufacture cheaper generic version of the drugs required for the control of HIV/AIDS and opportunistic infections in their own countries.¹⁷ The contravention of patent protection was extremely controversial and offending nations have been threatened with trade sanctions.¹⁸ It thus appeared that through the commercialisation of medical technology and expertise supported by patenting regimes such as TRIPS that clearly advantage bigger corporations and nations, biomedical science and its institutions seemed far more concerned with efficiency than equity.¹⁹

Thus the alignment of medical research interests with further exploitation becomes a salient marker of a new form of “neo-colonialism” where medicine both extracts informational resources from the developing world, and only redistributes developed technologies when it is suitable and profitable and with scant regard paid to equity, ethics or social outcomes.²⁰ However, it is often argued that this inequitable context of health access is further compromised by the processes of globalisation, where economic reform and indebted nations are unable to develop the capacity to adequately address health concerns in terms of its broader impacts, and the alignment

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¹⁵ King, p.776
¹⁶ De Zulueta, p.295
¹⁸ Banta, p.323
¹⁹ Poku, p.544, De Zulueta, p.310
of narrow and explicitly biomedical research interests with broader economic and political interest further confounds the achievement of positive health outcomes.

*Globalisation, Economic Reform, the Debt Crisis and Economic Colonialism*

A common argument in much of the critical public health literature related to the developing world is that the commercialisation of health not only consolidates inequalities due to its profit seeking proclivities, but the broader context of globalisation and the economic processes tied into it are actually responsible for the creation of both health and economic inequalities. It was discussed above how colonial legacies have impacted upon developing nation health capacity internally, however, equally important “external” factors are upheld as an explanation for inequality, and represent a deepening of the “neo-colonial” logic which not only opportunistically profits from both socio-economic and health inequalities, but has a vested interest in maintaining and extending them.

The major component of this argument derives from a concern with the impact of the debt crisis and the resultant structural adjustment policies pursued by the World Bank and the IMF. With the abundance of petrodollars available in the 1970’s due to the oil shocks of 1973-4, and with many developing countries wanting to accelerate economic growth, private lending institutions saw it fit to lend much of this newly acquired capital to developing states as way of mutually benefiting the banks and the developing nations.21 However, this was based on the assumption that the interest rates offered then (which were market determined) would continue, however, with the beginning of a world wide recession towards the end of the 1970’s, interest rates climbed upwards, and furthermore, export costs increased while demand for export

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21 Kanji, et al, p.987
commodities decreased due to partially to these oil shocks. Combined with the mismanagement of the loans by many of these nations leading to a distinct lack of the desired economic prosperity and the persistence of inequality, the servicing of the debt thus became untenable.

The solution to this problem envisaged by institutions such as the IMF was to introduce what are known as "Structural Adjustment Policies" or SAPs. There were based on the ideology that lack of economic reform in the manner of free market liberalisation was the primary reason that many of these nations did not attain the necessary prosperity that would enable the servicing of debt. By promoting domestic and external free market reforms, foreign investment in primary and secondary commodities which would potentially foster indigenous industry and provide jobs for the population would come about enabling greater productive capacity and an ability to earn foreign exchange in order to service loan repayments. However, this never eventuated and only exacerbated inequality in many of these countries which not only lead to further adverse health outcomes, but also limited the capacity of many nations to respond to pressing health crises.

The politically austere restrictions placed on states by these adjustment policies combined with the already economically impoverished conditions in many of these countries meant that first of all, state spending on health initiatives dramatically dropped during this period, ensuring that many nations remained dependant on external health aid had to contend with the conditions and exigencies that come with

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23 Kanji et al, p.987-8
24 Kanji et al, p.788, Ogoh Alubo, p.639-40
25 Shoepf, p.344-346, Lurie et al, p.210-211
this type of support.26 The free market ethic was also applied to health services in many of these countries, thereby limiting their capacity to adapt to the requirements of health equity and equality that had initially been part of some states post-colonial health strategies.27 Furthermore, the biomedically, behaviourally and curatively focused nature of many of these services, which are more profitable for medical interests than community focused preventative medicine,28 lead to the ignorance of the important socio-economic and socio-cultural determinants of health to the point where it generally rendered ineffective the biomedical and behavioural interventions in the management of infectious diseases such of HIV/AIDS. This is because the conditions of inequality and the broader social impacts that such policies have had, increase the likelihood of contraction, and that access to its treatment are limited to only a privileged or affluent few in many of these societies, further complicates effective disease management.29

The domestic and international commercialisation of health products and knowledge combined with the implementation of liberalised reforms in many of these societies clearly exacerbates the disadvantage of those who already suffer from inequality, whether it be health or economic, and as such it has been argued that SAPs have had an influence on the spread of the HIV/AIDS epidemic in many developing nations.30 This context of disadvantage is true both for relations between nations, as well as relations between people in states, and the operation of medical research and

27 Poku, p.531.
28 Van Rensburg and Ngwenya, p.372
29 Poku, p.538-9
30 Lurie et al, p.208
interventions within this political economy of exchange only aligns the interests of Western medical researchers and institutions with the assumed economic interests of the global corporations and financial institutions. This suspicion is only exacerbated by the commercial interests of medicine itself in extracting and selling medical knowledge and products, which is also upheld by international agreements on patenting and protection which are seen to be unfair.

Perhaps the major difference between the post-colonial context of concern with infectious diseases and the previous concern, is that the ‘colonial’ aspect is often articulated in economic terms rather than comprehensively moral or political terms, although some believe that the implementation of SAPs and the concomitant oversight procedures resembles effectively similar forms of political control because it undermines the already tentative sovereignty and legitimacy that many developing states have. Related to this is the insight that rather than the goal of “conversion” which dominated colonial discourses in the previous era, the goal of “economic colonialism” is rather “integration” into a world wide network of exchange, of which health is an important component.

The implication of this is that while the “colonial” impulse may well be less epistemologically and morally focused in terms of its concern with disease, (although as discussed in Chapter III this is still somewhat apparent), the political economy of exchange that globalized medical discourses and research operate within problematize its activities as it is seen to be directly involved in the exploitation of knowledge and persons for the selective ends of those in the more developed world. Furthermore the assertion of primarily narrow biomedical and behavioural explanations for disease obscures the socio-economic determinants of disease, many which are thought to have

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31 King, p.782
32 Kanji et al, p.640
33 King, p.782-3
been created by the inequitable forces of globalisation and their impact of the political economy of exchange. Thus the "obfuscation" of socio-economic and socio-cultural importance by biomedical and simplistic behavioural explanations for disease is seen as a way to avoid political or ethical engagement with this political economy of exchange.

**Narrative Four: Infectious Disease, Difference and the Political Context of Health Priorities**

As discussed in Chapter II, the focus on bacterial or viral components of disease, while not irrelevant, can limit the biomedical effectiveness of disease intervention if a proper appreciation of other causal elements is not apparent. If narrow and technical explanations for the reasons of disease sufferance are ventured, then it is also very likely that methods of intervention will utilise technically orientated methods. This is true of infectious diseases research in the post-colonial era. Most infectious disease is the result of the interaction between many different factors, many of them socio-economic and socio-cultural. Socio-economic factors refer mainly to issues directly related to poverty, for example nutritional well being. Socio-cultural factors are those that are related to societal composition for example how gender, religion, social stigma and risk behaviour, the processes of industrialisation and urbanisation, and political and social stability affect the attitudes and behaviours of individuals or groups within a society.

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35 Yach et al, p510-12
Why this is relevant to HIV/AIDS in particular is because while infection is indeed transmitted by a virus, early institutional and discursive focus on narrow biomedical and behavioural solutions did not adequately account for the aetiological salience of socio-economic and socio-cultural factors. Indeed, such a focus obscures the need for more broadly considered and interactive forms of intervention, something that in the neo-colonial narrative would threaten medical and commercial interests, and perhaps even expose their compliance in upholding health inequalities, particularly in regards to HIV/AIDS, which is as complex a disease as any.

Importance of Socio-economic and Socio-Cultural Factors in HIV/AIDS

Research

Socio-economic status is argued to be the most important indicator of infectious disease susceptibility in general, and this is also true of HIV/AIDS in developing nations at least.\(^36\) This is for two major reasons, the most obvious is that immunosuppression, which is related to a variety of factors such as co-infection with other diseases (many of them “diseases of poverty” and treatable) and malnutrition.\(^37\) Of course this is a vicious cycle because once HIV/AIDS is contracted, immunosuppression deepens, which in turn makes opportunistic infections even more likely, leading to the incapacitation of many individuals, and effectively communities, thus limiting the potential to provide for families nutritionally, educationally and medically and thus manage infectious disease in general. Those who occupy the bottom rungs of socio-economic status usually are not afforded access to education, appropriate health care and food, especially in economic and health systems more

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\(^36\) Farmer, p.51

\(^37\) Shapiro, p.2189, Ogoh Alubo, p.642-3
concerned with efficiency than equity, and thus this is particularly demoralising problem.

Socio-cultural factors are also important, and while perhaps not as powerful an indicator of disease susceptibility on their own, do influence the spread of the disease. Socio-cultural factors can include structural relations of gender, ethnicity and tribe that within nations and communities can determine access to information, medical supplies and protection, especially if these socio-cultural factors also correlate with socio-economic status, obviously leading to adverse health outcomes. Other factors, such as the influence of urbanisation and industrialisation, mobile workers, which are related to changing and economic modes of exchange, also have an important impact upon disease susceptibility as the movement of people that both leads persons to be spread around a greater area but at the same time have closer interactions with a diverse range of people, is also responsible for the spread of disease such as HIV/AIDS.

More specifically cultural factors, such as a focus on sexual behaviours, cultural customs, the role (positive and negative) of traditional healers and the use of prostitution affect the spread of disease, especially HIV/AIDS. However, while important, behavioural considerations of "culture" divorced from social and economic reality, which has been a feature of particularly early HIV/AIDS biomedical

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38 Andersson and Marks, p.520-4
39 Barrett et al, p.259, Lurie et al, p.208
40 The concern regarding the use of prostitution is related to both socio-economic and socio-cultural change where the mobility of populations, gender relations, and socio-economic deprivation interact to increase both supply and demand for sexual services. From a gendered point of view probably reflects socio-economic motivations in terms of the need to secure short term survival as opposed to the "luxury" of worrying about whether or not HIV/AIDS might be contracted, thus suggesting that risk is very much a relative term depending on the context.
discourse, lend themselves to advocating erroneous and stigmatising explanations for disease, and furthermore inadequate solutions based on these considerations. Thus, the ignorance of socio-economic factors, and misunderstood socio-cultural explanations, have lead to an inadequate focus on the biomedical and simplistic behavioural aspects and solutions to disease transmission in medical discourses, thus undermining their own effectiveness in combating the spread of HIV/AIDS, as well as health outcomes in general.

The implications of this “obfuscation” are three-fold and will be discussed in turn throughout the rest of this chapter. Firstly, it influences the articulation of medical priorities and thus funding in favour of more “technical fixes” to the problems of infectious disease. Secondly, through the narrow and sometimes erroneous explanations for disease outcomes, the (re)inscription of stigmatisation becomes a feature of such a research and interventionist focus, this being especially interesting considering the “social influences” on scientific categorisation and research in the first place as discussed in section two of this chapter. Thirdly, how such a focus undermines health mobilisation, both “medical” and “indigenous”, in order to counteract the development of disease, and how this leads to the development of “resistance” and reinvigorated accusations of neo-colonialism directed against the developed world.

*Technical Fixation, Priorities and Funding*

The assumption that scientific and technical expertise is the most effective means of managing the spread of infectious disease in the world is prevalent in much

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41 Parker, p.163-170
42 Poku, p.536-7
of the emerging diseases world view and also as argued previously, in HIV/AIDS research. Biomedical research, the development and dissemination of biomedical and biotechnological products, and the development of technologically orientated networks of surveillance and information management are assigned special importance in much of the discourse on infectious disease management.\(^{43}\) Furthermore, the necessity for developing nations to acquire this capacity is promoted, and even justified in moral terms.\(^{44}\) Despite the relative importance of socio-economic and socio-cultural factors in understanding the aetiology and management of infectious disease, there is a distinct paucity of discussion on the impact of such factors in public health discourses and policy documents relating to issues of globalized disease management.\(^{45}\)

However, the management of disease historically has usually been most successful when a wide range of strategies have been employed in the mobilisation against disease, and when social and political life has been stable and vibrant enough to recognise the need for and support effective management of disease.\(^{46}\) This was the lesson that should have been appreciated in the management and almost disappearance of the "old" tuberculosis where advances in medical science combined with improvements in economic development, housing, nutrition, political reform and health access broadly conceived, were responsible for the decline of tuberculosis during the twentieth century.\(^{47}\) Despite this, much of the discourse on the causes of the resurgence of tuberculosis focus on technical matters such as drug resistance and

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\(^{43}\) King, p.774

\(^{44}\) King, p.774

\(^{45}\) King, p.781

\(^{46}\) Andersson and Marks, p.524


\(^{47}\) Gandy and Zumla, p.388-9
pathogenic mutation, or the lack of "compliance" with biomedical interventions by communities as reasons for disease prevalence. ⁴⁸

Clearly biomedical assistance is necessary to help in the eradication of such diseases, but where large amounts of resources are continually invested in "technical fixes" for what are at the very least partially socially and economically created health problems, then it is not unfair to question the effectiveness of such interventions and whose interests such a focus is serving. ⁴⁹ Of course it would not be difficult to relate this back to the issues discussed previously where both medical and economic interests are served through taking a narrower view of disease causation; however, a perhaps more immediate problem of such a focus is the potential for such a biomedical or narrowly conceived behavioural focus to (re)inscribe stigmatising notions of culpability on to many developing societies and communities, both through explanation and bad practice.

**Stigmatisation of individuals and communities, and non-compliance**

The previous chapter discussed how certain assumptions and bias influenced the trajectory of scientific research, however, the corollary of this misapplied focus is that through the location of disease responsibility in generalised ‘risk’ groups by reference to sanitary or sexual behaviour, ⁵₀ the very same stigmatisation processes are facilitated by many discourses and interventions related to infectious disease research. Of course, few diseases has as much stigmatising potential both in developed and developing nations as HIV/AIDS, where early discourses in particular where focused on certain misunderstood risk categories and representations of sexual behaviour and

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⁴⁸ Gandy and Zumla, p.386-7
⁵₀ Shoepf, p.16
hygiene practices, and furthermore, the moralising overtones of much of this discourse was also potentially disempowering.\textsuperscript{51}

The implications for this in the developing world is that responsibility for disease is located in the societies, communities and individuals seems to demarcate socially conceived relations of superiority and inferiority and also exoticize cultural difference\textsuperscript{52} and this only made all the more damaging given the Western media and popular culture’s interest in and sensationalist portrayal of infectious disease since the 1980’s.\textsuperscript{53} This absolution of responsibility also seems to be politically expedient, as location of responsibility in others, and the hopelessness that is alluded to in the ‘diseased’ development narrative typical of biomedical discourse and accompanying media representations of disease in many underprivileged nations,\textsuperscript{54} seems to lead to a selective concern with health problems and emergencies, and furthermore, allow a moral high ground to be taken politically, despite the contentious causality of disease outcomes which are in likelihood influenced by political economic processes which benefits major corporate medical and general economic interests.

Furthermore, this stigmatisation accompanying disease representations is also responsible for the relative ineffectiveness of many medical and behavioural interventions in developing nations, where the risk of finding out if one was HIV/AIDS positive is accompanied by social and even familial ostracism, which obviously has impacts on the person far greater than psychological unease.\textsuperscript{55} Furthermore, where medical research or interventions interact with local communities in a stigmatising or culturally inappropriate way, or engage in a “fight against

\textsuperscript{51} Patton, p.67, Oppong and Kalipeni, p.47-54
\textsuperscript{52} Gausset, p.509
\textsuperscript{53} King, p.768-770
\textsuperscript{54} Shapiro, p.2189, Oppong and Kalipeni, p.47
\textsuperscript{55} De Zulueta, p.305, Castle, p.152
culture", it is not unlikely that denial of disease susceptibility will be the result or claims of counter-culpability in the manner of conspiracy theories being circulated through communities, thus further problematizing the effectiveness of research and interventions.

Therefore it is clear that a narrow biomedical focus plus questionably applied behavioural interventions, or "biomedical individualism" in many developing countries are unsurprisingly ineffective because of their tendencies to ignore the impact that socio-economic and socio-cultural factors have on disease aetiology, that leads to a "premature narrowing of research questions", and furthermore, disregard how many of these same factors actually complicate prophylactic and palliative care through stigmatisation and miscommunicated intentions. Furthermore, such projects are generally ill prepared to deal with politicized resistance against health research or interventions, where sometimes the more educated or elite members of societies engage in problem denial or circulate conspiracy theories regarding the intention of medical practitioners, and also express disinclination at not being included in the health planning processes, which is politically as well as practically important.

**Health Mobilisation and Problem Ownership**

The final way that narrowly conceived health interventions can obscure importance of socio-cultural and socio-economic factors is related to their tendency to override and even disparage "indigenous" attempts to mobilise effectively against infectious disease and general ill health. This however, is not just a matter of focus and funding, rather, a problem of exclusion. There is a variety of literature emerging in public health discourses which discuss the importance of collaboration and

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56 Gausset, p. 509  
57 Castle, p. 149, Shapiro, p. 2189  
58 Gandy and Zumla, p. 389  
59 Oppong and Kalipeni, p. 48  
60 Castle, p. 153, Mitchell et al, p. 1084, Shoepf, p. 22
incorporation of important members of communities into the planning and execution process of health research and intervention.

This has many practical benefits, such as enhancing the ability to express health issues and problems in more culturally appropriate idioms that reflect contextual understandings of disease and sufferance, meaning that such expression will be culturally compelling and potentially more effective at mobilising communities and populations to address the causal elements that underpin the spread of infectious disease.\(^6^1\) It may also increase interactivity between researchers and practitioners and members of society, thus yielding more useful information, and also potentially increase participation in healthcare programs, due to engagement in a more comfortable environment that is not as stigmatising or intimidating, in which to express health concerns.\(^6^2\)

Furthermore, these types of interventions are likely to also more adequately deal with the contextual politics that hamper explicitly biomedical interventions or research projects. Rather than appealing to scientifically justified authority as a means of ‘securing’ legitimacy for their interventions, some researchers have suggested that acquiring such legitimacy may be easier if a broader set of interests, such as traditional healers, community leaders and other important political or cultural elites, were represented in health interventions in developing nations.\(^6^3\) This acquisition of this legitimacy has become all the more important recently, because many developing societies are experiencing political turmoil, where the state has largely failed to

\(^{6^1}\) Willms et al, p.163-4
\(^{6^3}\) Castle, p.153

Gandy and Zumla, p.390, Willms et al, p.167
deliver the expected health outcomes promised by ‘modernization’ thus identification
with the state and many of the ‘westernized’ institutions that it is comprised of, which
as discussed have been prevalent in health mobilisation, is perhaps not as compelling
as it may have been previously.\textsuperscript{64} This is the lesson suggested by the success of
African nations Senegal and Uganda where a reduction of HIV/AIDS rates was
achieved by mobilising many different groups and interests to address the problem
through strong political leadership and effective function of “civil society”.\textsuperscript{65}

The failure to at least make some compromise in terms of the control of health
projects in developing nations is likely to ensure continued ineffectiveness in dealing
with pressing health problems in many of these nations. This is for a variety of
practical reasons, as discussed previously, where narrow explanations for disease
aetiologies and the solutions they imply, lead to unsurprisingly small improvements in
health outcomes. However, there is an important political reason to appreciate the
utility of participatory models of collaboration, as much of the “neo-colonial”
narrative which has been discussed previously relies on a certain degree of alienation
of communities and individuals from the interests of Western medical interventions.
By pointing to the specific lack of concern with equity in health and economics, and
the interests that are served by biomedically focused considerations of efficiency,
mobilisation and identification against the more remote and technically orientated,
and often culturally inappropriate or stigmatising types of intervention become
apparent, to the favour of more context specific and emotionally and culturally
compelling forms of identification and counter-identification.\textsuperscript{66}

\textsuperscript{64} Devisch, R., Dimomfu, I., Le Roy, J., & Crossman, P., “A Community-action Intervention to
Improve Medical Care Services in Kinshasa, Congo: Mediating the Realms of Healers and Physicians”
in Higginbotham, N., Briceno-Leon, R., and Johnson, N., (eds) Applying Health Social Science: Best
\textsuperscript{65} Gow, p.61-2
\textsuperscript{66} Yach and Zwi, p.1616, Devisch et al, p.133
With the growth of more specific forms of localized identity politics in many developing nations, which can often involve identification or re-identification with traditional cultural or medical practices, the contrast between Western economic and medical interests and the interests of communities in developing nations will continue to be accentuated in political discourses, and thus complicate the activities of Western health practitioners in these contexts. The key is to engage with this type of politics to ensure that the interests of medical science are not polemically positioned against those of important cultural elites in research and intervention designs. More collaborative efforts may also be helpful in the construction of novel forms of civil society where a variety of factors and methods of dealing with pressing health problems may be entertained without reproducing dominant relations of power. Indeed, it is likely that a certain degree of “ownership” by communities of health problems as facilitated through collaborative efforts, may not only result in more effective outcomes, but may well be important in fostering a positive and more equitable sense of communal identity on which to base broader political mobilisation on.

Clearly this will be easier said than done, as not only will such interventions have to allow a broader range of ‘expertise’ to impact upon the decision making processes, but there may well have to be reform and some degree of acceptance of

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67 Wills, et al, p.128,


68 Yach & Zwi, p.1615-20

69 Baylies, p.238

other moral and epistemological formulations and understandings of health and well being. Furthermore, there will have to be some sort of signification that the concern with health is at least substantially concerned with issues of equity in health and well being, as this is one of the more important features of rhetorical mobilisation (in terms of health and in general) in nascent civil society movements in many developing nations.70

The empowerment of these civil societies is seen as crucial in the mobilisation to solve pressing health and broader social problems, however, the failure to engage with them in a manner that allows a plurality of interests, not just the narrow interests of medical researchers and institutions, to be accorded respect, will only solidify accusations of “neo-colonialism” as it relates to infectious diseases and health in general. Engagement in this more collaborative manner, while unlikely to solve all the pressing issues, at least provides a point in which to break the circularity of this “neo-colonial” health narrative. This is because not only will it mean that the obfuscation of important socio-economic and socio-cultural factors will no longer be a criticism, but by broadening the range of stakeholders and upholding the relevance of their concerns, it will become more difficult to link the perceived interests and the ignorance of biomedical discourses and interventions to intuited senses of moral and cultural superiority that are said to pervade biomedical discourses. It is important that partnership is not only rhetorically and ethically articulated, but also that it finds a satisfying outlet to express political and economic concerns also, otherwise trust will fail to be obtained, something that is so very important in an area as personal as health, and more so given the historically perverse nature of colonial intervention in regards to health and disease, that should never be too far from mind. Indeed, many of

70 Yach & Zwi, p.1616
the same concerns have arisen in another field of scientific research, population genetics, where colonial arguments have served to narrativise the interaction between Western medical practitioners and researchers with people who perceive themselves to suffer from historical disadvantage attributable to colonialism.
Chapter V: Ideological, Ethical and Scientific Conundrums and a Vision of a Biocolonial Future in Population Genetics Research

While this chapter reflects upon “future prospects” of exploitation in regards to the biomedical investigation into the genetic basis of ethnicity, it should be noted that certain dimensions of the argument that raises this possibility have been already articulated to some degree. Rather than engaging in the verbatim detailing of arguments against such research, this thesis attempts to analyse the discourses surrounding the ethical issues of populations genetics in terms of the degree they reflect historical precedents of exploitation and how they discursively structure resistance in the modern ‘genetic’ era.

In doing so, I will focus primarily, but not exclusively on the Human Genome Diversity Project (HGDP) and the controversy that this project has engendered. Why the HGDP is pertinent to the analysis is due to it being a valuable source of rhetorical discordance and it is also a good example of direct political mobilisation against a large scale scientific endeavour that was touted as having beneficial outcomes for the very people who mobilised against it. As will be seen in the following analysis, the HGDP also served as lightning rod for a variety of other concerns surrounding not only the field of population genetics, but also medicine and science generally. Therefore it is a reasonable starting point in which to analyse the reactions of historically exploited groups to biomedical intervention in the modern era, and to reflect upon the ways that medicine and science persists in upholding systems and structures of dominance and control.
Before moving on to this analysis however, it is necessary to briefly outline the relevant terms and concepts being used in this chapter. The field of enquiry that the HGDP derives its authority from is that of “population genetics”. Population geneticists are involved in the detailing the scope and frequency of genetic variation as it relates to discrete human groups, otherwise known as “populations”. The practical implications of such research includes the understanding of human biological history and the potential to understand the aetiology of affliction and target medical services more precisely to afflicted groups.¹ Such research could also contribute to “genetic counselling”² in terms of being able provide information about genetic heritage and likelihood of inheritance, particularly to prospective parents, and pharmacogenomics.

The new field of pharmacogenomics in particular holds promise due to the possibility of being able to “design” drugs that cater to biologically specific metabolic conditions within a person or a group of people. These variations are believed to derive from genetic differences between humans and these variations are often believed to be “clustered” in distinct populations.³ To extract information on these differences it is necessary to “map” the genomes of these supposedly “genetically distinct” groups and this is where the Human Genome Diversity Project, as an explicit expression of the desire to detail the “relevant” genetic differences between human groups, derives its practical and epistemological legitimacy from.

However, while on face value the intention of such a project may seem somewhat benign and even practically beneficial for the groups under investigation,

the following analysis will attempt to detail some of the reservations raised against the HGDP and population genetics in general. This will reveal how historical narratives surrounding colonialism and medicine are enrolled for the purposes of mobilising against perceived modern sources of medical exploitation, often referred to as ‘biocolonialism’. It should also likewise reveal how the political context of resistance has changed in the post-colonial era, and that while medical practice itself may have been reformed due to reflection on the excesses and inconsistencies of past practices, it still continues to touch on sensitive points of ambivalence and often resistance towards interactions with science, medicine, and the hegemonic relations of power that they embody.

**Narrative One: The Ethical Justification for Intervention and Control**

While the ethical justification for intervention and control may no longer be articulated in a comprehensive sense, there is a persistent belief that a circumscribed ethical superiority is still prevalent in ‘dominant’ Western discourses on health and medicine. While the imposition of political authority and institutions onto non-Western societies is no longer as pervasive as it once was, a certain type of perceived arrogance is still intuited by those interacting with medical practitioners in the realm of population genetics.

The result is resistance against such imposition due to a variety of insensitivities perpetrated by practitioners, with the HGDP being a prime example of how the careless and assumed intellectual superiority of its representatives came to

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Deaven, L., “Mapping and Sequencing the Human Genome” in Cranor, C., (ed) *Are Genes Us? The*
represent a new type of "civilising mission", even if the parameters of such a mission were somewhat more limited in scope than in previous periods. The following analysis provides a sample of some of the issues raised in light of what could be called inappropriate interaction between HGDP representatives and the groups that came under the scientific gaze of the project. It also relates these issues to the exploitative narrative that articulates a view on interaction that, while not an overt form of "civilising mission" as was seen in the past, is still imbued with a sense of pretended superiority.

**Partnerships and Pretence**

Perhaps one of the more obvious, and therefore avoidable, controversies generated by the HGDP was related to the issues of participation and consultation. The first act of carelessness was the "announcing" by project organisers of the intention to conduct research into the genetics of human diversity, rather than necessarily discuss this possibility with the groups of interest. This was seen as conducting research "on rather than with indigenous people" and that an assumption of "eminent domain" was made by the researchers which supposed automatic rights to access of potentially interesting scientific information, irrespective of the wishes of and consequences for the groups being studied.

The distinct lack of consultation by the organisers in the initial stages of the project, and the decision to proceed before such consultation was engaged in alienated

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Social Consequences of the New Genetics New Brunswick: Rutgers University Press, 1994, p.29


Jackson, F., "Is there a Need for the HGDP, Now That the HGP is Interested in Human Variation?" in Politics and the Life Sciences Guildford: Beech Tree Publishing, Volume 18, Issue 2, 1999, p.301
many of the interested groups’ right from the beginning. In some cases there was even a distinct lack of an attempt to gain what is known as “informed consent” (which is discussed below); something considered a fundamental human right in regards to research on medical subjects. Whether this was due to general opportunism or a belief in the inability of such groups to comprehend the nature of the research, it is not surprising that many indigenous groups and their advocates took offence to such insensitivities and were all too willing to relate their experiences at the hands of the HGDP as being reflective of their historically situated experiences of colonial intervention. Furthermore, it helped undermine the notion of beneficence that was used in justifying the HGDP by some of the organisers.

As will discussed later on in the chapter, while it may have been possible to conduct research in fields relating to human diversity in previous periods with little regard to such ethical considerations, the new political context of indigenous identity politics combined with a historic distrust of medical institutions due to the experiences of colonialism, made the likelihood of the imposition of such research onto the groups of concern without negotiation almost impossible. Furthermore, not

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9 Dodson & Williamson, p.205-6
10 See chapter one and
11 Cunningham, p.214.
Furthermore, the inconsistency in ethical standards in regards to experimentation on “non-western” groups even in present times is considered to be problematic in this context.
only is consultation held to be politically important, the concept of "partnership",¹² where the groups of interest not only help set the goals of the research, but have a say over the appropriate forms of research design, was advocated as an equitable way of resolving the offence caused by assumed imposition. This would also appropriately reflect the politics of "self-determination" that has arisen in era of cultural rights advocacy.¹³

**Symbolic significance of the body in non-Western contexts**

As suggested above, a new era of cultural rights advocacy was often misunderstood by the organisers of the HGDP,¹⁴ and a good reason for this may be because cultural rights are distinct from individual rights. Cultural rights,¹⁵ as a broader set of rights, demand respect for different moral and cultural understandings in regards to things such as death, social relations, kinship, family¹⁶ and the body. One way that the HGDP may have undercut the work of indigenous groups in particular in terms of campaigning for these rights is in the way that researchers ignored differential understandings about the body and it relation to the "self".

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¹³ Dodson & Williamson, p.205-6
¹⁵ 'Cultural Rights' as used in the context of this thesis, basically refers to the idea that certain indigenous and minority groups believe that certain aspects of their culture, for example language, beliefs about appropriate protocol and respect for different moral and spiritual should be afforded legal and political protection where there is a strong likelihood that a majority culture of some sort might otherwise repress these rights. Often tied into these assertions are politics relating to land rights issues, political sovereignty and autonomy as it relates to matters concerning both the people and the land that they inhabit.
Cultural Rights are legally upheld in many states around the world, as well as by the United Nations.
¹⁶ Dodson & Williamson, p.204-6
The drawing of blood, which in a Western clinical context may be viewed somewhat more neutrally, can be highly symbolic in some non-Western contexts.\textsuperscript{17} Associated with notions of life and kinship, and potentially witchcraft,\textsuperscript{18} such traditions and taboos can be symbolically altered if blood was not drawn in a way that is culturally appropriate.\textsuperscript{19} The “immortalisation”\textsuperscript{20} of cell lines, for the purposes of continued information extraction after the initial act of drawing blood, was considered particularly problematic in this context of differential cultural and moral beliefs regarding the “body”, especially since this was not always the understood outcome of the extraction process.\textsuperscript{21}

The immortalisation of cell lines, and the eventual extraction of genetic information also caused offence to some groups because not only are blood and biological objects considered sacred, like many other objects of exchange in “pre-capitalist” societies, the “value” of the gift is not necessarily in the gift itself, rather, it is in how the gift establishes ongoing relationships or bonds of trust that exceed the immediate value of such a gift.\textsuperscript{22} However, it is not hard to imagine how gene prospecting as exemplified by the HGDP, contravenes this sense of partnership due to the possibility of the renewal of cell lines and DNA after the initial extraction process that does not require further interaction with the sources of the biological material.\textsuperscript{23} Furthermore, notions of ownership can differ between societies, and often the concept

\textsuperscript{17} Harkin, M., “The Devil, the Details, and the HGDP” in Politics and the Life Sciences Guildford: Beech Tree Publishing, Volume 18, Issue 2, 1999. p.302
\textsuperscript{18} Harkin, p.302,
\textsuperscript{21} Lock, p.69
\textsuperscript{22} Santos, p.83
\textsuperscript{23} Lock, p.69-71. How these differential values tie in to the commodification narrative will be discussed later in the chapter.
of individual ownership of property prevalent in Western societies is not shared by other societies, and this also extends to “genetic property”.

This lack of an ongoing relationship and negotiation of the terms of access, the possibility that reciprocity might not be found in reverse, and the differential understandings of social, moral and spiritual significance of bodily objects and ownership, all contribute to the potential contravention of such relationships if insensitive or dispassionate interaction with these groups persist. Furthermore, the articulation of much needed and valued notions of partnerships, which as previously suggested are held to important in the new context of cultural rights, will become all the more difficult. This is particularly true if the groups have suffered from colonial exploitation in the past where there is a belief that social disadvantage is attributable to the excesses of colonial exploitation, medical and general. The practical implication of this is that many indigenous or non-Western groups will become averse to participating in such research at a later date, on top of the ethical considerations.

**Self-indulgent view of benefits and costs**

Another issue relating to the perceived imposition of ethical norms is related to the assumption that such research will be beneficial to the groups being studied. Despite valid concerns regarding the possibility of exploitative outcomes that may arise from such research, the benefits still outweighed the costs according to HGDP proponents. In fact it was argued that the research would scientifically dismiss the biological basis for one type of feared exploitation, racism. It was also argued that even if adverse outcomes did arise from the project, the inability to know if this was really going to be the case would absolve the project of wrong doing, and that the

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24 Dodson & Williamson, p. 207-8. That said, notions of genetic ownership are problematic even in Western contexts, due to the shared nature of DNA.

causes of the misuse of scientific data is due to unethical implementation rather any inherent problems with the science itself.  

While later discussion will question the validity of the “good/bad” science distinction, the self-indulgent view of the benefits and costs of the HGDP caused some degree of consternation. First of all the imposition of this particular view of costs and benefits was somewhat resented. Secondly, many question whether or not such techniques would yield useful information, or if they did, whether or not in social contexts where access to medical resources is already a problem, the benefits would flow back to the groups in question. Thirdly, philosophers such as Nils Holtug doubt the claim that not intending to cause harm, especially when the possibility of harm is raised by opponents of the project, necessarily legitimizes continued perseverance with the research.  

Many of the project organisers argue from the point of view of beneficence. However it is clear that in appraising the costs and benefits of the project the costs do not take into account the unequal and inequitable social contexts of health that many indigenous and minority groups suffer under, and the doubts over the supposed value of the data combined with the previous articulated insensitivities belies the pretence of beneficence somewhat.

The imposed nature of at least the initial stages of the project also is argued to have contributed to the contravening of relationships of trust that are now realised to

26 Reznik, p.17
27 Reznik, p.17
31 Schukdenk, p.332-3
32 Stevens, p.1038
be important. Due to the controversies generated by the project by many of these insensitivities, there was an attempt by project organisers to adapt to the ethical and practical concerns raised by the groups of interest and their advocates. The development of a Model Ethical Protocol, and the innovations in terms of notions of consent were seen as potentially progressive. While there were indeed some improvements in terms of the manner of conduct, the aforementioned problems of trust still persisted, and there were some problems even with the adaptations, which will be discussed next.

*Informed Consent*

Informed consent, as dictated by the 1949 Nuremberg Code of ethics, is considered a fundamental human right when medical research is conducted on persons.\textsuperscript{33} The informed consent process requires that individuals be competent to give consent, are provided with the requisite information on which to base a decision about the risks and their interests relative to the research being conducted, have understood the information and lastly, have voluntarily given consent.\textsuperscript{34} As mentioned previously, informed consent has not always been attained by HGDP researchers and others associated with population genetics, and where informed consent has been sought and refused, instances of trying to find other avenues to extract the information, or misinformation on the intended uses of samples, have been prevalent.\textsuperscript{35}

\textsuperscript{33} Loue, p.14
\textsuperscript{34} Loue, p.15
\textsuperscript{35} Cunningham, p.216. Dukepoo, p.294, mentions that when consent has been refused by Indian groups it is not unusual for researchers to offer enticements to drunks, or find migrants to the city who have lost touch with their cultures. While this may be legally permissible, it still raises important political and ethical questions.
However, the concept of informed consent as far as it pertains to research in many indigenous contexts has been problematic. In terms of the practical issues, the means of communicating linguistically and scientifically the full meaning of the research being conducted are difficult.\textsuperscript{36} Furthermore, notions of informed consent are based on purportedly "Western" understandings of the nature of autonomy and individual rights that may not always be culturally relevant to some groups.\textsuperscript{37} Added to this is the insight that genetic research implies unique and somewhat unknown types of risk that can have impacts broader than just those experienced by the person subject to the research.\textsuperscript{38} Lastly, trying to obtain consent from an individual to conduct research risks contravening appropriate political protocol in regard to many groups, as informed consent may circumvent important political authority structures, sometimes seen as essential to group survival, especially when the protection of cultural rights is concerned.\textsuperscript{39}

However, the controversy over consent is one of the areas the HGDP organisers did try to innovate in terms of approaching the research in a more ethically suitable way. The notion of individualised informed consent was replaced by ‘group consent’,\textsuperscript{40} which recognised ethically and scientifically the importance of ‘groups’ or ‘populations’ to the study. However, while an improvement in some respects, the notion of group consent was still seen to be problematic. Firstly, the assumption that one can always identify the culturally appropriate institutions to consult in regards to the consent process is questioned.\textsuperscript{41} Secondly, the risk of imposing a certain type of artificiality on to groups for the purposes of research runs the risk of reifying these

\textsuperscript{36} Reznik, p.20
\textsuperscript{37} Reardon, p.373,
\textsuperscript{39} Sharp, p.41-3 Stevens, p.1072
\textsuperscript{40} Reznik, p.21
groups socially and may ignore the political complexity and tensions that exist within communities.\textsuperscript{42}

Indeed, demarcating groups for the purposes of research may again be seen as an attempt to “impose” outside understandings of cultural complexity on to such groups.\textsuperscript{43} The eminence of scientific authority still prevailed in the eyes of opponents. Running through many of the discourses defending the HGDP is the tacit assumption that more informed expertise and ethical implementation are the major considerations that would preclude further controversies, this of course contrary to the arguments being made by opponents regarding the real issues at stake.\textsuperscript{44} Therefore, an attempt to rectify these shortcomings was seen in terms of the formulation of a Model Ethical Protocol.

\textit{The Model Ethical Protocol}

The eventual development of a “Model Ethical Protocol” by HGDP organisers was seen as a somewhat progressive acknowledgement of the contextual complexity of conducting research in non-Western contexts.\textsuperscript{45} The main innovation, being the development of the notion of “group consent” and an attempt to afford protection for the research groups from patenting and commercial exploitation (which are discussed in the next chapter), are heralded as a step forward for the interaction between

\textsuperscript{40} Stevens, p.1072, Reznik, p.20-21
\textsuperscript{41} Reardon, p.376
\textsuperscript{42} Sharp, p.46-48, Reardon, p.372,376
\textsuperscript{43} Reardon, p.376. The problem is that even if groups are allowed to “define” themselves, then this runs the risk of undermining the utility of the data, as there is often a clash between how groups understand their integrity, and how scientists define the parameters of a “population” that is essential to illuminating the “meaning” of the research.
\textsuperscript{44} Reznik, p.20-21.
The details of the Model Ethical Protocol can be found at the address below.
Western and non-Western actors in medical contexts. However, the assumption by HGDP proponents that the Model Ethical Protocol, and a more refined consideration of the “scientific” issues relevant to the HGDP, was sufficient to address the concerns of such groups\textsuperscript{46} and that controversy would die down is revealing for a variety of reasons.

The concern is that while it looks like the organisers of the project are compromising to a certain degree over aspects of the research design, scientific authority and knowledge expertise is still assumed to be eminent in terms of discussing the issues raised by concerned groups. First of all, the ethical considerations addressed by the Model Ethical Protocol and for that matter, in the field of Ethics, Legal and Social Issues (ELSI) popularised by the Human Genome Project\textsuperscript{47}, are generally held to be circumscribed in technical terms.\textsuperscript{48} Not only is this potentially inaccessible to non-scientists or non-experts, but often the dynamics of social contexts in which scientific research is conducted are disconnected from the analysis, and furthermore, considerations of social justice are very rarely the concern of the field of ELSI as such.\textsuperscript{49} Research, particularly human focused research, is a collaborative and social process and scientific investigation into human genetic variability is no different, and this is revealed quite nicely by the inclusion of Carol Jenkins, an anthropologist who helped in the acquisition of biological material in the Hagahai case, as an “inventor” in the patent application for this cell line.\textsuperscript{50}

\textsuperscript{45} Greely, p.297-299
\textsuperscript{46} Greely, p.297-299, Reznik, p.20-21, Kidd & Kidd, p.314-315
\textsuperscript{49} Jackson, F., “African-American Responses to the Human Genome Project” in Public Understanding of Science Bristol: Institute of Physics, Volume 8, Issue 3, 1999. p.183
A second problem with the Model Ethical Protocol and the field of ELSI in general, is that it is too often asserted that if stakeholders were better informed and educated on the technical and scientific aspects of the research, then controversies would die away. Not only has this assumption been shown to be problematic in Western contexts, but the socially and historically embedded politics of identity and disadvantage that the HGDP organisers had inadvertently touched upon, limited the capacity of the Model Ethical Protocol to clarify the intentions of the HGDP and thus quell the controversy it engendered.

As the above discussion has emphasised, the imposition of scientific agendas and assumption of eminence by experts in terms of being able to dictate the appropriate range of concerns on to the groups under consideration has caused some degree of offence. To make things worse, the opposition to the project has sometimes been characterised as unsophisticated, intransigently 'anti-science', and most revealingly, social scientists who had tried to raise broader concerns regarding research were dismissed as "soft" intellectuals by some of the prominent scientists on the project.

While this suggests that scientists would like to see themselves as a "neutral filter of social reality" this role is often rejected by many of the activists and academics associated with the project and concerned with the broader context of population genetics. This is particularly true where scientists and scientific authority persists in limiting the potential for collaboration and does not accord indigenous and

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51 Cunningham-Burely & Kerr, p.657
52 Reardon, p.371
54 Stevens, p.1064
56 Cunningham, p.213
57 Cunningham, p.226-227
minority persons, their representatives and other concerned stakeholders due respect. Furthermore, it is possible to question the scientific objectivity and neutrality of the research, both in terms of the use of concepts and methodologies, which are covered in the next section. As many participants had been alienated by the at least initially somewhat self-indulgent and insensitive views taken by project organisers, this questioning becomes all the more likely.

_Narrative Two: Compromised Neutrality? Questioning the objective use of concepts, metaphors and methodologies in population genetics_

The previous section argued that scientific expertise, institutions and processes can influence social life in a way that is broader than its own technically orientated appraisal. However, social factors can also influence the way that scientists justify, understand and design their research methodologies. 57 While scientists attempt to demarcate quite clearly the difference between the “social” and the “scientific”, the following analysis provides an example of a narrative that disputes the neutrality that science bases so much of its epistemological and cognitive authority on. This becomes an issue of contention particularly when cross-cultural interaction in a research context is encountered, and shows how socialised understandings can affect the trajectory of research, which in turn affects the social and political world due to the potential implications of this research.

57 Cunningham-Burley & Kerr, p.651-2
Primitivism, Originality, Exoticized Indigeneity and Racialized Narratives

One of the more unfortunate and potentially avoidable ways that social understandings came to be represented in scientific discourse is seen in the initial justifications in regards to the notion of 'indigeneity' by the HGDP in particular, and for the field of population genetics in general. In justifying the need to sample the genetic heritage of the populations in question, often tacit notions of primitivism, originality and exotic difference were referred to.

The supposedly age old discourse of primitivism\(^{58}\) is unfortunately still implied in research designs of population geneticists. The "universal primitive"\(^{59}\) as a pre-civilised expression of some human past is not only a vestige of colonial area research interests, but still persists to the modern day in both popular and scientific discourses surrounding genetics research.\(^{60}\) Indigenous peoples are still seen to demarcate the difference between the "innate" and "artificial" in Western discourses,\(^{61}\) and not only does this permeate popular culture\(^{62}\), but as this New York Times\(^{63}\) articles demonstrates, scientists and science writers are still interested in the ways that certain indigenous tribes in particular might hold information for us on a pre-civilised past.

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\(^{59}\) Santos, p.86

\(^{60}\) Santos, p.88, 91


\(^{62}\) Klesse, p.32

\(^{63}\) Wade, N., “A Course in Evolution, Taught by Chimps” in New York Times Ann Arbor: New York Times, November 25, 2003. The article discusses the relationship between primates and human behaviour in evolutionary terms. At one point however, it makes an association between primate aggression and the Yanamano tribe in South America, which even if not an example of the type of thinking about “Civilisation”, it is potentially deeply offensive.
This “Originality” narrative quite was important in justifying the research, as groups “close to nature” are also assumed to be isolated and pure and thus potential sources of “uniqueness” that could be profitable for scientific investigation. However, aside from the historical offence that such narratives can cause, they are also of importance in a more immediate sense. The implication is that these groups represent a point in our developmental history, which is problematic enough in itself, however, this exoticization of difference also risks “naturalising” difference in not only a social fashion but in a biological way.

Furthermore, of considerable concern in terms of the political context of cultural rights, was the assumption that ran through many of the HGDP justifying discourses that somehow these groups was destined to fade away. “isolates” of “historic” interest, such groups not only were tainted by the brush of “progressivism”, but no one seemed to be concerned that they were indeed going to be allowed to go down the path of extinction. This was probably one of the most troubling aspects for indigenous persons, as not only did it show scientific contempt for the cultural rights of these groups, this contempt was based on somewhat insensitive, naïve, and archaic notions of social and cultural difference being used in research design justification.

At worst, the justifications used are revealing about a new type of scientific culture that, encouraged by the power of its new technology, may hasten a biologically sanctioned view of “otherness” that makes reference to a naturalistic-evolutionary framework that relies upon somewhat imprecise and at times discredited

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64 Bamford, p.45
65 Lock 1999, p.324
66 Bamford, p.38
67 Reardon, p.370, in this case, something as simple as the “the right to exist” is under siege
68 Lock 2001, p.78, Bamford, p.44
69 Santos, p.90-92, Dodson & Williamson, p.204-5, Lock 2001, p.79

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ideas about human developmental history. At best, such notions of difference are wishful thinking that in attempting to elucidate aspects of human history from a biological point of view, inappropriately demarcate a certain understanding of the “natural” and “social” order in its design. The assumption of the ability to find “pure” ethnic groups is also quite problematic, not only because it represents potential social bias in terms of the research design, but the lack of realism that such a point of view expresses may lead to undermining the utility of the data gained from such investigations, or worse, to over-interpretation of the meaning of the data. This becomes obvious in the discussion of the meaning of a “population”, which is discussed below.

Social Realism and the Integrity and Meaning of Populations

Over the course of time, there have been a variety of changes in the use of the terminology that describes perceivable differences between people in medical discourses. The shift from the concept of “race” to “ethnicity” for example, was seen as both ethically and methodologically superior due to the scientific and political misuse of the term “race”. While for the most part this was accepted as the appropriate term of reference for describing difference in a medical sense, when it comes to the field of population genetics, the use of “ethnicity” is somewhat more problematic as it often self-definitional, and not always related to an obvious sense of

70 Weiss, p.294
71 Bamford, p.44,
72 Reardon, p.363
73 Stevens, p.1060
74 Lock 2001, p.80-81. For example, by ignoring the historic influence of colonialism in terms of its impacts on the peoples and societies being researched.
shared biological unity. Thus the use of the term “population” became the frame of reference in which population geneticists and biologists described the type of difference that they particularly were interested in.\(^{76}\)

The use of the term “population” to describe biological variation is indeed a vast improvement on racial or “typological” thinking inherent in medical and human biological discourses of past times, as “population” thinking can to some degree embrace a wider range of variation within groups, and does not necessarily exaggerate the differences between groups based on superficial morphological markers.\(^{77}\) However, as we shall see, the usage of ‘population’ in population genetics, and the HGDP specifically was still seen to be problematic by anthropologists in particular, who worried about the appropriateness of demarcating groups based on genetic variation.

One set of concerns questioned how one could actual conceive of a population in practical terms. Issues with the designation of geographic parameters to be used, the impacts of colonialism, migration and other demographic issues on group integrity, and whether or not one can always assume hereditary in group descriptions are all considered to be problematic.\(^{78}\) The risk of committing a “category fallacy”, that is, the “imposition of one set of data on another set of another kind”\(^ {79}\) is high in this situation and suggests a lack of social realism that may have more to do with what hopes of the researchers than with trying to find the most appropriate way of designing such a study.

\(^{76}\) Reardon, p.362  
\(^{78}\) Lock 1999 p.324, Weiss, p.274, Stevens, p.1060  
\(^{79}\) Lock 2001, p.79-80
Another problem with the use of the notion of a "population" as the means of expressing biological variation is related to the nature of genetic variation itself. Variation is likely to be "quantitative" rather than "qualitative"; that is, variation in allelic frequency rather than different 'genes' at the same or different loci, otherwise known as "type", is more likely to be the case.\textsuperscript{80} The implication of this is two-fold. First of all, it means any subsequent interpretation of data will be more difficult due to the likely causal subtlety and complexity that will accompany the biological expression of such traits, and secondly, the notion of genetic distinction itself is questionable, despite its continued and pervasive use in population genetics discourses.\textsuperscript{81}

The problem for population researchers is that there are no perfectly "discrete types", as the "quantitative" nature of variation also means that the genetic point of reference for one group will end after 'another' begins. While individuals, and to some degree families could express this type of 'discretion', inferring that populations will also do so ignores social and biological complexity.\textsuperscript{82} Related to this is the observation that variation is "discordant" rather than "concordant"\textsuperscript{83}, which means that even if you can identify the genetic basis for a characteristic of one 'group', this does not necessarily imply other types of variations are shared by this group.

The problem with identification of groups is that it entails both social and biological processes that if duly considered, usually defy wishes to impose some sort of natural order upon them.\textsuperscript{84} Indeed a fundamental problem with this type of research is that there is no singular point of genetic reference in which to makes comparisons between individuals and groups and variation is so fundamental to the workings of

\textsuperscript{80} Gannett, p.487
\textsuperscript{81} Gannett, p.486, Weiss, p.294
\textsuperscript{82} Gannett, p.487
\textsuperscript{83} Gannett, p.487
\textsuperscript{84} Lock 2001, p.76
biology, or as Weiss says "there has never been a time when any species had an invariant genome".85

This is not to say that such research will not provide any useful information that could be used in a beneficial way, rather, the problem is that due to problems in defining what populations actually are, combined with the inherent scientific and social dynamics of diversity, such research runs the risk of "turning a weak hypothesis" into a "grand genealogy".86 This is especially true if, as has been done, researchers insist on using genetic markers to differentiate between individuals who are allowed to participate in research about certain populations, this being one example of how scientific design tautologies can self-validate the findings of scientists.87

This is a problem because not only is it potentially 'false' but the possibility that "genetic distinction" will be inappropriately emphasised underpins many of the concerns those critical of the HGDP for example have in regards to issues of commodification (discussed in Narrative Three) and political and social inequality (discussed in Narrative Four). In terms of the HGDP it is also likely to undermine its claims to beneficence, as it will not be able to deliver the benefits it is tacitly promising,88 (discussed in Narrative One) which in turn is likely to fulfil the expectations of those who believe that the project is nothing but a tool of "Western

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84 Pottage, p.761-2, Reardon, p.363
85 Weiss, p.281
86 Pottage, p.761-2
87 Stevens, p.1047
88 Alper & Beckwith, p.285, Stevens, p.1055-6 claim that the research design is far too broad to provide information of immediate use to medical applications. In terms of methodology, the HGDP also suffered from problems of differential use of the term "population" (Reardon, p.365), between its different branches, and the changing nature of its goals and other methodological problems also did not help.
Imperialism”. However, before moving on to discuss how such reified constructions of populations may influence issues of commodification, it is worth speculating further on the nature of the focus of genetics in modern society, and how that in turn also contributes to the saliency of “commodification” issues, a big part of the accusation of “biocolonialism” that is labelled against the HGDP and the like.

**Scientific Discordance and Contingency in the Interpretation of Complexity**

As discussed above, doubts about the integrity of populations and the inferences derived from such research about causality can have both a social and biological basis. Indeed scientific research itself is finding that mechanisms of inheritance and gene behaviour is much more complex than initially thought, therefore making the job of interpreting genetic data that much more difficult, especially when it comes to identifying groups from a genetic point of view. Furthermore, expanding the study of hereditary beyond the family unit often yields increasingly less compelling results, as inheritance is an often unstable and complex process.

However, both in the interests of fairness to scientific expression and the scientific community in general, it is important to note that within the general field of “biology” itself, not all researchers are as enamoured with the genetic focus, and simplistic assumptions about inheritance. Indeed, one of the scientists involved with the HGDP, Marc Feldman, has been engaged in a long running dispute with “socio-

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90 Weiss, p.279.
91 Stevens, p.1047
biologists” about the validity of the assumptions they make about genetics, evolution and inheritance.\textsuperscript{93} Others, such as Sarkar, and Tauber, point out the scientists themselves can and do methodologically study biological processes without necessary having to refer to a genetic analysis, and that genes alone do not always illuminate the ‘truth’ regarding the functioning of physiological processes, let alone the behavioural traits associated with them.\textsuperscript{94}

Aside from being an interesting observation, this tells us the nature of scientific study is somewhat more contingent than is often assumed by even scientists themselves. However, in situations where research into genetic inheritance and susceptibility may not be wanted or will be viewed sceptically, such discordance in scientific discourses is particularly problematic. The questioning of the genetic focus on health will become more prevalent, especially when the uncertainty about the meaning of genetic objects is not adequately acknowledged.\textsuperscript{95} One then comes to wonder what is hiding behind the façade of scientific explanation regarding genetics, and often it is suspected that social and cultural values themselves are being courted in service of a more sinister agenda, that of commodification.

\textit{Reductionism, Geneticization, and Commodification}

Many authors have questioned the appropriateness of the “elevated status” of both the human genome and genetic science in both science and society generally.\textsuperscript{96} Not only might such an understanding of human biological difference be scientifically dubious, but the risk of inappropriately “geneticizing” identity, destiny, culture,

\textsuperscript{92} Reardon, p.379, Stevens, p.1077
\textsuperscript{93} See Schwartz article.
\textsuperscript{95} Stevens, p.1077
\textsuperscript{96} Greely 1998, p.483.
history, spirituality and morality in general is seen as problematic.\textsuperscript{97} Others suggest that the popularity of "genetic reductionism", both in science policy and public science education, might be attributable to the relative "simplicity" that genetic explanation suggests.\textsuperscript{98} As alluring as genetic explanations for disease and other biological outcomes might be for scientists and public policy framers, an inappropriate emphasis can have potentially negative social, medical and scientific consequences.

As seen in the above discussion, this genetic focus has rendered "indigeneity" and "difference" a useful resource and contributed in some sense to an inappropriate and genetically reified understanding of the basis of populations, which, for all the neutrality that terms like "populations" imply, could lead to the naturalising of difference genetically.\textsuperscript{99} This could be dangerous in contexts where "social" beliefs about race, ethnicity and cultural superiority could plausibly mix with beliefs about genetic "essentialism".\textsuperscript{100}

Indeed a pertinent fear is that the simplification of reality in this way may enable the commodification of genes and persons that may both compromise ethical standards and undermine the political and legal rights of certain groups or culturally relative socio-moralities. Furthermore, this commodification, in a political economic context of exchange characterized by inequitable relations between dominant and

\textsuperscript{97} Stevens, p.1064, Greely 1998, p.495-6.
The "Geneticization" idea refers to the 'symbolic system' that defines normality by way of genetic discourses, and secondly, because of this, that genetic knowledge creates the potential for the more powerful to dominate the less powerful in society.
\textsuperscript{99} Jackson 1999a, p.184, Reardon, p.360
\textsuperscript{100} Wertz, p.336
minority and indigenous groups, will further disadvantage indigenous and minority
groups in terms of the distribution of benefits arising from commercial exploitation
(in its neutral sense), and furthermore, a genetic focus may also obscure what are
considered to be more pressing health priorities.

The next chapter will discuss in more detail both the concerns with
commodification and the broader political economic context of health, as it applies to
indigenous and minority groups and genetics research. However it is interesting to
reflect upon how the imposition of research agendas and notions of authority and the
eventual justification of relevance through the delineation of genetic distinctiveness,
and the concomitant ethical and scientific concerns it raises, have engendered
resistance in some of the groups that were to be scrutinized by the HGDP. Not only is
it unsurprising that a great deal of controversy was generated due to historical
insensitivity, but the somewhat biased ethical and epistemological application of
knowledge also, represents in the eyes of many opponents, the intellectual foundation
for the political-economic or “practical” exploitation of persons of difference. The
HGDP, in terms of its conduct and intent, appeared to be too closely aligned with the
political and economic interests of scientists, corporations and even nation-states, and
thus somewhat unsurprisingly got caught up in accusations of “Biocolonialism”.

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Chapter VI: The Political and Economic Possibilities for a Biocolonial Future

While the previous chapter was more concerned with the ethical and ideological aspects of exploitation, this chapter attempts to outline the political-economic basis of claims of "Biocolonialism" that has surrounded the HGDP and population genetics research in general. The previous chapter argued that not only were ethical considerations issues of considerable merit in themselves; they could also be seen as the intellectual foundation for "inevitable" and "practical" forms of exploitation. This chapter attempts to outline the more specific dimensions of claims to political-economic exploitation, starting with the issues of commodification as it relates to political, ethical, and economic issues to do with population genetics. The chapter then proceeds to discuss relevant political contexts of health and how genetics research may alter in detrimental ways the social and medical health of indigenous and minority groups.

Narrative Three: Commodification and Commercialisation of Genetics and Difference

"Commodification"\(^1\), as a more specific type of concern, is deemed to be a threat to the cultures of indigenous and minority persons, but also a threat to their prosperity and well-being.\(^2\) In the HGDP in particular, this threat of commodification

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\(^1\) Body Commodification, as both a political and philosophical concern, basically refers to the idea that objectification of the body parts or bodily themes can lead to potentially 'dehumanising' outcomes as in the process of rendering aspects of body a commodity of exchange, usually economic, such objectification can undermine the significance of bodily meanings as it relates to broader social and human understanding of the non-economic value of embodiment


This is relevant on a philosophical level, because where certain hegemonic Western understandings of embodiment (usually scientific) prevail in knowledge exchange, this can potentially undermine the
was represented as being a tool of Western imperialism that served to undermine cultures of difference, as well as extract resources from them for commercial profit. In terms of culture, "commodification" could potentially threaten the values of other cultures, which could become morally and politically troubling for these groups.

Commodification of the body as a threat to cultural dignity, both Western and non-Western, is something that has gained a lot more attention in recent years in debates over the ethics of biotechnology. However, especially in light of the representation of indigeneity and the biological basis of difference as discussed in Narrative Two, this reservation takes on a certain degree more salience. In some cases, it is not even the extraction of genes that was held to be offensive, but the immortalization of cell lines, and the manner in which they were extracted that was of concern. The immortalization of cell lines, which prevents the need to continually take blood samples, poses problems of ownership and the possibility of unauthorized application and misuse at a later date (discussed below), but also potentially leads to adverse moral outcomes for some groups. Lock for example believes that many groups, indigenous or otherwise, do not share our "commodity fetishism" in terms of the exchange of body parts, because they imbue body parts with more profound significance (in terms of both spiritual beliefs and social beliefs) than is sometimes recognised by scientific and clinical discourses.

The implication here is that in engaging in such research ignores cultural rights and undermines the value of differential identities. Added to this fear are

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3 Jackson, F., "Is there a Need for the HGDP, Now That the HGP is Interested in Human Variation?" in Politics and the Life Sciences Guildford: Beech Tree Publishing, Volume 18, Issue 2, 1999. p.300
traditional concerns with the procurement of non-Western bodies for scientific experimentation,⁵ and the concerns with different ethical standards of experimentation and research that is often encountered in non-Western contexts, which threatens to further dehumanise the cultural value of difference.⁶ The commodification concern, in terms of genetics, is concerned with how in the economic relations of exchange, genetic and biological materials and information are rendered objects for economic exploitation. This is where concerns regarding the misapplication of racial, ethnic or population categories discussed in the previous chapter are connected to a more self-interested scientific economic agenda, which is supported by a political economy of perceived inequality that threatens both cultural and material well being.

While these reservations may seem to be quite general, they take on a more salient form in concerns over notions of "ownership". Ownership of biological materials such as cell lines, or the eventually extracted genes, has been one area of particularly virulent outrage, as the controversy of "patenting" shows. Issues with patenting represented the clearest way that the HGDP, and population genetics in general, was part of a "Biocolonial" project whose purpose was to undermine culturally and economically indigenous and minority well being.⁷

Culturally, patenting is problematic because the notion of "ownership" is utilised differently in some non-Western cultures, where commodities cannot be owned by individuals but the group.⁸ Thus, if Western corporations or governments were heavily involved in the patenting of genes of indigenous people, this becomes in

⁵Lock 2001, p.68
⁸Dodson & Williamson, p.205-6
the eyes of many akin to “genetic slavery”. Furthermore, even if consent was allowed for initial scientific investigations, the lack of a need to continue to renegotiate access to such information, or the potential misuse (politically or commercially) of such materials at a later date is profoundly worrying to some peoples, especially considering the appearance for sale of cell lines of two Brazilian tribes on the internet that became a national scandal in Brazil and in the worldwide indigenous network.

Some writers associated with the HGDP, such as David Resnik, have discussed the ethical issues surrounding patenting from a philosophical point of view. Resnik argues that patents are not “ownership” as such but are more of a “limited property right”. Furthermore, while he recognises the potential threat to dignity that patenting of body parts poses, he argues that patenting would only threaten human “dignity” or culturally significant values if by patenting it somehow undermines its non-market value. While he believes that patenting is an example of an “incomplete” commodity in the sense that the patenting of DNA does not necessarily preclude or corrupt its “non-market” enjoyment, he does recognise that it is the political economic context that patenting takes place that poses a legitimate problem in terms of how certain disadvantaged groups will fare ethically under differential “regimes of value”, or economically in the commercial context. This commercial context is where, for opponents of the HGDP, its imposed insensitivity to the values of different

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12 Lock, p.69, that is differential systems of knowledge in regards to the values associated with important cultural and social symbols. In this case the implication is that one hegemonic system of values, “Western” is predominant.
13 Reznik, p.162-4
cultures colludes with somewhat more systematic interests in terms of the “Biocolonial” nature of the HGDP, population genetics and science in general.

**Commodification and Economic Exploitation**

Perhaps the biggest strategic error that the HGDP made in its planning process was not recognising the “pre-structured” nature of the debate that it was about to enter into in terms of the issue of patenting in particular.\(^\text{14}\) Accusations of “Biopiracy” had already become a big issue in the context of plant genetics prior to the HGDP’s announcement of intent. Western corporations “stealing” the traditional heritage of many indigenous cultures around the world had become a common occurrence. The taking of plant materials, such as Neem which had been used in India for 2000 years as a natural biodegradable insecticide,\(^\text{15}\) and the technological isolation of the useful genetic compounds that the plant produces for commercial profit, was extremely controversial around the time the HGDP became interested in human genetic variation.\(^\text{16}\)

The accusation of “piracy”\(^\text{17}\) is given logical consistency in that the commercial context that such research takes place in is underpinned by a regime of intellectual property rights (GATT-TRIPS) that not only favours larger and more powerful interests, and furthermore interests with the technological capacity to exploit the commercial worth of plant materials,\(^\text{18}\) but one that also denies the contribution of “Traditional Knowledge” in terms of isolating the practical usefulness of such

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\(^{16}\) Santos, p.92


\(^{18}\) Merson, p.289
products. The observation that such exploitation also may not result in reciprocal medical or economic benefits, further compounded the controversy. Clearly the stage was set for accusations of biopiracy and Biocolonialism, but on a human level, and as some authors noted, the early 1990’s may not have been a politically suitable time to undertake a project like the HGDP which could readily lend itself, by providing information on “novel” human variation, to commercial exploitation.

For opponents of the HGDP the issue of the commercial exploitation of human genetic variation became a reality with the “Hagahai” scandal. This involved the patenting of a cell line, infected with a virus from a man belonging to the Hagahai tribe in Papua New Guinea. The virus was related to a certain kind of T-cell leukaemia, which was benign in the Hagahai, thus suggesting some form of resistance had evolved, with potentially profitable applications. The patent was accepted by the US patents office, and controversy erupted throughout the indigenous world in particular, as other examples of such patenting were also made about the same time.

While the HGDP in particular was not directly involved in the patenting process, it was believed by many that such information could eventually be exploited for corporate gain, and due to the high levels of mistrust already engendered by the corporations in the realm of plant genetics, even the small possibility that this might happen was enough to assuage many indigenous groups of any notion that reciprocity of benefit may be acquired. The implied complicity of scientists and the HGDP in

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20 Santos, p.92
21 Lock, p.64-65


particular in preserving this potentially exploitative commercial context of exchange is discussed next.

Scientific Complicity, Biocolonialism and the HGDP

While some scientists, particularly HGDP scientists, would like to believe that their work is purely for the sake of investigation, this may not be a plausible position to claim in the modern political and economic context, especially as it relates to patenting controversies. However, even if we assume that scientific research is merely for scientific edification even this poses some problems. The colonial (Chapters I and II) and not so “colonial” (See Chapter IV) impulse for collection and information gathering is still problematic and engenders suspicion. Relating the collection of modern artefacts for museums to the collection of cells for repositories, many opponents believe that this in itself is offensive enough to warrant caution, especially in light of the subsequent controversies over ownership and reacquisition of traditional artefacts.  

The controversy however, goes one step further, as the fear that such genetic “artefacts” of interest may somehow be misappropriated for other, potentially commercial means, is of great interest to indigenous groups and their advocates. In this context, the “acquisitive scientist” meets the “gene hunter” in a complicity of interests in which it is hard to distinguish the intellectual fervour of the scientists from the desire for profit that compels the “gene hunter”.

A good example of this can be seen in the Hagahai patent controversy. While the drawing of blood in the Hagahai case was not actually done under the auspices of

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22 Lock, p.83
23 Lock, p.85
the HGDP, the presence of a biological anthropologist also affiliated to the HGDP in his support, Jonathan Friedlaender, became the "missing link" between the HGDP and the possibility of exploitation. Indeed there is a general concern by both scientists and social scientists that the connections between corporations and academic science are growing, and that governments, particularly the US, are not overly concerned with issues regarding patenting and indeed vigorously uphold the current intellectual property regime.

There is also a concern that many commercial and non-commercial interests "hype" the necessity to gain such genetic information, for purposes of gaining government or other funding. Furthermore, "gene fever" is a particular problem because it encourages scientists and corporations to patent as many "genes" in the interests of knowledge ownership and "potential" profit, before due consideration is given to their realistic use, as well as the ethical implications of such use. That governments sometimes give funding, or continue to uphold intellectual property regimes both at home and abroad that do not adequately address the complexity of genes, or the rights of other cultures in terms of cultural sovereignty and notions of ownership as it relates to biological materials, is particularly concerning.

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24 Rose, p.329
25 Cunningham, p.212
26 Reardon, p.359-60
27 Cunningham, p.214-217
30 Reznik, p.153-4, 163-5
Greely questions whether the current laws adequately address issues of genetic ownership, while Reznik discusses criticism regarding whether or not DNA isolation really does represent "human invention" which is one of the criteria of patentability.
31 Lone Dog, p.54
This only serves to implicate all these powerful interests in the “Biocolonial” narrative where each one contributes subtly to the general undermining of cultural, economic and political rights of indigenous and minority persons. This hegemonic “system of power”, both ideological and economically dominant, is not only seen to denigrate the rights of non-Western cultures, but also seeks to solidify and reify the unequal and inequitable relationships between these groups and the scientific ‘complex’, for the purposes of continued exploitation, such as the experiences of these group’s colonial history suggests. However, this “Biocolonial” narrative delivers a parting shot before ending its tale of woe, and this relates more specifically to issues of health, and how the genetic focus, and the commercial bias and structural inequalities not only contribute to the perversion of culturally significant values and the exploitation of indigenous and minority “resources”, but also undermines the very thing that the HGDP and population genetics in general has proposed to deliver: the enhancement of the health of indigenous and minority groups.

**Narrative Four: Genetics, Difference and the Political Context of Health Priorities**

**The Possibility and Distribution of Benefits Arising from the HGDP and Population Genetics Research into Ethnic Diseases**

Many have questioned whether or not any significant health benefits would accrue to the indigenous and minority person being sampled by the HGDP. Indeed, the fact that many of the initially controversial patent claims made by corporate interests on indigenous DNA were dropped due to a lack of scientific and

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32 Cunningham, p.206-7
commercially exploitative value, suggests that much of the "hype" around genetic
potency is perhaps exactly that. Despite also having caused initial offence, and failed
to return or destroy the materials extracted, the lack of any potential health benefits
also undermines the claims of many of those who claim that population genetics could
augment the health of those disadvantaged. This of course only engenders further
suspicion in those who are already distrustful of genetics research into ethnic
difference, and potentially alienates those, such as the Hagahai, that perhaps believed
that something valuable could be gained out of exchange.\textsuperscript{34}

Indeed some scientific organisations, such as the US National Research
Council have challenged population geneticists in general to show that there methods
work, that the categories that they are research could be useful in an epidemiological
sense, and that the quantifications or risks and benefits actually reflect reality,\textsuperscript{35} as
opposed to the "vague speak of benefits" that usually accompanies research
justifications.\textsuperscript{36} Many scientists believe that while the study of variation is important,
current claims regarding the scale of genetic discretion and molecular determinism are
"hubris" and should be thought about more carefully.\textsuperscript{37} Even if we assume that in the
long term such benefits can accrue to the groups under scrutiny by projects like the
HGDP and their commercial counterparts, the likelihood that such benefits will flow
back to these communities is also questionable.

Margaret Lock perhaps puts this concern most simply when she comments on
the possibility of designer drugs helping afflicted minorities by saying that "use of
them would certainly be limited to those individuals who participate in well-funded

\textsuperscript{33} Cunningham, p.210, Lock, p.82
\textsuperscript{34} Cunningham, p.210
\textsuperscript{35} Stevens, p.1037-8
\textsuperscript{36} Rose, p.329
\textsuperscript{37} Weiss, p.293
health systems". Indeed, inequalities and inequities in terms of access to health care as it relates both to minorities within developed nations and also in developing nations is problematic. Pharmaceuticals are often in short supply, misinformation and misunderstanding by health professionals, and even obvious cases of discrimination by these professionals are apparent. Furthermore, well being in terms of health also seems to correlate with intersecting "ethnic" and socio-economic variables.

Quantitative social science research finds that while socio-economic status (SES) is a very important determinant of well-being, "ethnic" or "racial" aspects are also important once SES is controlled for. This suggests that discrimination is apparent in medical care, and the fact that many ethnic minorities and indigenous persons also inhabit lower rungs on the SES scale, only compounds this problem. Furthermore, even where there is recognition of differential outcomes in terms of ethnic susceptibility to illness, the use of "ethnic" or racial categories is often misapplied and thus impotent, or worse, where discrimination or inaccurate stereotypes are prevalent, exacerbates health problems. Thus it seems naïve to assume that genetic medicines even if developed will necessarily flow back to the communities that contributed to their development by providing the "raw" materials of investigation.

38 Lock, p.76
39 Rose, p.329.
40 King, p.95, Greely, p.492
43 Stevens, p.1058
Furthermore, the genetic testing required to ascertain whether medicines will be of use could be potentially misapplied due to inaccurate assumptions about patients "ethnic background", culturally problematic trust relationships between doctor and patient, or even if a doctor is readily available. Such testing could also be looked upon sceptically by many ‘ethnically’ disadvantaged persons in particular, due to pre-existing misapprehensions about science, medicine, and the political economic context of health, especially in regards to concerns over privacy and discrimination in areas such as insurance and employment.

However, the impotence of genetic medicine, at least as far as its current progress is concerned, is not merely an issue of medical relevance. Not only could it be misapplied in discriminatory or inequitable contexts of health, but it could potentially obscure the importance and thus hold back other important health developments, due to the expenditure of "intellectual" capital on such research, the alteration of medical priorities and thus funding priorities, and in some cases, forestall "serious" consideration of the effect of genetics on the health of the disadvantaged.

**Genetic Investigations and Explanations of Differential ‘Ethnic’ Health as Obfuscation**

Lone Dog reasonably asks whether or not the funds used to fund the HGDPC have been diverted from other funds that could have helped “support and sustain

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43 Atkin, p.102-3
44 Atkin, p.92, Greely, p.491-2
45 Qureshi, N., "The Relevance of Cultural Understanding to Clinical Genetic Practice in Clarke, A., & Parsons, E., (eds) *Culture Kinship, and Genes: Toward a Cross-Cultural Genetics* Houndmills: MacMillan Press, 1997. p.116, explains how some health practitioners believe that “directiveness” in genetic counselling is more appropriate for minority groups, but suggests this merely reinforces previously held prejudices by health professionals, especially as non-directiveness is seen to be an important value in modern genetic counselling, by preventing the institutionalisation of eugenic perspectives.
indigenous communities". Indeed, a common theme in research in discourses on ethnicity, genetics and health relates to the best use of funds in terms of considerations of efficiency, especially when it relates to government or public funds. This reservation has both a medical and a social component. On the one hand, it is argued that the study of genetic susceptibility does not necessarily give a comprehensive picture of disease aetiology, thus funding of research may be better spent on research that investigates the full range of contributing causes. Often genetics research of this type is flawed precisely because it does not control adequately for other factors, thus attributing too much significance to genetic explanations. Furthermore, statistical importance does not imply casual significance, and thus it is important that as Parkin states, to describe the genetic and biological mechanisms of susceptibility to disease more precisely than has been apparent.

Ward argues strongly that many diseases relating to ethnic difference are actually “multifactorial”. Noting that “ethnic groups are characterized not only a unique constellation of alleles, but also by a unique set of environments” he argues that the genetic focus on for example, hypertension in African Americans, ignores the complexity of causes, however, despite this, the “invocation of genetic differences as the underlying cause of major health problem remains implicit in much of the epidemiological research”. The implication of this is that not only will there be an

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47 Lone Dog, p.62
48 Lock, p.82
49 Bhopal, p.34-5
50 Stevens, p.1043
51 Stevens, p.1044
53 Ward, p.100
54 Ward, p.103

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inappropriate focus on the genetic “deficit” of those ethnic groups under
consideration, but the complex medical causes of illness will be obscured in medical
research.\textsuperscript{55}

A good example from the “indigenous” world relates to the focus on the
prevalence of diabetes and other such metabolic conditions. The focus on some sort of
“thrifty gene”\textsuperscript{56} as an explanation for the rate of diabetes in many indigenous groups
clearly ignores the impact of “nutrition transition” on many of these groups who have
come into contact with Western diets, or in some way or form have had their
traditional diets compromised.\textsuperscript{57} This is not to say that there is no genetic component
in terms of hypertension, diabetes and other health problems, but that genetic focus
ignores the linked environmental, cultural and genetic ecology of causation,\textsuperscript{58} and thus
focus on narrow genetic solutions that are implied by this research will be both
ineffective, and ultimately inefficient in terms of funding utilisation.

The social component is an extension of the above in so far that it argues that
the ethnically biased context of medical access, and structurally, socio-economic
status, are powerful contributing causes, or in some cases, direct determinants of
disease outcomes. The undermining of traditional indigenous economies, the changes
wrought by colonisation and subsequent development policies, and the stratification
of ethnic difference along socio-economic lines are seen to be as important
considerations of health outcomes.\textsuperscript{59}

\textsuperscript{55} Ward, p.109
\textsuperscript{56} Newman, p.521
\textsuperscript{57} Shetty, P., “Variations in Health and Disease: Race, Ethnicity or ‘Nutrition Transition’” in MacBeth,
\textsuperscript{58} McMichael, A., “Diabetes, Ancestral Diets and Dairy Foods: An Evolutionary Perspective on
Population Differences in Susceptibility to Diabetes” in MacBeth, H., & Shetty, P., (eds) Health and
\textsuperscript{59} Newman, p.523, Nazroo & Davey Smith, p.50, 52, Anand and Yusuf, p.174

Interestingly, Nazroo and Davey Smith note that socio-economic status is an even more important
determinant of ‘racial’ health than smoking or diet. Furthermore, ethnic minorities are usually worse
off even within certain SES bands, thus implying a ‘racial’ factor that amplifies the impact of SES.
Thus the argument becomes one about social change, and thus politicizes the discourse, thereby relating the narrow genetic and medical bias of Western science to the maintenance of social ills and stratification (socio-economic and socio-cultural) by not only reifying categories of difference through genetics research, but also by asserting that the genetic focus obscures equally or in some cases more important causes of disease outcomes. This argument is indeed with some merit, as Rose notes civil and cultural rights movements, and political mobilisation have had as much to do with the improvement in health of disadvantaged groups as has advances in medical technologies over the years. Ward also notes that changes in the “macro-social” environment can affect the appearance or disappearance of disease in a much more rapid fashion than the genetic heritage of a group, or medical intervention often can, and that due to the complexity of causes implied in “multifactorial” disease, such a genetic focus, while not wholly unimportant, may not be the most effective way of guaranteeing health for susceptible groups.

One more problem relates to a concern over the use of “social” categories in research regarding medical “difference”. As will be noted in many of the discourses related to population genetics and other fields interested in ‘ethnic’ health, use dissimilar terms denoting difference and in slightly different ways. The variability of such terms, for example, ‘population’, ‘ethnic group’, ‘race’ is in part related to culturally different ways of understanding difference and often disadvantage, and furthermore, it may be appropriate to use one or another depending on the social context or the disease or health outcome that is being studied. While this is not necessarily fatal for study into ethnic difference, it does suggest that such “difference”

60 Rose, p.329
61 Ward, p.104, 109
62 Bhopal, p.36
63 Bhopal, p.28-31
is at least medically difficult to precisely articulate, and greater reflection on the use of such categories is appropriate. Indeed Bhopal argues that such fields of research are "between paradigms" and that "the biological paradigm of race having been abandoned by some scientists" still has "no clear successor".  

This is an issue because not only does this imply that scientists are operating in potentially hostile contexts (where such luxuries of conceptualisation may not be afforded) without a clear understanding of what they are looking at, but that the categories that are being used are in some degree subjectively circumscribed. While this has been discussed previously, it is important to reconsider this in light of the fact that science, is not only affected by "society" in terms of its research directions, and even at times in terms of its epistemological predispositions, but that science in return due to its cultural authority, affects society. However, the use of scientific ideas in society does not always mirror the precision that most scientists would believe is appropriate. This is demonstrated by the Time magazine interpretation of the HGDP finding that "ancestral Europeans are estimated to be an admixture of 65% ancestral Chinese and 35% ancestral Africans" which was interpreted by Time as meaning "All Europeans are thought to be hybrid population, with 65% Asian and 35% African genes".  

This is problematic because, science, especially genetics, as interpreted by mainstream culture can be potentially threatening on a political level to those disadvantaged and "different". Categories can be imbued with meanings that which are either imprecise, or in the worst case, potentially stigmatising in terms of the way they are used socially. The spectre of Eugenics, as the collusion of imprecise science with political interests, looms large over this debate. Furthermore, research into

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64 Bhopal, p.23
genetics can have an impact upon ‘local’ politics in itself which may not always have positive outcomes; all of these issues are discussed below.

**Stigmatization, Eugenic Potentials, Politics and Genetics**

The potential for abuse of genetic information is usually refers to the possibility that a type of ‘racialized’ Eugenics may be supported by the public, and eventually by policy makers, and that the articulation of differences in the way that the HGDP and population genetics does, may lead to the use of these stigmatizing for discrimination markers if societal conditions were to take a turn for the worse. In terms of discrimination, the possibility exists for two reasons. First of all is a fear that in terms of health insurance, education and employment in particular, genetic testing may be a source of discrimination as justifications for exclusion may now come to be based on “objective” scientific arguments. While this is a concern for all persons, the fact that indigenous and minority groups are being singled out for genetic attention makes it all the more likely that they may be discriminated against.66 Secondly, pre-existing contexts of racial and ethnic discrimination would only take this supposedly objective data, and reinterpret it in light of prevailing bias’, which would lead to the social stigmatization of certain groups, both in popular and medical discourses.67

While it is a commonly known fact in scientific and academic circles that intra-group genetic variation far exceeds inter-group variation, such knowledge is not always politically or publicly acknowledged.68 Thus somewhat archaic notions of ethnic and racial differences can come to dominate policy and public understanding of these differences. An example of would be the “one drop” rule that has during the

66 Lock, p.80
67 Reardon, p.367-8, Qureshi, p.113-114
68 Ward, p.93
course of US public health been a salient marker of difference. The “one drop” rule
basically designated a person to be African-American if it could be proven that they
had some African-American hereditary, even if everyone else in the family tree was
European. Many authors are not convinced that this sort of thinking about difference
has been totally expunged from dominant public or policy discourses.\(^{69}\) Neither, does
one suspect that this sort of thinking is purely restricted to hegemonic Western
discourses, as social interest in the meaning of racial purity and hereditary are
common the world over.

The conflation of simplistic and discriminatory categories of exclusion with
scientific knowledge could thus potentially lead to routine stigmatization of certain
groups. The sickle cell controversies of the 1970’s are one example of how African-
Americans were singled out for testing and counselling, ignoring the complexity of
inheritance and the fact that the groups who suffer most from haemoglobin disorders
are not always of African descent.\(^{70}\) This is an example of how both institutional
medicine and policy interests had an effect on the social understanding of disease and
susceptibility, and thus reified categories of stigmatization. While many population
geneticists, and proponents of the HGDP believe that technically correct science will
preclude such excesses, it is perhaps naïve to believe that first of all, this field of
science is comprehensively understood, and secondly that even if the science was
technically correct, that policy, political and public interests would not act in a way

\(^{69}\) Jackson, F., “African-American Responses to the Human Genome Project” in Public Understanding

\(^{70}\) Atkin, p.95, King, p.99-100
that would that would produce similar sorts of “genetic” scares as has been historically prevalent.\textsuperscript{71}

The ultimate expression of this concern comes by way of concerns of Eugenics. The aim of Eugenics\textsuperscript{72} is “to maintain and improve the human populations by positive means...and negative means” where institutional support exists for procreation of those persons designated ‘superior’ in some way is encouraged, and the scientific and sometimes institutional discouragement of the breeding of “inferior” persons is also apparent. As discussed in Chapter II Eugenicist movements were not only prevalent in Nazi Germany during WWII, but also in many other Western nations. Eugenicist movements are also of contemporary academic interest in non-Western nations, such as China, and Singapore.\textsuperscript{73} Therefore, the cultural, historical and international precedent for this is apparent.

This does not necessarily mean that Eugenics movements will inevitably derive from a renewed interest in genetics and inheritance as the cause of health problems. However, a variety of issues have been raised that need some serious discussion before more genetics research, particularly into the biological basis of difference, occurs. The first concern is related to the possibility of ‘Eugenics’ by the ‘backdoor’.\textsuperscript{74} Basically the relevant concern is that while modern ‘genetic counselling’ is non-directive and puts the rights of individuals first, either the


\textsuperscript{72} Dyson, S., “‘Race’, Ethnicity and Haemoglobin Disorders” in Social Science and Medicine Oxford: Pergamon Press, Volume 47, Issue 1, 1998. p.127-8 discusses how ethnic and racial categories as it relates to the haemoglobinopathies are usually quite problematic. The issue is not with the ascription of causality in this case to genetic factors or even that such diseases do not correlate with certain groups; rather the problem is related to how screening and definitions of group susceptibility when implemented in policy practice can lead to discriminatory outcomes.


This statement can also be accessed at: http://genetics.faseb.org/genetics/ashg/policy/pol-30.htm

\textsuperscript{74} Duster, T., Backdoor to Eugenics New York: Routledge 2003. p.129
counselling or the provision of information, or the broader context of disease understandings may still exert a subtle influence still might have a on individual decisions to go through with pregnancy.75 That issues in cross-cultural communication exist in medical practice76 as well as discriminatory bias77 and furthermore, that research into genetic difference might single out ethnic groups inappropriately, suggests that ‘eugenics’ might take a racialized character. The possibility that ‘genetic’ messages might be misunderstood by both the populations under scrutiny as well as the general public is also a particularly likely outcome, further augmenting the racialized eugenic potential of genetic research.78

Furthermore, it is also not entirely implausible that the state might take a more active interest in such developments, and indeed there has been discussion on the ‘states’ historical and contemporary interest in genetic ‘surveillance’.79 This might gain further support from the public if scientific research, especially flawed research, somehow manages to imbue ethnic differences with a biological essence that is inappropriate, or if scientific meanings are somehow misconstrued by public discourses. Perhaps the best of examples of how renewed interest in flawed genetic

75 Duster, p.130-131
This is because while ‘individuals’ have the right to decide in the immediate sense, broader scientific and policy discourses still influence decision making by inculcating ‘rational’ values into the population which place an emphasis on the ‘value’ and meaning of disease and genetic illness.
Issues in cross-cultural communication range from linguistic barriers and the use of medical jargon to spiritual or moral views on the aetiology and thus ‘meaning’ of disease.
77 Qureshi, p.116
79 Atkin, p.95-6, Duster, p.130
ideas could have potentially eugenicist outcomes comes by way of renewed concern
with ‘behaviouralist’ genetics.

While this interest is not comprehensive, and in the most part not scientifically
serious, it is by no means clear that it will continue to occupy the margins of scientific
or public concern. Research into ‘ethnic’ problems such as crime, alcoholism, and
psychiatric disorders have been ventured.\textsuperscript{80} Furthermore, research and interest in
‘ethnic’ intelligence\textsuperscript{81} has also caused a significant degree of controversy,
particularly in the US. This clearly could have morally and politically repugnant
outcomes. Equally concerning is that while for the most part research of this kind is
seen as scientifically incorrect as behavioural or intelligence traits, even if they do
have biological components, are not necessarily genetic, or if they are, the immense
complexity of their expression would be enough to dismiss most modern research in
to their causation, such concerns over IQ and genetics still occupies a disproportionate
amount of public attention. Furthermore, statistically narrow research that says nothing
of causation can lead to much scientific and public speculation over the nature of
disease and inheritance, broadly conceived.\textsuperscript{82}

It may be obvious that many of these “behavioural” traits have environmental
or social causes also,\textsuperscript{83} but this biased focus on genetic predisposition, combined with
“individualistic and therapeutic idioms for changing [behaviour]” could potentially
distract from the socially embedded expressions of behaviour, of which culture is an

\textsuperscript{80} Alper and Beckwith, p.287
Dukepoo, F., “Its More Than the Human Genome Diversity Project” in Politics and the Life Sciences
Bowman, J., “The Human Genome Diversity Project as a Complement to Human Population Genetics”
\textsuperscript{81} Grey, S., “Reading Racism: A Reflection on the Politics of the Production of Knowledge” in Critical
\textsuperscript{82} Grey, p.467, Bowman, p.290
Littlewood, C., “Culture in the Field of Race and Mental Health” in MacBeth, H., & Shetty, P., (eds)
\textsuperscript{83} Dukepoo, p.295, Bowman, p.290
important aspect of this expression. Indeed Littlewood speculates on why certain types of 'ethnic' mental illness have been emphasised in psychiatric literature, while others have stayed understudied. He argues that Western bias in psychiatric discourses, for example normative assumptions about individualism and behaviour, are still prevalent in the study of psychiatry, and that where the "individualistic and therapeutic idiom" of counselling fails, it is assumed that some sort of genetic predisposition must correlate with the culturally differential expression of behaviour. This is instead of letting the importance of socio-cultural and socio-economic expressions and explanations for behaviour, and for the most part, intelligence, speak for themselves.

While many scientists refute the scientific importance of the genetic behavioural focus, and the misapplied categories of difference that could lead to stigmatising or eugenicist outcomes, there is a belief that such concern is too passive and muted. Clearly, scientists who base their cultural authority on being "objective" may feel uncomfortable with transgressing the line between the 'scientific' and the 'social', however, their cultural authority would also be undermined if the misuse of their work, by policymakers, corporations, or other scientists, became apparent.

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84 Littlewood, p.212, 218.
85 Littlewood, p.210-212
This Washington Post article reports a study that suggests previously biased studies into the nature of IQ heredity have had potentially negative outcomes in terms of the utilisation of funding resources. This study suggests that because previous studies on IQ and Inheritance focused on middle to upper class families, it was assumed that the 'positive' heritability results also applied more generally. However, when broadening the research sample the findings suggested that up to a point, environmental factors played a large part in IQ outcomes. This 'point' is significant however, and thus certain programs like the 'Head Start' program may have certain benefits if funded.
88 Alper and Beckwith, p.287-8. They also discuss the lack of education that many scientists have about the social uses and influences of science and thus a minimum prerequisite for engaging with ethical issues of genetics and ethnicity is not only technical expertise, but a clear and vigilant understanding of the potential abuses that research can lead to, much in the way Anthropology and Physics have.
Furthermore, the lack of social activism, or the tendency for the scientific press to "fail" to report "negative" findings regarding genetic links, can make them look complicit in regards to pre-existing contexts of mistrust that surround the work of the HGDP and population genetics.

*Genetics and Influence on Indigenous and Minority Politics*

Indeed it in this social indifference that the "Biocolonial" narrative gains a certain degree of circularity. Even if we assume that the worst case scenarios such as eugenics or the development of genetically targeted weapons are not likely to come to fruition, the focus on genetics could potentially undermine the health of indigenous and minority persons, because much health activism is tied to political and social activism, especially in terms of access to funding and political institutions. If all genetics research did was to circumscribe a neutral genetic basis for existence, even this would be somewhat controversial, as this basis could have an effect by undermining cultural mythologies regarding origin and arrival, jeopardise institutionally protected cultural rights, potentially alter the basis for access to funding.

An interesting example of this is the "Black" Seminole group in the United States, who as "Black Freedmen" became integrated into one of the Seminole tribes in

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Wertz, D., "A Needed Boost for the HGDP" in *Politics and the Life Sciences* Guildford: Beech Tree Publishing, Volume 18, Issue 2, 1999, p.336 also notes that if significant differences are "found" in genetics research, how they might be handled appropriately from a political and social point of view has not really been discussed, which is a potential weakness.  
88 Stevens, p.1040  
Jenkins, p.310  
Jenkins, a South African medical researcher discusses how attempts were apparent in South Africa to develop such weapons before the end of apartheid.  
90 Indeed, despite what some scientists might believe, the "Genome as Biography" ideal where historical movements are tracked through gene admixture in human societies, while interesting for some, may not be appreciated by some political organisations, especially if it becomes an important factor in deciding who is considered part of some group in policy decisions.
the nineteenth century. However, genetic testing has thrown up quite a controversy as
the Black Seminole’s could now be excluded from the Seminole nation, with all the
benefits that this entails. More interestingly, it some aspects of the Seminole
community that are responsible for advocating this exclusion, and a good example of
how such a focus could potentially be used either by dominant powers against certain
groups, or in this case, how other competing groups with political interests could
marginalise others in political contests. Clearly this a political context that one would
want to tread carefully, even if it does prove somewhat that “essentialist” perspectives
on genetics and discrimination is not solely a vice of the hegemonic West.91

If such apathy to the concerns of these groups continues to exist, then it will
not be difficult for indigenous and minority groups to link the social indifference or
obfuscation of social and political expression of health back to the more ‘imperialist’
dimensions of the ‘Biocolonial’ narrative. This lack of concern for at least as
compelling social and political determinants of health and disease, and the social and
political uses of categories of difference, suggests that the knowledge that the HGDP
and population genetics in general is trying to gain is really for the edification of
scientists and could eventually lead to greater exploitation in the future. Thus it is seen
to be likely that this obscuring of the contexts of health is almost “intentional” or
“preconceived” for the purposes of imposing hegemonic beliefs about science, culture
and politics on to those who have suffered historical disadvantage. This is how the
‘biocolonial’ narrative attains inevitability and circularity both backwards and
forwards in time and space. These dimensions of mobilisation are to be discussed in
the next chapter.

Ben Ari, E., “Molecular Biographies: Anthropological Geneticists are Using the Genome to Decode
Human History” in Bioscience, Washington: American Institute of Biological Sciences, Volume 49,
Issue 2, 1999, p.98-103 is an example of a narrative that upholds this biological view of human history.
91 Johnston, p.265-8
Chapter VII: Biocolonial Activism, Telecommunications and Political Mobilisation in the Genetic Era

Part IV seeks to explore further the character and implications of the rhetorical constructions outlined in previous chapters as they relate to the debate on population genetics and the study of ethnicity. This chapter is thus divided into three sections for the purposes of discussion, while Chapter VIII, the concluding chapter, is also divided into three sections. The first section aims to discuss the relationship of the specifically ‘biocolonial’ narratives to mobilization by members of the indigenous communities and relations within and without these communities. The second section will further discuss the important insights implicated in section one by alluding to the function of the internet in helping to mobilize resistance against population genetics in general and the Human Genome Diversity Project in particular. Section three will take this discussion and shows how these particular representations functioned as rhetorical devices which shaped the political terrain that the proponents of the Human Genome Diversity Project had to negotiate.

A rhetorical map for understanding embedded bio-colonial resistance

Previous chapters have argued that whenever accusations of colonialism are leveled against dominant health research agendas supposedly representative of Western power, the rhetorical composition of these arguments are shaped by four interrelated narratives that specify the sources and intentions of exploitation. Indeed the previous two chapters discussed this overarching ‘biocolonial’ narrative with reference to population
genetics, and outlined both the historical relatedness of these narratives, as well as the contextually relevant political terrain that they operated within.

In terms of similarities however, we can see some analytical overlap between the three areas of inquiry. In terms of narrative one, we see that in each area, hegemonic medical discourses and actors have been accused of harbouring moral arrogance in terms of dictating justifications for intervention, as to what are the appropriate considerations of ethical discussion, and who has the right to decide for 'post-colonial' groups what is entailed in health priorities. In terms of narrative two, in all three periods we see a tendency to exotocize the meaning of 'otherness' within the pertinent medical frame of reference in a way that benefited both the scientific and broader 'commodity' interests of Western scientists and Western economic and political interests. This is argued to create the ideological space for practical forms of exploitation through the stigmatization and diminishment of the identity of the 'other' in all three periods. Also of note is the perceived tendency of Western medical discourse to 'reduce' aetiological explanations to a single unit of analysis, whether it be bacteria, virus or gene, which in turn allows a certain ordered view of health to be promoted, often to the detriment of groups somewhat stigmatized by these conceptions. This reduction is argued to be representative of Western philosophy and science, and as such underpins narrow health policies which also just happen to benefit certain 'Western' financial and political interests.

The third narrative relates concerns over control and exploitation of resources but also over how inequality in political-economic relations disadvantages post-colonial peoples in terms of health outcomes. In the infectious diseases and population genetics we see that with the processes of globalization supposedly becoming stronger post-WWII,
post-colonial persons suffer from inequitable relations in terms of intellectual property regimes supported by GATT-TRIPS, which both restricts access to medical advances and potentially enshrines in law ownership over knowledge gained in these contexts, but for the benefit of western governments and corporations. Furthermore, globalization is also seen to hold dangers in terms of its potential to undermine local economies and compromise health delivery due to more narrowly defined economic and health regimes of which governments can use to influence these outcomes. Lastly, the fourth narratives argues that denial of the true causes of disease and furthermore, the health priorities of post-colonial persons themselves implies disrespect for local politics and serves to undermine discursively and institutionally the capacity for such groups to influence decision making processes in regards to their health well-being, thus ensuring the vicious circle repeats itself.

However, to some degree the previous analysis relied heavily on academic appraisal of such ‘biocolonial’ resistance. This was both essential and insightful, however, there is a need to briefly circumvent the analysis of the academic community, some of whom are politically invested themselves in the circumscription of the ‘biocolonial narrative’ to try and ascertain whether ‘colonialism’ is invoked in service of protesting such biological research by the communities or representatives of the communities themselves. Not only will this increase the robustness of the analysis, but specific characteristics of resistance will be noted with their implications discussed later in the chapter.

In regards to the ethical dimension of the biocolonial narrative, we see that indigenous groups and those actively involved in protesting against population genetics
and the HGDP, are acutely aware of both ethical issues regarding such research, as well as the stated divergence between Western and non-Western ethical points of views. Indeed there is a stated relationship between the imposition of a purportedly particularistic Western point of view, as it relates to both the ownership and the ethics of research, alluded to in many statements by active indigenous groups. Many treaties have been issued by many groups, or congregations of groups in protest of what some see to be ethically repugnant research. The Ukupseni Declaration for example states that “research projects on Indigenous peoples genome go against human life and, in particular, violate the genetic integrity of Indigenous Peoples and their values” and also states that the notion of “individual consent” is contrary to indigenous peoples beliefs about cultural norms and collective rights.¹

The Ukupseni Declaration, along with the “Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project” and the “The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous People” ² also argues that such research is a contravention of the harmonic principles, and the intimate relationship with nature and reciprocity with each other that indigenous people enjoy. Western science and research projects like the HGDP thus come to be represented as inherently contrary to the natural order that indigenous people in particular claim to

uphold culturally and pragmatically. The 'Western Hemisphere' declaration in particular goes on to directly associate this contrariness with exploitation when it states that "In the long history of destruction which has accompanied western colonization we have come to realize that the agenda of the non-indigenous forces has been to appropriate and manipulate the natural order for the purposes of profit, power and control."

One article featured on the Third World Network website discusses in depth how the relationship of biotechnology, as a Western invention (let alone a tool of exploitation) is contrary to indigenous principles, but is imposed upon such peoples in any event.3 Indeed, 'biotechnology' has become a site for struggle over the human rights that are normally assumed to belong to indigenous people.4 The dispute is not only related to supposedly distinct moral differences in regards to culture and social life, but also over who gets to define the ethical terrain that governs relations in the social life of many indigenous groups. In this sense, the assertion of the need to map the genomes of indigenous people is only seen as being for the edification of Western scientists in regards to knowledge acquisition, and devoid of any humanitarian content as far as health is concerned,5 especially given that there is some concern over why indigenous groups


"after being subjected to ethnocide and genocide for 500 years, which is why we are endangered, the alternative is for our DNA to be stored and collected...why don't they address the causes of our being endangered, instead of spending $20 million for five years to collect and store us in cold laboratories? If this money will be used instead to provide us basic social services and promote our rights as Indigenous Peoples, then our biodiversity will be protected. (Victoria Tauli-Corpuz, Cordillera People's Alliance, Philippines)
were not considered worthy of consultation in the early parts of the HGDP\textsuperscript{6}. However, population genetics and research into indigenous people is not only seen as posing ethical concerns, but also concerns regarding scientific objectivity itself are posited by activists, as seen in previous sections.

The second aspect of concern relates to objectivity and the use of categories within scientific research. However, there seems to be a small divergence between academic and "lay" accounts in terms of the expression of these concerns. Clearly, when questioning scientific objectivity, academic accounts will employ technical language in raising concerns about objectivity and methodology. However, the 'lay' accounts tend to employ more emotive and decisive moral language when questioning the objectivity and methodology of Western science.\textsuperscript{7} However, the outcome is fundamentally similar. Indigenous groups and their representatives argue that the ‘reduction’ of life into discrete categories, such as race, ethnic group, or gene is inappropriate, offensive and potentially dangerous.\textsuperscript{8} This is not to suggest that such groups necessarily lack the capacity to engage in technical scientific critique, rather, they have a more immediate need to protest

\textsuperscript{6} Ibid
\textsuperscript{7} Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project.
\textsuperscript{8} Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project. Tauli-Corpuz, “To negate the complexity of any life form by isolating and reducing it to its minute parts, western science and technologies diminishes its identity as a precious and unique life form, and alters its relationship to the natural order.”
such research by more politically emotive means due to historical experience and the lack of concern with these experiences.⁹

There is also a realization that such scientific categorization contributes to exploitation, both now and in the future. Of course the spectre of patenting and intellectual property rights is apparent, with groups like RAFI¹⁰ in particular pre-existing the fight over research into the diversity of the human genome. Similar to the resistance against bio-prospecting in regards to plant life, population genetics research is contrasted unfavourably against indigenous people’s cultural, human and economic rights.¹¹ Furthermore, some accounts are suspicious as to how such research might help stigmatise groups, contribute to further racism, or provide a foundation for the racialisation of society. In some cases a worst case scenario which claims the development of genetic weapons is the intention of Western scientists is ventured, so to be used against indigenous or other groups of difference.¹²

Clearly, especially in regards to claims about biological weapons, the capacity of ‘Western’ science to affect such disastrous outcomes is in contradiction to other claims about the inadequacy of science that is made within this overarching biocolonial narrative.

¹⁰Etc Group, was formerly known as RAFI. <http://www.etcgroup.org/> accessed on 20th February 2005. One example of a communiqué expressing the warnings that RAFI gave to the indigenous communities before this controversy had become fully mature can be found here: <http://www.gene.ch/info4action/2000/Jan/msg00054.html> accessed on 20th February 2005.
Often the argument is made that Western science is both ineffectual and inevitably powerful. While this is not necessarily a complete contradiction given the social influence of science and genetics research in the modern world, both perspectives are clearly enrolled in service of questioning the objectivity of such scientific research, even if it does imply a certain degree of cognitive dissonance. Mitigating this somewhat, there seems to be a tendency in the research for more academic accounts to raise concerns mainly about the faulty methodologies regarding research, while many non-academic sources seem to accept a certain degree of inevitability and furthermore assume that the intentions of the research is to subjectify and colonise further, the minds, bodies and societies of indigenous people in particular. Indeed, in this type of rhetorical posture, science comes to be both the cause and consequence of exploitative motives.

Nonetheless, the combination of both accounts in interacting with controversial projects such as the HGDP seems to rhetorically define the science of population genetics as being necessarily exploitative, irrespective of its ability to substantially alter the physical or biological universe around it. Both are also very sensitive to who may or may not benefit from genetics research of this kind in a commercial context defined by a certain intellectual property regime which advantages larger market players. This property regime is considered politically and economically unfair as well as ethically and symbolically contrary to the at times self-constructed stereotypes of indigenous cultures. Indeed, much of the vitriol generated by the HGDP derives from the debate on intellectual property. Not only are intellectual property issues more politically salient and to some degree compelling due to their enshrinement in both domestic and international

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13 Awang, p.120-134
law, but there is a pre-existing arena of debate which preceded discussion regarding research into the diversity of the human genome, which is where we turn our attention to in discussing the third aspect of the biocolonial narrative.

The specific nature of claims about the exploitative potential of population genetics and the Human Genome Diversity Project made by indigenous people boil down to a very strongly worded and recurring theme; that theme being ‘biopiracy’. Not only is ‘biocolonialism’ the imposition of ethical and symbolic constructions of culture and society on to other groups, it is also involves direct extraction from these groups valuable resources, extraction which is seen to be unfair and responsible for continued subjugation of indigenous peoples. For example the three declarations mentioned at the beginning of this section make it very clear that the patenting of indigenous genetic intellectual property is nothing but an act of aggression and colonialism. Stating that “the process of genetic collection, based on deception and exploitation of poverty and marginalization” it is an “an act of piracy and theft, and consists of an assault against Indigenous Peoples”.14

Demanding the immediate return of all biological and informational materials so far extracted in service of any number of population genetic projects, there is a direct association made between the exploitation of GATT, NAFTA and the WTO and the intellectual property mechanisms that they uphold, and even universities, governments and other NGO’s that supposedly make up the “apparatus of informed consent as tools of

14 Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project
legalized western deception and theft". More than a couple of press releases from groups acting on behalf of the HGDP for example, have labeled the project “the Vampire Project”. There is clear view that the “commercialization” of life, which projects like the HGDP contributes to by making the genes of indigenous people objects of ownership, manipulation and appraisal, will only disadvantage indigenous people in a historically constructed context of inequality, on top of the claimed ethical concerns with the ownership of genes. Clearly there is a clear lack of appreciation for the stated benefits of diversity research, as well as the potential health partnerships some of the more enlightened members of the HGDP have suggested.

Lastly, we come to the fourth component of the biocolonial narrative, that being the obfuscation or ignorance of the politics of health and health priorities. This aspect claims that despite at times stated intentions by certain government, corporate or scientific entities that indigenous health is of key concern, in reality, the politics of the groups themselves is obscured by scientific motives which derive from a broader context of exploitation, such as has been outlined previously. Not only does the biocolonial narrative claim that genetics research is directly involved in exploiting indigenous people in particular, but that it is also, through the cultural influence of genetic research on

15 Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project
society, a major factor in denying the importance of indigenous politics and health priorities. In this sense, Indigenous health politics is claimed to be concerned the social causes and consequences of detrimental health outcomes in these communities rather than with the biological and genetic solutions to such problems.

'Social' or 'cultural' solutions to indigenous health problems are claimed to have a greater impact on reducing morbid outcomes than genetic solutions, especially in the long run. Thus, any attempt to fund genetics research on indigenous peoples genomes without equal or greater funding being devoted to public health orientated programs that empower communities, will be seen as emblematic of suspect motivations to either directly exploit indigenous people such as has been suggested previously, or deny the importance of indigenous health politics and health priorities. One declaration on the HGDP demands that "scientific endeavors and resources be prioritized to support and improve social, economic and environmental conditions of indigenous peoples in their environments, thereby improving health conditions and raising the overall quality of life". The question of ownership, whether it be over intellectual property rights, or having the right to self-determination such as expressed by the Mataatua Declaration is a common theme in protesting the HGDP in particular. Calls for a moratorium on

18 See footnote 5 , Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project.
19 Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project
Ukupesi Declaration, Kuna Yala on the Human Genome Diversity Project (HGDP)
The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous People
20 Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project
21 The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous People
research into the diversity of the human genome are common, with the assertion of fundamental and universal human rights being a key feature of this demand.\textsuperscript{22}

This aspect of the biocolonial narrative is becoming more important for two key reasons. One reason is that indigenous and ‘post-colonial’ politics in general are becoming more important over time and claims for greater authority and empowerment to be given is apparent. Health outcomes and the capacity to decide on health priorities are considered to be a salient marker of such empowerment.\textsuperscript{23} A second reason relates to the broader cultural context in which such politics operates within. If we entertain the notion previously alluded to that modern Western society has become more fascinated with genetics research and genetic explanations for health outcomes, and that somewhat shared understandings of such health phenomena exist between scientists, government and corporate policy makers, and the general public, then this will be in direct opposition to a more socially and culturally focused health agenda, such as what characterizes indigenous health politics. Whether or not there is a shared there is such a complete shared understanding or fascination with genetic explanations, there is enough acceptance or at least acquiescence to allow research into human genetics to become normalized, so much so that protestations against something as seemingly harmless as research into

\textsuperscript{22} Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project

genetics could come to be characterized as merely the irrational fears of marginalized and radicalized groups.  

Nevertheless, it has been argued previously that such fears are in no respect irrational given the context of racism and colonialism that typifies large sections of the history of Western and indigenous health interaction. However, the problem is that even if we accept that some claims are quite unreasonable, such as for example claims about genetic weapons, the issue then becomes one of how to ensure the appropriate representation of such fears. It seems that to actually have your concerns about certain research addressed there is a necessity to engage in using more emotive and controversial language. There is no mechanism in which to allow the expression of such concerns in a way that involves mediation and negotiation. Therefore, recourse to more dramatic and decisively worded discourse might well have been the inevitable outcome of the way the HGDP conducted itself, particularly in the early stages. This is an especially important insight given that a ‘ready made’ biocolonial narrative pre-existing this debate as explained previously.

Thus the combination of a greater awareness of indigenous peoples own politics of self-authorship, and a lack of awareness of these politics and the generalized politics of

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24 California State University, Occupational Studies Department, Biotechnology, Biopiracy, and the Mentality of Science <www.csulb.edu/depts/cost/DL/Oest4171/Handout4.pdf> accessed on 20th February 2005 p.11
Prior, L., Glasner, P., McNally, R., “Genotechnology: Three Challenges to Risk Legitimation” in Adam, B., Beck U., & van Loon, J. (eds) The Risk Society and Beyond : Critical Issues for Social Theory London: SAGE, 2000. p.109 discusses how scientists usually stereotype the public as being emotional, irrational and ignorant while not realizing that “risk” evaluations in regards to the safety of genetotechnology are “often conducted in rhetorical terms” by both scientists and non-scientists and have as much to do with “culture, institutions, perceptions, control and activity” than about “how risks are framed by experts”.

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biotechnology on behalf of HGDP scientists and policy makers is one of the major reasons for such debate to get out of hand. However, there is one more factor which merits discussion in regards to the rhetorical mobilization of resistance, and that is the role of telecommunications, particularly the internet, in allowing the politics of resistance to be so effective in inhibiting the progress the HGDP.

The Juxtaposition of the ‘old’ and ‘new’

As mentioned above, a variety of changes in the political landscape over the last forty years has lead to a greater questioning of scientific expertise and the consequences of research. These changes include the assertion of special cultural rights by indigenous groups, resistance against bio-technological innovations by a broader range of interests and the growth of telecommunications. This is borne out by some of the interactions surrounding the HGDP. In terms of cultural rights, the eminent domain assumed by scientists in regards to the extraction of knowledge and access to biological materials was clearly contrary to a new awareness about rights to cultural and social integrity that indigenous groups were asserting.

Furthermore activists from further a field were willing to lend their ‘activist’ expertise to protesting another potentially dangerous biotechnological innovation. These activist networks such as RAFT had been previously involved in campaigns against things such as the patenting of plant genes, and a quick glance over the homepage of the website of the Indigenous Peoples Council on Biocolonialism (one of the prominent websites for
Biocolonialism on the internet) gives the reader the indication that there are far more than the concerns of indigenous people on the minds of the activists.25

It is clear that there has been a confluence of interests in the utilization of the internet to protest the HGDP and population genetics research in general. Furthermore, protests against the HGDP on the internet had been launched well before the internet gained its place as one of the integral parts of modern living. This was a surprise to the organizers not only because they did not fully comprehend the radicalized nature of the political context they were stepping into, but also because the internet, along with activists expertise, came to organize resistance and define the intentions of HGDP scientists before they could even get to the point of interacting with many groups.26 It allowed protestors to disseminate information quickly and efficiently to interested parties, organize conferences, make declarations and ultimately confront the organizers of the project themselves.27

Hasian jr, along with others argue quite clearly that the internet "has served as a leveling device, creating alliances among indigenous communities that would have otherwise been separated by time and space".28 Internet activists in particular according

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Woods, C., Native American Netizens Gather and Organize Online <http://www.wired.com/news/politics/0,1283,711,00.html>

to Hasian jr, used four rhetorical strategies to beguile the organizers of the HGDP. First of all, they impugned the motives of the scientists themselves, followed up by criticism of the lack of international oversight for the project. This was backed up by the promotion of the validity of indigenous rights within the broader legal culture and the contest over priorities and funding, internationally and domestically, and also characterized the HGDP as a form of “biopiracy” and the scientists as “biopirates”. 29 Here we see aspects of all four components of the bioccolonial narrative which feed into the general debate about the exploitative potential of population genetics. Hasian goes so far to argue that internet mobilization conducted in this way one of the major reasons that the HGDP has failed to get further funding from governments in particular. 30

While theoretically the Internet allowed a great diversity of marginalized interests to congregate and voice their concerns, it is prudent to recognize that there are some limitations in thinking about mobilization in this way. The major issue hanging over such a perspective is in regards to what could be claimed as being the “authentic” voice of indigenous resistance. While there probably is some truth to the statements about the shared nature of indigenous moral values and experiences at the hands of interfering outsiders, and at the same time the collective divergence from Western modes of thought, it seems a little suspicious to regard all of the concerns of indigenous people in the same light. However, the narrative, especially that as represented on and through the internet, is quite homogenizing in terms of this aspect.


Furthermore, the internet may well still harbour many of the same inequalities that are present in the non-virtual world, is so far as ability to access and use may be an issue. Thus we are left with a variety of questions to answer, such as whether or not most of the vitriol generated on the net by activist networks is largely attributable to “privileged individuals” within such communities. 31 The IPCB website gives a declaration form wherein all you need to do is fill in the blanks to officially declare your tribal opposition to the HGDP and funding of population genetics in general. 32 To push this argument further, it may be necessary to ask whether or not the biocolonial narrative has also been ‘hijacked’ by activists generally ambivalent about biotechnology, who have the resources to dedicate to the battle and thus influence the trajectory of the fight. Many of the same names reoccur when reading both academic and non-academic articles, and the websites often have links to websites of other organizations that fall within the antibiotechnology and anti-globalization category. Thus it is possible that the concerns of indigenous people and thus their method of interacting with the HGDP is shaped by a greater or lesser degree by reliance on academic and activists sources.

This is not meant to impugn the authenticity and compassion of those who are raising concerns on behalf of indigenous people, rather that is necessary to recognize that on top of the interaction between ‘West’ and ‘non-West’ there is another realm of sub-

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31 Pervasive critics such as Debra Harry are kind enough to give us a guide to “what indigenous people must do” in regards to the HGDP. Harry, D., Patenting of Life and Its Implications For Indigenous Peoples <http://www.ipcb.org/publications/briefing_papers/files/patents.html> accessed on 20th February 2005.

32 The IPCB has a very well designed site that has a plethora of information and resources in aid of the protest against biocolonialism and claims itself as “being one of the very few non-profit organizations to address the impact that science has had on indigenous communities” which “is an awesome responsibility”. <http://www.ipcb.org/about_us/biowarriors.html> accessed on 20th February 2005.
politics operating that may belie the seemingly clear and dichotomous nature that is portrayed within this biocolonial narrative. Nevertheless, there are some clear rhetorical devices used by both sides of the argument surrounding the HGDP and population genetics, which demarcate the boundaries of this somewhat polemical debate, and thus merit discussion.

**Rhetorical Devices: Past, Present and Future**

It is clear that the current state of political ambivalence in regards to population genetics research is unsatisfactory and the rhetorical devices employed by both sides are somewhat over-circumscribed. Previous chapters have already dealt with the problematic representations of indigeneity and difference that were an essential part in justifying the need for the HGDP in particular. However, it is also necessary to illuminate the types of rhetorical devices employed to counteract these initial representations used by or on behalf of indigenous people.

As explained in the previous chapter the four components of the biocolonial narrative are in indeed logically interrelated. The ethical dimension of exploitation serves as the ideological basis for science to intervene in the affairs of marginalized persons, which in turn creates the objective basis for commodification and eventual commercialization of knowledge extracted from this intervention. The political dimension claims that an obfuscation of local politics and concerns, and self-described health priorities is essential to maintain this context of economic exploitation, which left unaddressed, proves that the ethical justification for control is nothing more than a way to self-righteously impose beliefs on to others in the service of further exploiting them. This
has been made all the more clear by this chapter, wherein indigenous people seem to have refuted the humanitarian claims of benefits associated with the HGDP, assailed the simplistic and inappropriate focus of science and investigation, and connected this with an international economic context of exploitation, such as the TRIPS-GATT agreements and national laws on patenting, and lastly, sharply criticized scientists for ignoring the 'real' meaning of health for such groups.

The problem is that even where some of the links may be tenuous, historical memory may be invoked to uphold the logic of the debate by reference to past deeds. Indeed, the mention of colonial exploitation, or the unethical treatment encountered by indigenous and minority people in regards to modern infectious diseases such as HIV/AIDS, only serves to reinforce the likelihood that this narrative may well hold some relevance for the future as well. The perceived complicity of varying types of Western 'institutions', past and present, also seems to strengthen the relevance of this narrative in the minds of opponents. Some scientists may well want to ignore this past and argue that criticism of the project is merely attributable to misinformation, miscommunication and misunderstanding of the science, and the projects goals. However, they clearly will not be allowed to explain away the significance of the risks involved in this research in such a rhetorically weak fashion. While a rhetorical device used by scientists in justifying the project, the "bifurcation of a political past and an objective present", may well in the minds of scientist render themselves both detached from past exploitation and associate

33 Hasian jr. and Ploc, p.302
34 Hasian jr. and Ploc, p.309, this device became more prominent as scientist finally decided to address the concerns of Indigenous people within the ambit of the project. Scientists also tried to claim that the project was a way of ending scientific racism and to prevent corporate patenting of indigenous genes. Unfortunately such claims were not so readily accepted.
themselves with a more humanitarian agenda or even anti-racist agenda,\textsuperscript{35} clearly groups antithetical to the project engage in no such bifurcation, and associate the political past and present with a potentially even more hideous 'objective' future.

The biocolonial narrative, infused with assumptions supported by references to past deeds, assails the science of genetics by taking its successes, failures, contradictions, stories of ill repute and associates it with the cultural importance of science in the West. It then goes on to give this association a greater degree of homogeneity, purity and intentionality that cognitively amplifies the social and economic power of population genetic science and science in terms of its influence to alter the world around it, and the Western dominated economic system that investigation and intervention takes place within. Thus, genetic science, economics, and the politics of both are seen to be intimately related and thus inherently exploitative, especially given that many of the groups subject to research still suffer from disadvantage.

In terms of addressing this exploitation, this surveillance and control ability is invoked because it would, if demonstrably true, compel greater responsibility in terms of the trajectory of science and its impacts, which in turn, would supplement calls for even greater ethical engagement of science in a postcolonial world where equality and equity

\textsuperscript{35} Van Ness, P., "The Concept of Risk in Biomedical Research Involving Human Subjects" in Bioethics Volume 15, Issue 4, Blackwell Publishers, 2001, p.367-9, argues that this is rhetorical strategy used in a wide variety of medical contexts dealing with research on human subjects. He argues that it is problematic because the specific benefits are seldom quantified, meaning that if they do not arise, no responsibility can be associated with the outcomes. The difference in this 'biocolonial' context is that vague references to benefits are treated with a significant degree more suspicion, given both historical experience, and contemporary sensitivity to commercialization.

Hasian jr, and Plec, p.312 argue that anti-racism and anti-eugenicism were invoked as arguments allowing the project to proceed. Indeed the humanitarian justification for allowing the project to go on consisted of both anti-eugenics, anti-racist justifications, and reference to potentially health benefits accruing to such groups.
is by no means apparent. However, scientists, governments and corporations are clearly seen as not willing to engage with groups in this manner creates the impression that only the steadfast recognition that indigenous groups must have full control over the direction and legitimacy of scientific research to prevent adverse outcomes.

The rhetorical turn taken by these groups is probably somewhat justified given some of the historical experiences that this thesis has outlined. Nonetheless, there is a greater need for both sides of the argument to recognise social and political complexity as it relates to these sorts of interactions. Any effort to try and mediate this controversy will need to understand exactly how both sides employ rhetorical devices in service of upholding their own interests and crystallising their world view about the other. Hajer’s three factors of interaction, as outlined in the introductory chapter, are of particular relevance here for understanding both sides of the debate. In terms of “mutual positioning” and the “terms of policy discourse” Hajer claims discursive analysis can be broken down again into three categories, those being storylines and myths, “policy vocabularies” and “epistemic notions”.

For Hajer, “storylines” are “(crisp) generative statements” which serve as “vehicles for the discursive reproduction of complexity, allowing people to communicate effectively over complex policy issues”. In regards to the HGDP and the population genetics debate, we see that in terms of generating support for the project, scientists and science organisations used an evolutionary conception of why genetic diversity was important in the modern age. The story of evolution mandates that people who have lived

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37 Hajer, p.93-94
somewhat beyond the messy influence of modern civilisation must have inherited a range of intriguing evolutionary adaptations on the one hand, or debilitating diseases on the other. Linking this story to one that upholds the power of modern, particularly genetic innovation and also a humanitarian story about how genetics can help these people, or on the other hand, how these people can help others in the world, are the ways scientists in trying to maintain support, gave coherence to their actions and statements.

Those coming from a more sceptical point of view usually invoked the story of colonialism to gain support for resisting the HGDP’s attempts to conduct research. Indeed, they took this evolutionary conception of human difference and humanitarian claims on behalf of scientists and argued that colonial medicine in the past also used evolutionary and scientific humanitarian arguments to justify cultural intervention, but ultimately only for economic and political ends. In an era where the possibility of gene patenting and ownership of “life” by outsiders is possible, the “colonial” storyline looks all the more compelling and enticing, thus making it of great argumentative and ‘enrollment’ value.

Policy vocabularies according to Hajer, are “concepts structuring a policy, consciously developed by policy makers”. These vocabularies are important, as they refer to what each dimension of an argument believes are the pertinent aspects of a debate and how their apprehension of these aspects augments their authority to shape policy and discourse, and why this adds to or subtracts from the value of a policy or research agenda. In the case of the HGDP and population genetics, scientists clearly borrow from the authority of science, and evolutionary science in particular, in arguing for a certain conception of discourse importance. Here, the argument that certain populations are

38 Hajer, p.94-95
“isolates of historic interest” who may harbour unique genetic diversity is very much the essential policy basis for shaping research interests in this case. Using neutral and technical language to discuss the nature of this diversity, scientists quite reasonably and intentionally tried to distance themselves from the obviously intended biased and emotive modes of discussion on genetic difference, experienced both in the past and present medical discourses revolving around ethnic and minority status in health. The undeniable scientific interest plus the responsible and claimed potential humanitarian repercussion of the research, added to the value of the project.

Those opposed to the research structured the policy discourse obviously by referring to the colonial history of exploitation. However, other vocabularies that surfaced in the debate include rendering indigenous people as valiant guardians of nature resisting western exploitation, human rights and cultural integrity based arguments, and reference to eugenics and scientific racism, both past and present. Clearly, the vocabularies engaged in both those opposed, as described throughout the course of this thesis, were clearly constructed not only to dispute the truth and authority of scientists, and thus the value of the project, but also to provide a more emotive moral framework in which to frame the ‘right to decide’ dimension as a policy and research alternative.

Lastly, Hajer argues that “epistemic notions refer to a regularity in the thinking of a period, structuring the understandings of reality without actors necessarily being aware of it”.\(^{39}\) He quotes Foucault when he argues that in a discourse “certain rules of formation that underpin theories/policies but ...‘not formulated in their own right’” are present. In terms of the scientific perspective, the major regulating epistemic notion is not just evolution, but also a “reductionist” perspective. That is the importance of reductionism in

\(^{39}\) Hajer, p.94-96
science in general, and ‘genetic reductionism’ in particular, frames identification of health problems and comprehension of health causes and consequences. The implication is that attribution of evolutionary meaningfulness to the research, and the upholding of an overtly genetic perspective on many health problems regulates the discourse in a way that is amenable to upholding scientific expertise.

The oppositional point of view of course, understands this reductionist focus on genetics from an “epistemic” assumption of colonial interests, and furthermore, interests that are intentional and collusive. This regularised perspective on the ‘reality’ of historical and contemporary discourse gives meaning to the actions of the exploitative majority and positions opponents of biotechnology in general debate as an emancipatory force imbued with a sense of guardianship, who are deserving of moral and discursive authority because of this resistance against a scientific complex of interests that desires to undermine the true complexity of life and is necessarily intentional in its exploitation. This intentionality is given greater force by the ‘truth’ of purported links between science, corporations, governments and other Western institutions that do not actively protest the current political and economic regime. Through these three aspects of mutual positioning we see how “actors intersubjectively create and transform political conflicts using language”\textsuperscript{40} and thus uphold their claims to authority and thus, arguments in service of generating support.

Indeed, the support element was also very important in deciding the current outcome of this debate. “Discourse coalitions”\textsuperscript{41} referred to in the introductory chapter are important in regards to how actors manoeuvre politically to gain greater traction in

\textsuperscript{40} Hajer, p.95-98
\textsuperscript{41} Hajer, p.95-98
the debate. While science is supposed to be apolitical in its methodology, clearly its priorities are dictated somewhat politically. Research depends on the support of a network of governments, corporations, and scientific research organisations who give both authority and funding to research. In the case of the HGDP, while at first emboldened by support from a variety of organisations, when controversy surrounding the project became endemic, the HGDP not only isolated itself from potentially important academic moderates and critics, but an inability to articulate its priorities in politically and scientific terms, meant that it had support from very few interests. With government organisations like the NIH not wanting to be tainted with political controversy, corporations preferring to conduct research into genetics in a more predictable context, and with much of the legitimizing support of representatives of indigenous and concerned minority groups and the non-scientific academic community completely dissipated, it seems that the organisers of the project were somewhat hasty and politically ill-advised and impotent in trying to justify the need for such research in the modern world. Ironically enough, this is slightly contradictory of claims by opponents that collusive interests are at the fore in shaping such research.

Opponents on the other hand benefited greatly from “discourse coalitions” wherein the rhetorical frameworks constructed allowed many nodes of resistance to congregate around a persuasive and pervasive rallying call. The HGDP was assailed from many quarters, including indigenous groups and their advocates, general anti-genetic and anti-biotechnology activists, anti-globalisation activists, and concerned academic critics and moderates. Using modern communication methods, the justifications for the HGDP was attacked wherein doubts over humanitarian, methodological, economic and political
consequences were raised, many with reference to colonial exploitation past and present. These concerns allowed opponents to link the exploitative concerns of indigenous and minority people to the exploitative concerns of a much broader anti-exploitation proponents, and thus allowed utilisation of rhetorical, political, financial and technology resources.

Here we can see that we have a polarised debate where the use of language has taken on radicalised qualities because of an increasingly diverse and complex political terrain. However, a major problem with the conduct of the discourse however has to do with Hajer’s final factor of interaction, that being “institutional practices”.[42] While from the scientific proponent’s point of view, the long established practices of scientific methodology and ethics should have been sufficient to quell debate, we see that this stubbornness is one of the major factors in preventing the formulation of institutional practices that would lead to more effective consensus building. Mere reference to scientific authority as justification for action has clearly been shown in this thesis to be anything but convincing and an important reason why the debate became polarised.

However, from an oppositional point of view, while there was significant mobilisation to protest the HGDP in particular, the lack of institutional practices that could lead to responsible and plausible alternatives to the current regime being proposed, and the less than clear articulation of interests other than mere opposition to scientific innovation, has also lead to debilitating discursive discordance. The lack of ‘civil’ society mechanisms that can lead to agreement over what actually are the interests of the groups at the centre of the debate is troubling because not only is merely ‘radical’ but because there is a danger of reifying the marginalised status of many of these groups in this

[42] Hajer, p.98-102
radicalised discourse, rather than giving voice to concerns on matters that could allow compromise.

This might also lead to the rhetorical restriction of the range of options that these groups might entertain in the future whereby previous claims may regularise the debate in a way that prevents fluid position. Indeed, the exoticization and essentialization\(^{43}\) of one’s own culture has been a politically potent weapon in the hands of the marginalised in other cultural rights debates, and it is the responsibility of all sides of the debate to prevent this becoming a necessity for political salience, both pro- and anti-biotechnology, as it currently seems to be. It is possible that a simplification of Indigenous peoples’ own cultures’ is being experienced due to a perceived rhetorical need to contrast the differences of such groups with that of a morally culpable ‘West’. As seen in Chapter VI, there is even a possibility that some groups buy into the notion of a ‘geneticized’ identity if it suits political interests. On a related matter, there is a need to be cautious in that it is not assumed by interested parties that political apprehensiveness is associated with an ‘anti-science’ agenda, as some declarations such as the Mataatua declaration have warned.\(^{44}\) These are only a few aspects of concern arising from the analysis of oppositional rhetorical representations in the HGDP and population genetics debate.

Nevertheless, addressing these concerns through institutional forums that involve discussion and negotiation in a purely rational fashion with sensitivity to politically inspired rhetorical mobilisation, while necessary, is probably not sufficient. Indeed there


\(^{44}\) The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous People
is a need to balance the political mobilisation perspective with a somewhat more comprehensive understanding of the processes of representation that individuals and groups engage in with those who occupy a different social context complicated by power differentials. The reason for this is two fold; firstly, a perspective that focuses purely on political interests threatens to taint support, resistance and acquiescence to compromise with an air of inauthenticity. Secondly, there are some concerns that the research on aspects of representation focus too narrowly on assumptions of perfect and imperfect knowledge regarding the appraisal of interests. The “information deficit”\(^{45}\) model of addressing concerns about scientific research assumes that if all the information is properly disseminated and rational interests are adequately addressed, dissonance then should fall away. However, while an essential part of dealing with problems of science and society, this will not be sufficient. There is a need to consider notions of ‘risk’ and ‘trust’ when trying to understand the invocation of narratives such as ‘biocolonialism’ in particular in political contests, in addition to appreciating their rhetorical utility in radicalising discourse for the purpose of political mobilisation and enrolment.

Chapter VIII: A New Politics of Science and Conclusions

"I say that intelligence has never saved anyone: and that it is true, for if philosophy and intelligence are invoked to proclaim the equality of men, they have also been employed to justify the extermination of men." – Frantz Fanon

This chapter is comprised of three sections. The first section somewhat modifies the political mobilization perspective by discussing how issues of risk and trust in particular shape inter-ethnic relations in an apparently ‘colonial’ and ‘Western’ dominated world. In particular, how the failure to adequately address issues of trust, and how they in combination with subjective perception of objective risk factors, lead to political intransigence or outright resistance, is discussed. The second section will then take these insights and discuss briefly the types of political interventions that might be better suited to engaging in scientific and biotechnological research and policy when issues of ethnicity, particularly those with a ‘biocolonial’ flavour, become salient. As an extension of this, the concluding section will offer some insights as to what merits further discussion and potentially productive avenues for further investigation, which would augment the practical use of what has for the most part been a narrative exploration of a politically and rhetorically explosive issue.

Risk, Trust and Politics

As a means of balancing this somewhat cynical perspective on the political outcomes surrounding discussions on population genetics, it is necessary to discuss how
the concept of ‘risk’ is important to understanding the development of the politics of representation, and thus understand how to modify such politics for more constructive ends. However, before proceeding it is important to point out exactly what is meant by the concept of ‘risk’.

Discussions on the importance of risk in understanding science and society interactions have become commonplace of late. The ‘Risk society’ ideal in particular has been invoked on many occasions to explain the reasons for disagreement between different factions within society in regards to scientific research and innovation. As a perfunctory summary of this discourse, the ‘Risk’ society ideal suggests that as scientific innovation becomes increasingly a feature of post-industrial society, attempts to forestall the potential consequences of such innovation are thwarted by both the unknown consequences of increasingly more technical and elite driven science, and the increasing complexity in society itself. Thus, scientific innovation leads to greater insecurity despite attempts at technical management, which in turn leads to the questioning of scientific expertise by groups in society, and erodes the consensus around the assumed benefits of science.

It is somewhat easy to see how this is relevant to the research that this thesis has presented, especially in regards to the ‘objectivity’ and symbolism strand of the biocolonial narrative previously discussed. However, this thesis will not preoccupy itself with this type of risk analysis, nor will it discuss in depth the range of research that

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suggests that ethnic minorities worldwide, both are objectively more ‘at risk’ and perceive themselves to be ‘at risk’ in regards to medical and scientific research and innovation. This is because neither perspective can provide a reasonable analysis of why certain types of narratives like the biocolonial narrative are used in protesting scientific research. Joffe argues that the ‘Risk Society’ thesis while having some merit is a little elite driven and does not provide much information about identity processes that underpin rhetorical representation, other than giving a purely cognitive view about political mobilisation. Indeed, if we look at the writing on the risk society thesis, very few articles discuss the issue of “risk” in post-colonial contexts, and clearly the characterisation of risk relationships consisting of lay and expert interactions, is a little bit homogenising and ‘monolithic’. The type of language used in the biocolonial narrative probably differs from the generalised risk society discourse even more than the difference in language between ‘experts’ and ‘lay’ people in post-industrial societies.

Thus it is important to briefly discuss the importance of identity processes in the construction of such representations, and relate that to the discussion of the biocolonial narrative presented in this thesis. This, alongside the insight that a greater apprehension

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Indeed, this thesis recommends that more research is done into how indigenous groups view the interaction with medical practitioners in terms of difference in risk perception associated with this interaction, and how this plays into representations of outside groups and the politics of identity.

4 Joffe, H., Risk and the Other Cambridge, UK ; New York, NY, USA: Cambridge University Press, 1999. p.6

5 Joffe p.5-7
of political complexity is needed when dealing with innovation and research in post-colonial contexts, will inform us as to what types of interventions are likely to succeed or fail when interacting in these contexts. Work done by Joffe in the area of social psychology provides us with a variety of interesting insights in regards to the construction of identities in situations where an “other”, particularly a colonial or imperialistic ‘other’ exists. Her perspective while social psychological rejects a purely “cognitively biased” model of understanding representations and politics, and instead argues that information and apprehension of practical risks and interests is not the only factor that determines the types of social and thus political representations constructed by marginalised groups.6

The problem is that group based processes which influence the types of representations that are referred to in these political debates are seldom discussed in social and political theory. Joffe discusses a variety of social psychological models which can help understand at least describe more than a superficial basis for understanding political mobilisation between peoples of difference. Objective circumstances of many indigenous people for example, present very real dangers to these groups, but it is the manner in which such circumstances are interpreted that is important for understanding the representations that arise from this context. Thus, “Attribution theory”7 points to a type of process whereby groups engage in ‘egocentric’ illusions, by assigning positive events to the self at the same time that negative events are attributed to the ‘other’. The implication of this is that responsibility and intentionality is thereby associated with the

6 Joffe, p.8-10
7 Joffe, p.64-6
out-group. Similarly, ‘Social Identity Theory’\(^8\) is interested in how gender and racial identities form part of personal identity, whereby the response to situations which are felt to be risky, is one of splitting and projection. Both theories are argued to explain how representations of ‘otherness’ is usually as much a psychological protective measure as it is a political measure.

The key difference from other theories is however, that these processes are heavily influenced by the social context and the experiences entailed within those social contexts, and a more embedded, emotive type of thought and decision making process. Social, Political and even Psychological theory, according to Joffe all inadequately deal with the role of emotions, and relatedly, group connectedness when trying to understanding social representations, and thus the substance of political mobilisation. Joffe, along with Cohn, argues that feelings and risk and danger, while cognitively influenced, are not purely rationalist. Instead, she argues that such perceptions are actually “relational” at their “root”\(^9\) in the sense that it is the perception of relationship with the in-group and in turn the perception of relations to the out-group that dictate how much danger is attributed to any situation involving interaction between in and out groups. Social Identity Theory discusses how such perceptions are shaped by early group influence, whereby social representations are shared, and are derivative from the social context that people inhabit. In other words, social representations are often inherited and

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\(^8\) Joffe, p.80
constructed from an early age, in so much that 'historical experience', however it is rendered, becomes an assumed and intrinsic part of identification with the in-group. 10

Therefore emotional connectedness between individuals within a group or society, which governs all human relations, utilises historical, cultural and societal understandings in shaping social representations of risk.11 This is not to argue that such representations cannot be changed, that people attitudes are purely constructed by their surroundings, or that such concerns are even inherently reasonable, rather, that in trying to address the way that radicalised groups engage in dialogue, a purely rationalist and cognitive approach will probably fail. Instead, a communicative and relational approach is needed to try and address the concerns of those that have suffered historically and have been the victim of the 'Western' world's own types of representative constructions.12 Jackson puts it well when he says that in these intersubjective encounters, whether walls or bridges are built between groups particularly affected by colonial alienation depends on the "degree to which a person or group feels ontologically secure".13

The implication is therefore that to form new types of connections between people that foster both good political outcomes as well as positive associations with in and out group interactions, a new understanding of political phenomena is needed. Essentially, the argument being made is that positive interaction will only be achieved

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10 Joffe, p.98
11 Joffe, p.105
12 Crawford, R., "The Boundaries of the Self and the Unhealthy Other: Reflections on Health, Culture, and AIDS" in Social Science and Medicine: Oxford: Pergamon Press, Volume 38, Issue 10, 1994. p.1347-51 discusses how representations of disease functioned as self-protective measures for colonial society, as a way to assuage concerns over danger to both body and society from new types of interactions, and how this also feeds into modern debates on HIV/AIDS in particular, where unknown dangers associated with the "unhealthy other" are presented as "risk categories".
13 Jackson, p.344
when relations of ‘trustfulness’ are apprehended.\textsuperscript{14} Of course, ‘Trust’ in this sense is not purely emotional, indeed, trust could be argued to consist of both a sense that one is intentionally trying to do the best by another, as well confidence in the capacity of the ‘other’ to actually execute the outcomes promised. Competence and sincerity are thus both factors that are required, however, as the biocolonial narrative has elucidated, the history of such relations consists of anything but trustfulness.\textsuperscript{15}

Indeed, the biocolonial narrative outlined here is an example of the types of attributional representations that come to dominate a political discourse. It is important to point out that many of the same ideas discussed above apply equally to the dominant and marginalised groups. Indeed, one aspect of the biocolonial narrative is that it is a description of the Western world’s own attempts at rationalising the dangerous and unknown world around them, both past and present. It argues that over time, the manner in which Western medical discourses understood health and disease usually involves a ‘reductive’ focus, whether it be gene, virus, bacteria, which in turn, allowed a cognitive simplification of health phenomena for the purposes of representing a controlled and safe (for Western interests) social order. Nevertheless, the narrative as it relates to population genetics, takes historical experiences, and the somewhat awkward and careless actions and pronouncements contributed by Western scientists to the discourse, and turns them

\textsuperscript{14} The topic of ‘trust’ is starting to be discussed in relation to methods of dialogic interaction, however, it is mainly in Western contexts at this point. Rose, H., “Risk, Trust and Scepticism in the Age of the New Genetics” in Adam, B., Beck U., & van Loon, J., (eds) The Risk Society and Beyond : Critical Issues for Social Theory London : SAGE, 2000, p.73


into a much purer, more logical and 'reductive' system of perceived moral culpability and political manipulation, where the actions of scientists if contrary to the wishes of indigenous and activist groups, are represented as inherently suspicious and intentional.

It is indeed very difficult for scientists to act in a situation where most scientific expertise and discourse is seen as a self-justifying strategy for intervening in a situation where the objectification of knowledge could lead to further economic exploitation and the undermining of social, political and even bodily integrity. Thus, in trying to proceed in such a situation, there is a necessity for scientific research designers to become both more politically astute, as well as being able to engage in a communicative and relational approach to dealing with research subjects. They must be politically shrewd so as not to walk into the 'narrative' traps that HGDP organisers clearly did. At the same time they must also take a more comprehensive approach in engaging such groups to try and formulate and maintain relations imbued with a sense of 'trust' and demonstrated respect that is so important for understanding the relations between dominant and marginalised groups that have a less than optimistic history. A discussion of examples of these types of in interventions from other areas of medical science will entered into next, to demonstrate that such sentiments are more than just hopeful pronouncements on a clearly difficult subject.

Engagement and Communication Methods

Interest in more dialogically orientated and communicative approach to policy making and public education in regards to science research has become a feature of science and society interactions since the late 1990's in particular. This has meant that
both scientific and government institutions have modified their way that they communicate with the public about science issues. Furthermore, the use of dialogic tools like the "Consensus Conference" which is a public participation model for technology assessment has increased over the last decade. Combining the features of a town hall meeting with that of a citizen jury, this model is said to allow broader deliberation over policy options regarding technologies.\textsuperscript{16}

Explanations for this development point to the ascendance of post-modern or perhaps more accurately, post-material values in many Western countries in which the public come to emphasize 'quality of life' issues as opposed to concern with simple economic prosperity as their major political concern. Also, the aforementioned legitimacy issue surrounding the nature of modern scientific expertise is also a key factor in the rise in importance of such methods of communication, wherein the public demand to be treated as an 'active' stakeholder in research design and policy making processes.\textsuperscript{17} However, while such methods may have had success in some Western contexts\textsuperscript{18} it is by no means clear that concerns of ethnic minorities within these countries, and more importantly, indigenous people in non-Western nations, are benefiting from similar types of engagement.

The problem of course is that as explained above, the key to successfully interacting in such contexts requires a more culturally comprehensive approach to


\textsuperscript{17} Healey, S., "Extended Peer Communities and the ascendance of post-normal politics" in Futures, Guilford, Eng: Butterworths, Volume 31, Issue 7, 1999.

\textsuperscript{18} Einsiedel, E., Jelsoe, E., and Brecq, T., "Publics at the Technology Table: the Consensus conference in Denmark, Canada, and Australia" in Public Understanding of Science Bristol: Published by the Institute of Physics in association with the Science Museum, Volume 10, Number 1, 2001.
engagement. While after initial mistakes, organizers of the HGDP did try to organize
dialogue with some of the concerned groups, it was mainly through the internet and there
is no evidence of any larger scale conference or forum set up to discuss issues frankly and
in person. While a small step forward, clearly such dialogue was inadequate as it did not
address one of the most fundamentally important things in dealing with such a
controversial and emotive issue, which is the need to foment ongoing and robust
relationships between scientist and community.¹⁹

However, there have been some attempts to deal with groups in a more
comprehensive way who have historically suffered from colonialism in medical research
contexts. Chapter IV discussed how the incorporation of recognition of local politics and
novel forms of civil society into research design and policy was necessary and to some
degree successful. These attempts emphasize a variety of key features essential for
adequately dealing with cultural difference in situations where trust is an issue, especially
in contexts of perceived power inequality. Not only did we see much the same types of
representations being used in the assertion of colonialism in infectious disease research
and treatment, but we also saw that many of the same insights regarding the way to
conduct research and dialogue in a more constructive way intuited.

To summarize, first of all, research design and interventions must be “culturally
appropriate”. This might seem somewhat obvious; however, the insensitivities of the
organizers of the HGDP in justifying the project are testament to the fact that these
concerns are not always considered. Nevertheless, this cultural appropriateness entails
more than just statements in regards to the desire to communicate. As such, “culturally

¹⁹ Lone Dog, L., “Whose Genes Are They? The Human Genome Diversity Project” in Journal of Health
appropriate health interventions...are sensitive to the language, idioms, expression and nuances of the targeted socio-cultural group"²⁰ and must also pay respect to not only cultural practices, but the cultural institutions that are important to the social and political integrity of groups. Implied in this is some sort of respect for conceptions of health, and the need to express the intent and meaning of the research in a more linguistically appropriate fashion. Or put another way, communication must move from being "culturally appropriate" to being "culturally compelling".²¹

Indeed, there is also an expressed need to move beyond even a mediating form of engagement, to a "partnership" model of interaction.²² This means that greater incorporation of indigenous people’s health preferences into research design, statements about the control and use of biological and intellectual knowledge and materials, and perhaps most importantly, ensuring the health outcomes of such groups are improved, not only by merely guaranteeing access to the benefits of the research itself, but by also addressing non-genetic aspects of health as it relates to indigenous people. Essentially, this will not only pay due respect to cultural difference and priorities, but it will demonstrate a concern with more than narrow self-interest, which is one of the precursors

²² Willsms et al, p.167-8
of engaging in more 'trusting' relationships that could rectify to even a small degree the amount of alienation that is perceived by these groups as characterising current relations.

These examples also demonstrate that "transdisciplinary" thinking is important in dealing with issues of political, historical and cultural alienation. Indeed, as mentioned in previous chapters, the organisers of the HGDP managed to not only alienate from the process indigenous people's representatives and activists, but also social scientists who had knowledge regarding the very things that came to inhibit the project.\textsuperscript{23} As it is probably unreasonable to expect scientists to have all the skills to engage in this type of engagement, it should be mentioned that there are many examples of collaborations between public health experts, social science experts and scientists in the field of research into a range of health concerns, particularly HIV/AIDS.\textsuperscript{24} Further research should seek out these models and evaluate them in regards to the lessons learnt from the case of the HGDP in particular, and see how they could be applied in regards to similar concerns regarding population genetics.

To be sure, genetics research does pose specific problems that will need to be handled somewhat differently than those issues in infectious disease research. While issues of ethical ownership, stigmatisation, and the social economic cause of disease are very much contested in both infectious disease and population genetic research, the key


These two books contain excellent in-depth examples and discussions on this topic.
differentiating issue is of course the matter of genetic ownership. Clearly, agreement on both the ownership of genetic material and eventually genetic information needs to be negotiated. Furthermore, considerations of the subsequent use of and access to biological materials need to be addressed.

While Greely\textsuperscript{25} argues that the likes of the HGDP have already addressed these issues in the Model Ethical Protocol, there does not seem to be any specific statement or practical plan detailing how such arrangements might be negotiated. Neither is there any practical reassurance as to how legal protection might be afforded to such groups should genetic information or material be acquired by ill means. No doubt, given the current mistrust of Western medical and economic structures, many of the groups involved with the HGDP in particular would prefer a more comprehensively articulated agreement on the matter of intellectual property and ownership and treatment of biological materials before engaging in such research. Of course a precedent for this aspect of the debate can be found in the debate over ownership of plant material and rights to profits of subsequent innovation in many parts of the post-colonial world. This debate shows that different models of ownership in regards to such materials are problematic for reconciling differences between Western and many non-Western peoples on this matter, and thus also requires further research in order to develop a model of interaction that might be acceptable.\textsuperscript{26}

Clearly, there is the possibility for more constructive engagement. Organisers of the HGDP, to some degree have been willing to discuss the need for compromise, and


some like Greely, are also aware of the way “narratives” have come into play in
delegitimizing the project’s intentions and viability.27 Furthermore, there are examples
from other public health areas that emphasise the possibility that if such
recommendations where taken under consideration, that not only would projects be
medically possible and beneficial, but some of the science itself might be improved by a
more comprehensive approach. In terms of genetics, previous chapters discussed the lack
of social realism in terms of the categorisation of ethnic groups which seems to dominate
the discourse. This is indeed something that could be addressed by a more
communicative, collaborative and transdisciplinary approach to engagement.

However, while there have been many promising overtones stating the desire to
engage in a more ‘enlightened’ fashion with indigenous groups, very little has been
practically done about it. This could be for many different reasons, some cynical like a
lack of sincerity on behalf of scientists, to a lack of competence or resources, or the
hopelessly radicalised nature of the discourse itself. Clearly, there is a need for both sides
of the argument to foment better and appropriate relations before more constructive
relationships can be built; however, it is probably the responsibility of “Western
scientists” to take the first step given the superior resources and ideological power that
they have to shape political interaction.

In light of that, the next step would be to discuss the practical implications of such
research. While this is clearly beyond the scope of this thesis, it is important to reiterate
the basic argument, which is that for any practically successful engagement in
polemicised post-colonial contexts such as has been discussed in this thesis, an awareness
of the narrative constructions that must be negotiated is needed, as well as a dedication to

27 Greely, p.297-299
conducting research by addressing health concerns in a way that is perceived to be more substantive than merely allowing the edification of scientists own curiosities. This includes attaining a greater understanding of the cultures that may become the subject of study. Before concluding, however, it is important to discuss precisely why and for what reason both sides should attempt to engage in a more thoughtful way with the ‘representative other’.

Motivations for Reconciliation

The implication of the argument above is that when trying to understand resistance to population genetics and the HGDP in a post-colonial context, it is necessary to view such resistance as consisting of more than just misunderstanding and miscommunication as has characterised the opinion of some scientists associated with the HGDP in particular.28 Rather, it is necessary to become aware of the existence of a ‘biocolonial’ narrative, an activist network and accompanying political and cultural politics and the ways that they complicate the ability of scientists to engage with such groups in a research capacity. Furthermore, it must be recognised that issues of ‘risk’ and ‘trust’, which underpin the construction of representations that dispute Western motives and interests, inhibit the ability of scientists to assuage groups of the concerns that they have.

Thus, the biocolonial narrative should be viewed not only as a socio-political narrative, but as one having its roots in the perception of danger which contributes to the process of ‘othering’ whereby negative perceptions of moral and political intent are

28 Hasian jr, & Plec, p.302.
associated with engagement in both protesting and communicating with research scientists. In other words, the biocolonial narrative is also a ‘risk’ narrative. To moderate such a narrative, not only will scientists need to become politically and culturally aware, but they will have to engage in more comprehensive dialogue which may involve concessions in terms of research design. Furthermore, ‘real’ efforts will have to be made to guarantee political and legal protection in regards to economic exploitation of genetic information in particular, as well as dealing with the issue of how the science itself could influence societal attitudes in terms of race and ethnicity and its consequences for these groups.

The motivation for scientists to engage in this redefinition of scientific engagement in a post-colonial world is somewhat obvious. First and perhaps foremost is the desire to conduct research in itself. This will not proceed unless a better grasp of the political terrain is realized. Secondly, ongoing and substantive relationships might yield better quality information or “insight” which might address concerns over sampling methods and definitions of ‘population’, and thus allow the adoption of more appropriate methodologies. Thirdly, there is an opportunity to demonstrate that a new type of engagement is possible, which in turn might have follow on effects in other areas of scientific and particularly medical research. The role and expertise of the scientists has indeed been questioned in modern times, both within and without Western society, and merely sitting back and referring to this dispute cognitive authority as the justification for action is hardly going to make the conception of the scientist any more relevant.

For indigenous groups and activists, while the motivations for engagement might not be clear at first given that it appears that they have successfully inhibited the HGDP

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29 Cunningham, p.227-8
from engaging in any further research, there are some very real reasons why a moderation of types of politics and narratives used to assail the HGDP might be constructive. First of all, while disputed, benefits, health or economic, accruing from such a project are possible. Relatedly, there is a need to discuss candidly what the real interests of indigenous people are in regards to this research. This is where the aforementioned structuring of the debate by activist groups in particular may become problematic, as politics for politics sake may not always be in the best interests of the groups in question.

Similarly a second reason for engagement is that while the HGDP has made some mistakes in terms of the way it tried to acquire support for its objectives, subsequent engagement has demonstrated at least a somewhat more flexible approach is entertained by some scientists and organisers of the project. The contribution of money to the discussion of ethical, legal and scientific issues associated with the Human Genome Project, and the modification of the notions of informed consent and a creation of a ‘Model Ethical Protocol’, demonstrate more flexibility on the part of science organisations in the modern era, even if the issues are still not being discussed comprehensively enough. What this means is that, especially since the HGDP is not purely corporate funded, there is a greater ability in which to negotiate the manner in which control can be exerted over the direction of the research, and allow the activation of some of the rights claimed by these groups by giving them institutionalised support.

This insight becomes all the more important when it is realised that population genetics research either is being or will be conducted by other government or
academically affiliated contexts and also in the corporate world,\textsuperscript{30} where privacy issues and concerns about profitability preclude broad discussion of the issues at stake. The HGDP might have been the victim of its own visibility and it's, even if inadequate, eventual sensitivity to indigenous issues. While the politics surrounding the HGDP may be seen as a victory for indigenous rights and concerns, and one that is potentially encouraging from their own point of view, there are still many challenges ahead, many of them already presciently articulated by the biocolonial narrative itself, and engaging in a more constructive manner may well be the only way that such politics in the long run can become both salient and effective. This is not to say that compromising on everything is necessary, rather that, while indigenous concerns have achieved the necessary visibility through the types of steadfast politics seen in the case study of the HGDP, it is not sufficient in the long run to achieving the desired emancipatory ends of such politics.

Indeed, these politics, like the politics of traditional knowledge and intellectual property of plant life before it, should be viewed not merely as counter-hegemonic discourse but as the enactment of the social politics of definition and re-definition in a context of globalisation that offers both dangers and opportunities in terms of social and political life for indigenous peoples, and post-colonial politics in general.\textsuperscript{31} Further research on more interactive policy making and research design in the “network


\textsuperscript{31} Cunningham, p.227-8,
Takeshita, p.259-262, Kunitz, p.1526-31

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society" is required. However, the European focus of this research must be replaced with sensitivity to the admittedly difficult task of engaging actors in a 'networked' and 'post-colonial' world. This will involve upholding the importance of identity as key theme in research design and policy making, but identity that is lamentably even more politicised along the lines of perceived contemporary and historical exploitation, than we see in more familiar participatory contexts.

Nonetheless, simply attempting to gain the approval of intransigent actors should not be the sole aim of such research. The possibility that engaging in more comprehensive and ongoing dialogue, and providing the resources to do this, with such groups is important in the sense it could lead to a greater sense of empowerment within these communities. This in turn could augment some group's potential to deal with many pressing health problems internally, especially if broader health priorities are acknowledged in this dialogue. Also, there is a need to institutionalise some means of mediating conflict in regards to these issues. Governments and policy making organisations have so far failed to even acknowledge problems raised by controversies such as seen in the HGDP debate.

However, shying away from the problem is only going to cause greater discomfort in the future and it is probably best to honestly engage with some somewhat troubling realities. Indeed, taking the lead from Hajer, the realities of modern policy making and politics in terms of demands for greater representation also apply to the post-colonial world, wherein the politics of identity should be "analysed and indeed appreciated as sites for the articulation of conflict and difference, as a place of social

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contestation”. Clearly, the complications for scientific research and innovation politics of the politics of identity detailed in this thesis will be an undeniable fact of interaction especially where something as crucial as ‘genetic identity’ is at stake. Therefore, honest engagement with the legacies of the past, present misgivings over political and economic exploitation, the means of mobilising resistance both for and against such groups, and finally frank discussion on the respective interests of engaged actors is needed if viable and legitimate research on issues of genetics and ethnicity is to be undertaken in the future.

Nevertheless, very real dangers do exist for indigenous and minority groups in regards to scientific research on genetic diversity. These dangers include the presence of racism or inappropriate use of racial categories in both science and society, the somewhat unknown effect on the provision of health in terms of diagnosis, treatment, prophylaxis and prevention and the questionable nature of information provision and access in contexts of inequality. As “genes” have taken on an iconic status in being ability to explain health outcomes in at least the popular media, and furthermore, with the developing danger of former categorisations and discourses of disease inheritance, susceptibility, or being “at risk”, coming into public discourse, there is concern that this could adversely influence the politics of genetics in regards to ethnic and racial identity.

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33 Hajer, p.106-110
Lastly, there is concern about the general danger posed by the ‘essentialization’ of non-essential health outcomes. This is problematic because of the potential for stigmatization by reference to genetic difference and associated susceptibility to disease, which is all the more concerning given the interpreted ‘inherent’ nature of genetic dispositions, where health is perceived to be tied up in something as crucial and personal to individuals and societies as reproduction. Also of concern is the impact that such ‘essentialization’ could have on the public acceptance of indigenous politics and health politics in particular, and general societal representations of indigeneity and minority status, of which to this day still do not correlate with the best interests of the groups themselves. These issues all, on their own merits, require further research into whether or not they are becoming a problem and how, and if so, how to mitigate the worst excesses of the developments. Clearly, these issues need to be more actively bought into mainstream debate on genetics. This is despite the fact that they pose some rather searching questions for all concerned groups regarding the nature of diversity in the modern era, and crucially, as to how we conceive of such difference by way of our own identifications with structures of cultural, social, political and economic power.

Conclusion and Summary

The primary concern of this thesis has been the ‘biocolonial’ narrative and how it impacts upon the modern politics of resistance to biotechnological innovation and research and in particular contemporary population genetics. Chapters I and II framed the

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Indeed, Wallow discusses how risk designation is also a problem in HIV/AIDS research as explained previously, and gets about discussing how similar problems in the era of the “heterozygote” could become problematic for trying to apprehend an appropriate understanding of biological and genetic phenomena.

93 Ellison and Rees Jones, p.276-7
narrative dimensions of the thesis by utilising revisionist scholarly research on the issues surrounding early colonial and colonised relations to understand the relationship between health and indigenous and minority status in this period. It was found that research structured the debate on health and disease in four different ways, ethically, scientifically, economically and politically, and that these dimensions were often seen to be interrelated in terms of how they supported colonial interests in colonised worlds. A description of these facets, and their relationship was engaged in, and its application to later periods was then attempted.

Chapter III and IV discussed how research into infectious disease in developing countries and particularly HIV/AIDS reflected many of the same concerns in the literature on health and colonialism. The concerns articulated also fell into the four narrative categories as previous described and that references to the colonial past also shaped attitudes and explanations for adverse disease outcomes in the infectious disease discourse. This was relevant because not only does it reflect persistent biases in terms of how ethnic difference itself is perceived within scientific and medical circles, but that they are actually related to an ongoing sense of colonialism despite the relaxation of explicit political control in many of these countries and contexts.

Not only was this important because it both rhetorically prefaced and paralleled the debate on genetic issues, but the attempts to provide solutions to perceived problems of colonialism were seen to show the possibility of adaptation of research design in the context of genetics and 'biocolonialism'. The similarities in terms of both political mobilisation and representation, and the perceived solutions to the problems of such representations in both infectious disease and genetic disease research, provides further
substantiation of the need for science to rethink how it engages with peoples of all kinds in post-colonial contexts, and how conceptions of disease itself influence both political and scientific considerations of research design and health policy priorities.

Chapters V and VI utilised information garnered from the debate surrounding the Human Genome Diversity Project and population genetics in general and described how similar to previous periods of concern with health and colonialism, the presence of a colonial narrative was invoked to explain health outcomes and politics. In this case, the ‘biocolonial’ narrative utilised both historical and contemporary perceptions of exploitation to assail the Human Genome Diversity Project in particular, and delegitimise its ethical, scientific and socio-political standing. These chapters described of the content of this narrative and also alluded to how such a narrative shaped the politics of resistance encountered by the HGDP.

Chapter VII took this research and explained how it also reflected mobilised indigenous groups perceptions of exploitation or possible exploitation in regards to the HGDP in particular and biotechnology in general. The usefulness of the internet in terms of allowing quick communication and information dissemination, how it facilitated coalition building and ultimately directly assail HGDP organisers themselves was discussed. Next, a discussion on the way rhetorical representations functioned as political devices to call into question the motivations, interests and intent of research organisers was entered into, which was followed in Chapter VIII by a discussion on how ‘risk’ and ‘trust’ perspectives on how to understand narrative representations was necessary. This provided some balance to an overtly political and perhaps somewhat cynical perspective of political mobilisation, which not only threatened to taint politics on both sides of the
debate with an air of inauthenticity and artificiality, but would have also severely weakened any attempt to evaluate the required qualities of potentially successful research and intervention designs.

After discussing these qualities this chapter described the reasons for why both sides of debate regarding human population genetics should engage in more constructive politics, which involves moderation of both the way politics and narrative representation is done. It argued that while indigenous and activist groups are also responsible for dialogical discordance in the debate on the HGDP in particular, Western scientists also need to recognise that mobilisation and resistance against the project is not simple cynical politics but a process in itself wherein the assertion of social power through identity politics and mobilisation in a globalising world could eventually lead to the development of new types of political interests and eventually new forms of civil societies willing to discuss the impacts of scientific research and intervention.

The argument stated at the beginning of the thesis therefore was that not only do scientists and research organizations need to become more politically aware and astute in regards to interacting with groups who identify with the 'post-colonial' condition, they must also be prepared to make some concessions regarding how research design itself is implemented in relation to these groups. In reaffirming this argument, this thesis has tried to answer the question of 'how should genetic science proceed in controversy prone contexts where issues of ethnicity and accusations of colonialism are politically salient?'. While some general provisions have been provided more work clearly needs to be done on how to engage with specific sub-groups in constructive discourse, as well as how time and financial resources being dedicated to this end might be acquired. These provisions
are essentially minimum requirements of consideration when attempting to conduct science research, intervention and policy making particularly in contexts of health where perceived aspects of colonialism still dominate political thought. Thus, the manner in which science and biotechnological research organisations in particular recognise nascent forms of political organisation motivated by old ideas will be a significant predictor of how successful they are in engaging them in the future, and ultimately the quality of the science itself.
## List of Acronyms

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<td>HGDP</td>
<td>Human Genome Diversity Project</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>RAFI</td>
<td>Rural Advancement Foundation International</td>
</tr>
<tr>
<td>WTO</td>
<td>World Trade Organisation</td>
</tr>
<tr>
<td>TRIPS</td>
<td>Trade Related Aspects of Intellectual Property Rights</td>
</tr>
<tr>
<td>GATT</td>
<td>General Agreement on Tariffs and Trade</td>
</tr>
<tr>
<td>AZT</td>
<td>Azidothymidine</td>
</tr>
<tr>
<td>SAP</td>
<td>Structural Adjustment Policy</td>
</tr>
<tr>
<td>DNA</td>
<td>Desoxyribo Nucleic Acid</td>
</tr>
<tr>
<td>ELSI</td>
<td>Ethical, Legal and Scientific Issues</td>
</tr>
<tr>
<td>SES</td>
<td>Socio-Economic Status</td>
</tr>
<tr>
<td>NAFTA</td>
<td>North American Free Trade Agreement</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>IPCB</td>
<td>Indigenous People's Council on Biocolonialism</td>
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References


Balarajan, R., “Challenges and Policy Implications of Ethnic Diversity and Health” in
MacBeth, H., & Shetty, P., (eds) Health and Ethnicity London: Taylor and

and the Commodification of Biodiversity” in Social Analysis Adelaide:

Banta, D., “Increase in Global Access to Essential Drugs Sought” in Journal of
American Medical Association Chicago: American Medical Association,

Barrett R., Kuzawa, C., McDade, T., & Armelagos, G., “Emerging and Re-Emerging
Infectious Diseases: The Third Epidemiological Transition” in Annual Review

Baylies, C., “Community-Based Research on AIDS in the Context of Global
Inequalities- Making a Virtue of Necessity?” in Kalipeni, E., Craddock, S.,
Oppong, J., & Ghosh, J., (eds) HIV and AIDS in Africa: Beyond Epidemiology

Ben Ari, E., “Molecular Biographies: Anthropological Geneticists are Using the
Genome to Decode Human History” in Bioscience Washington: American

Benatar, S., “Commentary: Justice and Medical Research: A Global Perspective” in

Bewell, A., Romanticism and Colonial Disease Baltimore: John Hopkins University

Bhopal, R., “Ethnicity and Race as Epidemiological Variables: Centrality of Purpose
and Context” in MacBeth, H., & Shetty, P., (eds) Health and Ethnicity

Bogdanich, W., & Koli, E., “2 Paths of Bayer Drug in 80’s: Riskier Type Went
2003.

Bonneuil, C., “Science and State Building in Late Colonial and Postcolonial Africa,

Bowman, J., “The Human Genome Diversity Project as a Complement to Human
Population Genetics” in Politics and the Life Sciences Guildford: Beech Tree


Deacon, H., “Racism and Medical Science in South Africa’s Cape Colony in the Mid- to Late Nineteenth Century” in Osiris Bruges: St. Catherine Press, number 15, 2000.


Einsiedel, E., Jelsoc, E., and Breck, T., “Publics at the Technology Table: the Consensus conference in Denmark, Canada, and Australia” in Public Understanding of Science Bristol: Published by the Institute of Physics in association with the Science Museum, Volume 10, Number 1, 2001.


Latham, A., Patenting the Commons: Biotechnology Becomes a Critical Arena in the Struggle for Human Rights


Morrison Institute, Human Genome Diversity Project
<http://www.stanford.edu/group/morrist/ hgdp.html> accessed on February 20th
2005.

Msiyaphazi Zulu, E., Nii-Amoo Dodoo, F., and Chika Ezeh, A., “Urbanization,
Poverty, and Sex: Roots of Risky Sexual Behaviours in Slum Settlements in
Nairobi, Kenya” in Kalipeni, E., Craddock, S., Oppong, J., & Ghosh, J., (eds)
HIV and AIDS in Africa: Beyond Epidemiology Oxford: Blackwell

Murphy, B., “Debating the Politics of AIDS: AIDS Obscures Injustice and
Medicalizes Poverty” in Canadian Dimension Winnipeg: Canadian

National Human Genome Research Institute, <http://www.genome.gov/> accessed on
February 20th 2005.

Native-L Net, Human Genome Diversity Project Articles from Native-L Net
<http://www.native-net.org/archive/ nl/hgdp.html> accessed on 20th February
2005.

Differentials Between Ethnic Groups: Evidence From the United States and
Britain” in MacBeth, H., & Shetty, P., (eds) Health and Ethnicity London:

Newman, S., “The Role of Genetic Reductionism in Biocolonialism” in Peace Review

North American Regional Committee Human Genome Diversity Project, Model Ethical
Protocol for Collecting DNA Samples
<http://www.stanford.edu/group/morrist/hgdp/protocol.html> accessed on
February 20th 2005.

O’Connor, T., Qualitative Social Science Research Methodology
<http://faculty.ucw.edu/toconnor/308/308lect09.htm> accessed on February 20th
2005.

Ogoh Alubo, S., “Debt Crisis, Health and Health Services in Africa” in Social Science

Oppong, J., & Kalipeni, E., “Perceptions and Misperceptions of AIDS in Africa” in
Kalipeni, E., Craddock, S., Oppong, J., & Ghosh, J., (eds) HIV and AIDS in


Tauli-Corpuz, V., *Biotechnology and Indigenous People*


