The racialization of disease: a qualitative and quantitative analysis of race and

ethnicity in biomedical research.

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ABSTRACT

The racialization of disease: a qualitative and quantitative analysis of race and ethnicity in biomedical research.

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For several years, there have been published guidelines covering the use of the term "race" and "ethnicity" in biomedical research. When used inappropriately, the linkage of race or ethnic categories to cause and/or effect in biomedical research can have significant negative impacts on individuals and populations. Genetic research rejects any strong biological association/difference, between or within races. This research will determine to what degree the recommendations for the use of "race" and "ethnicity" within biomedical publications has been followed. Papers, retrieved through Pubmed were selected if they used of the terms "race" or "ethnicity" in the title or abstract, These selected papers were then examined to determine the basis for assigning population to racial categories (inclusion/exclusion), the reasons for selecting the group(s), the disease by organ system and the association made to medical outcome.. The analysis of the publications revealed that none of 205 surveyed papers defined race while 67% of the papers associated a medical outcome to race. This research suggests that despite guidelines for the use of the terms "race" and "ethnicity", researchers and editors are neither using nor enforcing the use of them respectively. Further research should use alternative selection criteria and larger sample size to confirm these findings.

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It has been a great opportunity and my pleasure to be able to study and contribute to the discourse regarding the conceptualization of race and ethnicity, during these exciting times of increased acknowledgment of the population diversity in North America.

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Introduction

Many institutions – including scientific institutions -- use the labels "race" and/or "ethnicity" to identify, classify, and categorize individuals despite no formal agreement about how these terms should be objectively defined. In addressing this question of the politics of classification in society, Steven Epstein (2007) writes:

> "that when we speak of how "groupness" is constructed, we are also calling attention to the practice and politics of classification. And the classification of human populations is a consistent preoccupation of many institutions in society. Classification is central to scientific practices of description and generalization. At the same time, governments often are empowered to decide which categories will count as legitimate and to provide benefits on the basis of categorical membership. (The politics of affirmative action policies is an obvious example.) Yet classification projects also emerge from below: as Rogers Brubaker and Frederick Cooper have observed, "the literature on social movements...is rich in evidence on how movement leaders challenge official identifications and propose alternative ones. Thus many different sorts of people, groups and institutions may become involved in projects of human classification." (p.90).

Epstein accurately points out that society spontaneously fabricates classifications. Institutions such as government develop classifications that

create access for some groups and barriers for others. In contrast, oppressed individuals strive to challenge classifications developed by institutions through social movements; they try to develop alternative identities that they feel will reflect better who they are as a group.

This challenge is particularly important in biomedical science research when individuals are grouped according to poorly defined standards, which are then assumed to be associated with inherent biological (genetic) differences. The results of the human genome project have convinced most geneticists that "racial" classification is not useful in biomedical research, since it reflects a fairly small number of genes that describe appearance and there is no basis in the genetic code for race (Burchard et al, 2003). But although genetics research does not support a biologic basis for categorizations of individuals into traditional racial categories, investigators in biomedical research continue to use the terms "race" or "ethnicity" in their research and publications, while naturally failing to offer any precise definitions for these terms. Such an approach is problematic for two principal reasons: 1- Inadequate definitions of population terms hinder study replication and slow scientific progress. 2- Inadequate definitions of population terms could result in harm to patients by generating misconceptions about the relative benefits of treatments for individuals. The issue of race categorization in biomedical research, therefore, is not only particularly relevant as a sociological topic but can also prove potentially dangerous for patients who are treated according to false or poorly scrutinized categorizations.

The way by which biomedical research publications conceptualize race and/ or ethnicity is important as peer reviewed scientific publications are used to evaluate current policies and set new ones. Ann Morning (2011) writes: "The scientific enterprise is central to American thinking about race because its claims are often the bedrock upon which academic, business and government interpretations of the nature of race purport to rest" (p.4). Scientific research is supposedly always based on rigorous investigations in which variables are controlled and hypotheses tested.

But in contrast to this mandate, biomedical science publications often utilize racial groupings or categorizations that are not standardized, consistent or validated. Even though it has been demonstrated that terms and groups change over time, the notions of race and ethnicity are still utilized as universal variables and related to measurable outcomes. Although, in their paper "Race and Ancestry in biomedical research; exploring the challenges", Caulfield (2009) et al, point out that "Racial definitions can fluctuate according to social context, geographic location, historical period and personal experience" (p.1.2), most people in the field still consider race and ethnicity to be independent and irreducible variables. Lee (2009) states that "Health officials have seen and treated these categories as static, self-evident, and easily recordable" (p, 1185).

The challenges of using traditional race categories within biomedical research (despite the undefined and changing nature of these categories) occur when the data from arbitrary racial groups are extrapolated to individuals. In his publication

"Ethical aspects of Psychopharmacological studies in Different Ethnic groups,"
K.M Lin (1992) outlines the issue of misunderstanding and interpretation in terms
of using race and ethnicity in biomedical research. He writes

> "Data suggestive ethnic/racial differences could be misunderstood if and
> when interpreted in a simplistic manner. Statistical differences in the
> means are often misunderstood as indicating absolute differences. As a
> result, intra-group variability and overlaps across groups are neglected.
> Such misunderstanding could potentially lead to grave clinical
> consequences. For example, clinicians   who learned that Asians tend to
> respond to lower doses of neuroleptics may routinely prescribe only low
> dose of the medicine to all Asian patients, and by doing this fail to
> adequately treat a portion of their Asian patients whose drug response
> pattern may fall into the range that is similar to the majority of non-Asian
> patients." (p.484A)

Categorizing individuals based on less than rigorous criteria has the potential to
exclude or include individuals from research in an inappropriate manner. In his
book *Inclusion, The Politics of Difference in Medical Research*, Steven Epstein
analyses the inclusion of racial groups in biomedical research. One of his
discussions focuses on generalizing group data to individuals within biomedical
research. Epstein (2007) writes: " When do researchers believe that results from
experiments conducted on one group can be extrapolated to other groups, and
when are they hesitant to make such generalizations? (p.31) Ascribing group
characteristics to individuals is problematic, but as Epstein rightly points out the

problem becomes worse when there is no framework for how the data is selected.

The inconsistencies and inaccuracies that exist within the scientific methodologies are reproduced in the greater society (e.g. local healthcare) and larger public (e.g. popular media). Author Ann Morning discusses how our personal understanding of our race or ethnicity end up been often overshadowed or interrupted by the consistent need for bureaucracies and institutions to categorize or identify us as individuals through the lens of race or ethnicity. She argues that "Our understandings of racial difference are undoubtedly shaped by our families, friends, neighbours and peers. But in a society where racial classification pervades bureaucratic life, our everyday experiences in settings such as schools companies, state agencies and medical offices leave their mark on our notions of race" (Morning, 2011, p.3). Society uses racial and gender classifications by profiling individuals visually and associating behaviours with appearance.

The use of race and ethnic background as a variable in biomedical publications has potential harmful consequences. In their paper "The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice", Burchard (2003) et al. state that "In the United States, race and ethnic background have been used as cause for discrimination, prejudice, marginalization, and even subjugation. Excessive focus on racial or ethnic differences runs the risk of undervaluing the great diversity that exists among persons within groups" (Burchard, 2003, 1171). One of the concerns regarding the inconsistent use of

the concepts of race and ethnicity is that the historical oppression associated with these concepts may be continued based on the medical outcomes that science associates with race. In addition, the discourse about race and ethnicity may influence healthcare workers approach to certain groups, which may cause more health disparities. This pattern has direct consequences on the medical treatment a patient may receive. Racially defined races will receive racially defined treatments. Given the misclassification of race in biomedical research it is a possibility that a physician may develop an inappropriate treatment pathway for a patient based on their skin colour. The treatment of patients in health clinics is therefore be influenced by stereotypes or assumptions that are reinforced by referring to traditional race categories and the propensity to ascribe group characteristics to individuals. In their discussion regarding concerns with the use of "race" in genetic research in terms of clinical/ healthcare, Caulfield et al (2009) write:

> "The descriptive use of race in genetic and biomedical research can lead to racial stereotyping in clinical practice. For example the use of perceived or self-identified race as a proxy for genotype in prescribing most often overly simplifies the concept of pharmacogenomics. Diagnosis or assessment of disease risk on the basis of race can similarly result in serious medical error." (p.1.3)

As Caulfield et al. point out, there is potential for unintended consequences such as racial profiling in frontline healthcare situations and over simplification in

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clinical treatment and diagnosis has the potential to create health disparities. We already know that disparities exist in receipt of recommended medical care. Conclusions about individuals based on race classifications impact face to face interactions or intake processes. It is therefore important that we understand better the consequences of using racial terminology in the delivery of medical treatments. Such interrogation has led me to undergo this research……

Chapter 1 Research Questions

The use of race and ethnicity in biomedical research continues to be an issue. In 2003, there were recommendations put forth in an attempt to develop a framework by which researchers could utilize race and ethnicity in a more accurate way. It was also an attempt to encourage greater exchanges regarding race and ethnicity between different specialists and lay people (Soo Jin Lee et al, 2008). The conversation regarding the use of "race" and "ethnicity" in biomedical research has advanced from a broad concern about the lack of basis for these terms to an agreement that these terms should be defined and applied consistently. The recommendations are as follows:

1. Account for the use of the term race/ethnicity in the research

2. Separate genetic/biological from cultural/environmental factors

3. Reliance on one type of information for the descriptors of race/ethnicity

4. Researchers need to be aware of the social constructions and change over time.

5. Biomedical research should not reinforce stereotypes

6. Researchers who use racial/ethnic categories should be accountable for the use and assignment into categories

7. Data on group characteristics should not be ascribed to the individual

8. Acknowledge all stakeholders in the outcomes

9. Ensure a consistent message to laypeople (The racialization of disease: a qualitative and quantitative analysis of race and ethnicity in biomedical research.

(Soo-Jin Lee, et al,2008)

This thesis will examine the extent to which these recommendations have been adopted by biomedical researchers by focusing on two general questions:

1) How do we know that racial or ethnic categories in biomedical research are appropriate?

2) How do we know that the biomedical associations within these categories are appropriate? (Sankar et al, 2007).

Chapter 2. Literature Review

This literature review will examine the origin of traditional race categories. It will discuss how race was historically defined and conceptualized in an attempt to illustrate the changing nature and impact of social and political forces. Additionally, it will endeavor to represent how the concepts of race and ethnicity are interpreted by individuals in society beyond a biological basis in order to establish and legitimize hierarchies. Evidence of the process will be illustrated by examining the work of Linnaeus and Blumenbach. Studies that have applied the guidelines for best practices for the using of race and ethnicity will be examined and issues with self-reporting of race and ethnicity will be discussed. The review concludes with a comparison of how the terms race and ethnicity are interpreted by examining the Canadian and American census methods of racial and/or ethnic categorizations and illustrations of the negative impacts on health outcomes that the misuse of the terms have.

The origins of the scientific study of race and ethnicity

It is essential to understand the history of the use of racial categories in order to contextualize the current practices of grouping individuals according to "race" or "ethnicity", both in general and with regard to biomedical research. Investigating the history of racial categorization provides insight into how healthcare or medicine has been informed by race.

Individuals in society understand and define the concepts "race" and "ethnicity" based on socio-political processes. The concepts of race and ethnicity apply not only to individuals and/or groups but also to institutions, policies, bureaucracies, and social events. Adopting a historical approach shows the fluidity of the concepts over time and how they have been used to create and perpetuate hierarchies and oppression. Omi and Winant write that race:

> should be understood not as a fixed essence but as "as unstable and decentred complex of social meanings constantly being transformed" - by political struggles as well as by a wide range of social activities (including for instance, biomedical ones). Rather than seeing their meanings as stable, we should be attentive to the historical processes by which categories come to be imbued with significance - what Omi and Winant, in the case of race, refer to as "racial formation" And we should likewise track the efforts by which differently   situated social actors seek to control the production, circulation and receptions of   public   and   mass media discourses about difference. (cited by Epstein, 2007).

On the surface, the concept of race or ethnicity is based on visual or physical differences between individuals or groups. However, as Omi and Winant and others point out, that the concept of race constantly changes because of socio-political interests, generally those of the privileged class. It is important to note that people's physicality does not change, but its significance politically and socially does. Catherine Lee asserts that "The meaning, significance and use of

the concept of race are historically variable and contingent upon a host of economic, political and cultural practices" (Lee 2009, p. 1183).

Author Ann Mourning (2011) discusses the concept of "race science" and its beginnings. She writes:

> The beginnings of "race science" can be traced to eighteenth-century Europe, when the forerunners of today's biologists and anthropologists sought to name, catalog and describe the races of the world. Linnaeus (1770-78) is perhaps the best known of the early taxonomists, but other influential human classification schemes were presented by Francois Bernier (1625-88), Georges-Louise Leclerc, Comte de Buffon (1707-88) and Johann Friedrich Blumenbach (1725-1840, "The Father of anthropology")(p.44).

These descriptions and categorizations of races lacked medical accountability and were based on using the White race as a measure for perceived normality. These descriptions also used perceived physical differences as a way to reinforce medical inferiority, which was used as an explanation for shortcomings and low achievements for people who were seen as falling outside of the white race norm. This race science or racial categorization was generalized to justify theories of many disciplines and theories. Morning (2011) writes:

Eighteenth-century naturalist taxonomies, which extended to all manner of flora and fauna formed part of broader "project of a general science of order"

(Foucault 1973, 71) that was spurred in part by Europeans' "discovery" of unfamiliar lands (Harding 1998). They epitomize, moreover the constructivist contention that race is an ideology that arose as a part of European attempts to make sense of - and dominate- others. The historian George Fredrickson (2002), for example, traced the emergence of racial essentialism to sixteenth-century Spain, particularly the belief that the descendants of Jewish and Muslim converts to Catholicism retained indelible makers of their ancestors' taint. According to this argument such essentialist beliefs were then married to the color-coded social hierarchy that formed in the wake of European colonization in the Americas, Africa and Asia. The end product was the essentialist and hierarchical black/white/yellow red race concept that Linnaeus and other taxonomists formalized and that we recognize today (p.25).

The historical representation of race classification marries two perspectives: the Essentialism and Constructivist perspectives. In the Constructivist perspective, Europeans frame their perspective as anthropological but the goal is to control and exploit groups that are different from them. In Essentialism, the visual representation of difference worked well to provide a narrative to reinforce white dominance (Mourning, 2011). Two examples of "race science" from the eighteenth century that has had great influence are Linnaeus' Systemae Naturae and Johan Blumenbach's beautiful skulls. Both theories and perspectives first identified the white race as normal, linked physical traits with behavior while simultaneously developing a social hierarchy where the white race sits at the top

(Tashiro, 2005). Author Cathy Tashiro, outlines the beginnings of racial grouping through the Systemae Naturae. Tashiro (2005) states:

> The classification of populations into races began in earnest in the 18th century, with the rise of development of the natural sciences. In 1735 Linnaeus classified all known living organisms, including human beings, in the *Systemae Naturae*. Linnaeus demonstrated the common tendency of his time to associate behavior traits with physiognomy in his descriptions of the different groups. For example, the physical description of the 'Americanus" groups (presumably based on American Indians) is followed up by the adjectives "obstinate, merry, free; paints himself with fine red lines; regulated by customs (p.208).

The examination of the Systemae Naturae and its evolution illustrates how as early as the 18th century, Linnaeus formalized unsubstantiated generalized associations between behavioral traits and the appearance of individuals. Another example that Tashiro offers is that of Johan Blumenbach. Tashiro (2005) states that:

> The most influential racial classification system of the 18th century was that of Johan Blumenbach, considered to be the German father of physical anthropology (Schiebinger 1993). Blumenbach divided humanity into five varieties with regional associations. They were Caucasian, Mongolian, Ethiopian, American and Malay. According to Schiebinger (1993), Blumenbach theorized that humanity originated in the Caucasus and that

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the darker races represented degeneration from the purity of the white-skinned inhabitants of that region.   Blumenbach is remembered for his coining of the term "Caucasian" to refer to the descendents of that region (p.208)

Blumenbach used a racial classification system to separate races he felt were inferior and place the White race in a position of power. As an anthropologist he supported the validity of his claims by proclaiming that white skin is purer and any detour from this (in terms of darker skin) is inferior. His authority was reinforced by his academic credentials and his… race.

Of course, as could be expected, the concept of race was always instrumental in reinforcing oppression of certain groups. For instance, the practice of slavery was based on the notion that Blacks are inferior and needed to be tamed and controlled. Steven Epstein (2007) writes: "Claims about biological differences also were invoked in nineteenth century Europe and the United States to justify racial hierarchies in general and the practice of slavery in particular" (p. 36). In this case as in all others, race science was just another name for white politics.

.**Race and ethnicity in biomedical research in XVIIth-XIXth centuries**

Chairman of a committee appointed 150 years ago by the Medial Association of Louisiana to report on the diseases and peculiarities of the Negro race, Samuel Cartwright offered a description of the black man that underlies North American society's preoccupation with racial difference/superiority based on skin color predicting character, behavior and physiology:

Samuel Cartwright […] described in a biomedical journal in 1851 on how the skin color of the black man reflected a difference that went all the way inward "his bile […] his blood […] the brain and nerves, the chyme and all the humors "were" tinctured with a shade of the pervading darkness" (Epstein, 2007,p.36).

Dr. Cartwright's reference to "black" was not scientific but simply a contrast to what is perceived from a visual standpoint as "normal". Dr. Cartwright went on to develop a diagnosis called "Drapetomania". The definition of this diagnosis was specific to the tendency of slaves to run away. Duster et al. write that "It is what Peter Conrad and Joseph Schneider characterize as the "medicalization of deviance"" (Duster, 2006 p.486). The medicalization of deviance serves to not only make non-white races medically inferior but it sought to legitimize the policies regarding slavery at the time. In essence, slaves were not running away because slavery was oppressive, but because they were suffering (as compared to white men) from inferior mental capacity.

Duster writes of Samuel Cartwright's explanation that "The violence and aggression of blacks is here said to be 'natural' - when they are not under the white man's authority, they beat each other far more seriously than whites beat them. Worse there is a certain kind of "negro" who becomes viciously violent towards the women and children of his own race when again he is not under white control" (Duster, 2006, p.489). In this last quote, Cartwright's explanation of

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the "negro" illustrates an individual who is prone to violence and aggression and cannot be trusted when not under white authority. Additionally, Cartwright's depiction shows the white man as helping the Negro by keeping him as a slave. This description uses medical authority to maintain slavery and promote it as a necessary practice.

Another historical illustration of race science practices is a study published by the *Journal of the American Medical Association* (JAMA) by Dr. Seale Harris who noted in 1903 that: "the lesser development of lung tissue and the accessory muscles of respiration among the negroes than for the whites" reflected the fact that" the negro, a century or two ago was a savage perhaps a cannibal" (Epstein 2007p.37). But the data collected to arrive at this conclusion show the biases that were sometimes built in the technology itself. The normal functioning of black people's lungs is typically presumed to be 10-15 percent below that of white people's. As Lundy Braun (2005) who studies the intersection of race and biomedical science and technology has shown the presumption stems from a poorly supported idea that blacks inherently have lesser lung capacities than whites. Yet, spirometers are calibrated to account for this difference. Some machines actually have a "race" switch built into them, which technicians flip depending on what race they believe the patient to be. Pegging the lung function of blacks at a lower level means among others things that they have be sicker than whites in order to qualify for worker's compensation or other insurance for lung related illness. (p 137)

The history of racial discrimination within healthcare can be seen in literature and clinical interactions. The improper use of these terms within biomedical publications reinforces stereotyping and has the potential to contribute to misinformation at a clinical level.

Race and ethnicity in biomedical research in XXth-XXIth centuries

In the nineteenth century, Blacks were seen as inferior by a number of institutions in society because people were uncomfortable with emancipation and needed to justify slavery. Surprisingly, individuals today are still (arbitrarily) placed in racial categories. In science and medicine gross assumptions and generalizations are still made about racial/ethnic groups even in a system designed to rigorously control and exclude such conjectures. Even today biomedical research publications utilize White or Caucasian groups as the norm and non-White races are the comparator used to investigate difference in treatment, hospital process and pharmacogenomic outcomes. As we will see, the data from these publications have the potential to be interpreted and implemented inaccurately by healthcare worker, which may create health disparities they are intended to address.

One of the problems comes from the fact that, over the last two decades, there have been demands from activists and reformers to include minorities and women as part of the study of human subjects in biomedical research. An example of this is The National Institute of Health's (NIH) Revitalization Act. This act "required the racial classification of biomedical research subjects" (Epstein,

2007, p.205). In 1993, Revitalization Act was outlined as a criterion by the NIH to acknowledge women and minorities as viable human subjects in biomedical research. An example from this act is the following:

> "in the case of any clinical trial in which women or members of minority groups will under subsection (a) be included as subjects, the Director of NIH shall ensure that the trial is designed and carried out in a manner sufficient to provide for a valid analysis of whether the variables being studied in the trial affect women or members of minority groups, as the case may be, differently than other subjects in the trial" (National Health Institute Revitalization Act, 1993, p.21)

As a result of the emergence of the Revitalization Act in the early 90's along with other similar policies, questions about defining race were raised, such as 1) how to determine race and ethnicity and 2) who would determine it? These queries reflected issues regarding the validity of the terms used to define race. Was race a socially constructed notion or was it based on biology? Additionally there were questions about who the information about race would come from? Academics or human subjects?   As time went on there were more direct messages regarding the use of race and ethnicity in biomedical research but they were not specific. Epstein (2007) writes about the guidance offered from biomedical journal editors. He writes that:

> By the latter part of the 1990's, biomedical journal editors also were paying increased notice to these contentious debates. In 1997 the major journals

released the fifth edition of the "Uniform Requirements for Manuscripts

Submitted to Biomedical Journals" a consensus document meant to guide

authors in the preparation of manuscripts submitted to hundreds of

biomedical journals. For the first time, authors were instructed that the

definition and relevance of race and ethnicity are ambiguous. "When

describing research subjects, "authors should be particularly careful about

using these   categories. (p.207)

At the time, four issues seemed obvious 1) there was an agreement that there

was a problem; 2) there was a general agreement that this problem had to be

dealt with; 3) but no one understood how; 4) no one wanted to take responsibility.

Currently, it would seem that the same debates are going on now with little

advancement. Some changes have been made and they are important but not

impactful.

In 2002, for example, Dr. Pamela Sankar critiqued the Medical Subject Headings

(MeSH) terms used by MEDLINE. MeSH and the way they are used to index the

millions of publications in the Medline database. Sankar (2002) critiqued the

MeSH terms used by MEDLINE, "a search for race in MeSH returned the phrase

"racial stocks" which MeSH defines as" major living subspecies of man

differentiates by genetic and physical characteristics"(p.119). Clearly this very

definition of the MeSH terms is in conflict with the spirit and guidance of the

recommendations for the use of the terms "race" and "ethnicity" in biomedical

research. Additionally, it shows a lack of governance for ensuring that the terms

and information are culturally sensitive and/or currently relevant. MEDLINE did however comply with Sankar's. The new requirements for expanded inclusion and the revelations of existing gaps in health care led to a figurative addiction to difference finding in biomedical research in the 1990's. This would leave one to wonder whether the differences are legitimate and who would be able to call them legitimate or not. Is racial profiling in medicine an acceptable practice? And when researchers do it, do they give up on social justice on behalf of scientific progress?

Defining "Race" or "Ethnicity": Comparing USA and Canada

The use of race and ethnicity is confronted to the multifold problem of their definition. One can measure the degree of difficulty this can represent by analyzing the different approaches adopted by the U.S. and Canadian census. The United States and Canada collect data from populations using different methods, but none are without issues. "Both the U.S. and Canadian censuses have varied the main question for collecting racial or ethnic data greatly over the years but U.S. census has always based its division around the idea of "race", whereas the Canadian census (up until 1996) has consistently centered around "ethnicity"" (Wegmann-Sanchez, 2003, p.49). To be more precise, in the U.S., the concept of "race" is defined as an individual's skin color and associated biologic and social traits while, in Canada, the concept of "ethnicity" is more determined by an individual's culture or language. Wegmann-Sanchez (2003) states that:

For the last twenty years the United States official federal government's racial categories have been: White, Black, American Indian, Asian or Pacific Islander, and Hispanic (with the option to consider Hispanic as a race or as a separate category in addition to race). These categories have expanded over time to include native or aboriginal peoples but they are always based on physical representation. In the Canadian census the categories are linked to culture and heritage over biology. In the 1996 long version of the Canadian census, categories included: French, English, German, Scottish, Canadian, Italian, Chinese, Cree, Micmac, Metis, Inuit, and 12 more followed by an "etc" (Wegmann-Sanchez). This comparison indicates that the Canadian census supports "multiple and self-defined ethnicities" (p.50).

These different approaches suggest that the census reflect a country's intention in terms of how new citizens will be asked to integrate society. The "race" approach in the case of the United States suggests that differences in society will be acknowledged through people's physical presentation. Wegmann-Sanchez (2003) illustrate the consequences of dividing people by race. They write that:

Not only does the U.S. government historically divide according to exclusive races, but it sets up a dividing line specifically between Whites and non-white people (where whites receive privileges from which non-Whites are excluded), as exemplified in the country's history of segregation, the one-drop rule defining African Americans and its early

court cased arguing for exclusion of immigrants based on their " non-Whiteness" (p.50).

Using a race categorization approach has led to historical oppression and exclusion of so-called races. A patent example of this segregation is the Jim Crow laws. Through the 1880s into the 1960s, a majority of American states enforced segregation through "Jim Crow" laws (so called after a black character in minstrel shows).   From Delaware to California, and from North Dakota to Texas, many states (and cities, too) could impose legal punishments on people for consorting with members of another race. The most common types of laws forbade intermarriage and ordered business owners and public institutions to keep their black and white clientele separated. (Morning, 2011)

Whereas the American Census gives citizens a forced choice of race categories with those categories determined by the dominant socio-political culture of the time (Historically white, Christian males in the US), the Canadian Census relies on the concept of "ethnicity". It is based on the idea that one can be Canadian and still retain his or her specific cultural identity. That is not to say that there are still not issues with how the Canadian census classifies individuals. Wegmann-Sanchez (2003) writes:

> The problem with the Canadian system, conversely, is simple that it becomes difficult to tabulate statistics that could reflect discrimination against a particular group linked by a common perceived skin color or perceived race, thus making it easier to deny on a federal level the

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prevalence of racism in Canada. It wasn't until 1996 that Statistics Canada

made the still very controversial decision to include a category tabulating

"visible minorities" similar to the American race category - although

pointedly avoiding the word " race" a move in direct contrast to the

decision in the U.S. to allow respondents to check more than one racial

category for the first time on the year 2000 census (P.51).

The use of the concepts of "race' and "ethnicity" in either case is complicated by

historical events and current policies, the impacts of which are felt by not only

immigrant minority groups but the indigenous Aboriginal peoples."Over the years,

both countries have taken away rights granted to Aboriginal people in treaties by

progressively limiting the legal definition for who qualifies as American Indian or

Aboriginal" (Wegmann-Sanchez, 2003,p.51). Current policies that have been put

in place for both countries based on past discrimination are hard to assess and

cannot be represented effectively in terms of hard data or statistical outcomes.

Defining "Race" or "Ethnicity": A Self-Reporting

A census is a data collection tool that systematically acquires and records

information about the members of a given population. But, as discussed

previously, many of the current forms of data collection in society ask individuals

to classify themselves by race and/or ethnicity from a menu of choices. Collecting

race/ethnic data in this manner is referred to as "self-reporting". This is

problematic because although this is called "self-reporting" the methodology is

better called "forced choice reporting" as obviously not all potential races or

ethnicities are listed in the menus. Thus, people may be forced to choose a group that they would not normally identify with but represents the closest alternative to how they would actually self-identify. The article "Beyond Black and White Metropolitan residential segregation in multi-ethnic America", which explores racial segregation in America, offers a good illustration of these very problematic limitations. Discussing the office of Management and budget's census framework, author John Iceland (2004) states that,

> In 1977 the office of Management and budget (OMB) issued its Statistical Policy Directive 15, which provided the framework for the federal data collection on race and ethnicity to federal agencies, including the Census Bureau for the 1980 decennial census. The OMB directed agencies to focus on data collection for the four racial groups – White, Negro or Black, American Indian, Eskimo, or Aleut; and Asian or Pacific Islander and one ethnicity – Hispanic, Latino or Spanish origin. The questions on the 1980 and 1990 censuses asked individuals to self-identify with one of these four racial groups and whether they were Hispanic or not (Iceland, p.253)

It important to note that as the directive to use specific race categories originates from the (OMB) it assumes that (OMB) has a priori knowledge of the race/ethnicity of the people in America and the ability to classify them although never actually defining the inclusion/exclusion for any category.

The problem of generalization

Another issue that emerges from the improper use of the terms race and ethnicity is generalization. Researchers tend to focus on differences between groups and overshadow inter-group differences. Issues with generalization are illustrated by a study done in 2003 titled "Unequal Treatment, the Institute of Medicine's exhaustive study of racial and ethnic disparities in healthcare" (Smedley, Stith & Nelson 2003). The authors examined peer-reviewed journal articles from 1992 to 2002 that had documented healthcare inequities and disparities based on race and ethnicity. Some of the publications revealed the following:

Less access to kidney transplants for black patients when compared to whites (Furth et al 2000),

Fewer psychotropic medicines provided to African Americans than whites youths (Zito, Safer, dosReis & Riddle, 1998),

Fewer prescriptions provided to African American and Hispanic children (Hahn, 1995),

An association between non- English speaking families and both increased charges for diagnostic testing and length of stay in pediatric emergency departments (Hampers, Cha, Gutglass, Binns and Krugg 1999)

Parental reports of worse care by African American, American Indian and

non- English Hispanic and Asian parents (Weech-Maldonando, Morales,

Spritzer, Elliot and Hayes, 2001).

It is impossible for one to ascribe a biologic basis for the above outcomes. In this

case the inequalities must be based on social and cultural disparities in society

and not on individual or group characteristics. Disparities in access and level of

service within the medical system are a social and political issue. Health

disparities are often represented as gaps in the quality of health care across

racial, gender and socioeconomic lines. From an epidemiologic standpoint

differences between racial groups with regard to the presence of disease, access

to healthcare and/or medical outcomes have been reported. Researching health

disparity in minorities is at face value a reasonable motive for biomedical

researchers to engage in racial or ethnic categorization within their studies.

For example, the article "Disparities in the Use of Immunomodulators and

Biologics for the Treatment of Inflammatory Bowel Disease: A Respective Cohort

Study" by Mark H. Flasar, Tamara Johnson, Mary Claire Roghmann and

Raymond K. Cross. Flasar et al (2008) discuss how treatment disparities

between African-Americans and Caucasians in Inflammatory Bowel Disease

therapies correlate with race even when controlling for disease severity. They

state that their study was undertaken to "assess medications used and the

presence of covariates by race" (Flasar et al, 2008, p.13). Racial classification in

this study was made retrospectively from patient's medical records, where a

"review of practitioner notes was used to determine how the provider classified the patient's race" (Flasar et al, 2008, p.14). But if the notes indicated the race of the patient assigned by the physician, there was nothing about how the physician made that assignment. Was the race simply the impression of the physician or was the patient asked to self-identify? Any interpretation of the results is biased as no common method or definition of racial grouping/identification was utilized. The conclusions from the study were inconclusive and it was stated that "Further studies are needed to determine if these differences are due to less severe disease in African American patients or due to disparities in care" (Flasar et al, 2008, p.13). Revealingly, this conclusion is made even in the absence of any instruction as how to identify a patient as "African American". In a response to the article, Dr. Thomas Ullman states that despite the lack of data in this case there are health disparities in health care. She states that "disparities in IBD certainly exist" (Flasar et al 2008, p13). If a researcher is attempting to examine health disparities in minority groups they risk exacerbating the problem if their data sources are inaccurate or lack sufficient details. This article not only reinforces the socio-political impact of race and ethnicity but it also highlights the importance of defining individuals accurately in biomedical research when using the terms "race" and "ethnicity". Biomedical researchers need to engage rigorous methodologies (precise and consistent) to collect data that can be applied to populations or individuals. Failure to engage in rigorous processes of methodology can create bias and ultimately reinforce stereotypes about race and ethnicity. Perhaps, the more fatal error is how can we assess and design health

services when the cultural division of patients is flawed? The results are unreliable as well as the conclusions

Race based medicine

So far in this discussion, it has been stated that racial and/or ethnic classifications are often created and utilized based on the priorities of institutions. The emergence of race-based medicine is no different. As the interest in race based medicine increases, people have questioned the use of racial or ethnic categorizations based on socially (politically) visible groups within biomedical publications. Currently, biomedical research uses the same seemingly antiquated and potentially useless categories for race based medicine. In their paper entitled "Bidil; recontextualizing the race debate", Seguin Hardy, Singer and Daar, (2008) discuss a statement made by the Food and Drug Administration (FDA) regarding personalized medicine. The FDA states that "Personalized medicine today may mean that you have classifications by ethnicity. Personalized medicine, as you move ahead and you know more and more what these markers are should become incrementally independent of ethnicity" (p171).

This means that personalized medicine will continue to utilize potentially incorrect categories. This is problematic because the consequences of such as actions have not been discussed. For example, the new drug BiDil is specifically recommended for African Americans with heart disease but it has been under scrutiny for pharmaceuticals are profiting off 'race-based medicine'. Seguin (2008) et al go on to state "Although it has been argued that commercial opportunity drove the development of BiDil, others suggest that this is merely a

reflection of drug development" (p.170). This suggests that the drug was not

"designed" for African Americans just that in the drug trials and in post-hoc

analysis, it appeared to work more effectively in the group of patients identified

as African American. It has been proposed that profit, not science, has prompted

this development of specific drugs for specific ethnic groups. Furthermore, the

lack of availability to African Americans (who are an underserviced population

according statistics) creates more health disparities. The development of the

drug "Bidil" is the latest outcome of using race in biomedical research. It is

imperative that, moving forward, biomedical researchers adopt recommendations

about the use of race and ethnicity in their publications. Moreover if a genetic link

is suspected then genetic testing should be undertaken rather than using "race"

as an assumed maker of underlying genetics. The technology is readily available

to carry out these genetic studies and will likely become the norm in the future.

Critiquing the use of race and ethnicity in medicine

Further discussion of how the biomedical research communities use of the terms

"race" and "ethnicity" are problematic is found in the publication by Sankar et al.

entitled "Race and Ethnicity in Genetic Research". In this paper they compare

recent recommendations developed within the medical genetic community to

biomedical publications dated from 2001 - 2004. Sankar (2007) states: "Despite

differing opinions about their basis or relevance, there is some agreement that

investigators using these terms should; explain why the terms of categories were

used, define them carefully, and apply them consistently" (p,961). Regarding the

results of their investigation, Sankar et al (2007) go to state that:

The recommendations that authors using race or ethnicity terms explain

the basis for assigning them to study populations was met infrequently at

(9.1%), and articles that used race and ethnicity as variables were no

more likely than those that used them only to label a sample to provide

these details. No article defined or discussed the concepts of race or

ethnicity (Sankar, p 961).

Sankar et al's investigation of publications between 2001 and 2004 illustrated

that repeated recommendations regarding a careful and consistent use of the

terms "race" and "ethnicity" within biomedical research were generally not

adhered to. Some of the discourses surrounding the use of these terms have

therefore called to eliminate the use of racial categories altogether and simply

refer to people's ethnicity. The idea is that ethnicity can be more accurately

defined via tangible and measurable variables such as language, diet, and

culture. Catherine Lee (2009) comments on this:

Many social scientist's claim that ethnicity is group defined and

voluntaristic. They argue that an ethnic group is self- consciously ethnic

and one's ethnicity is an achieved status. Citing this difference, both social

and biomedical researchers have advocated the use of ethnicity over race.

(Lee 2009 p.1185).

However the use of term ethnicity over race in research may lead to the same

issues in that the notion of "achieved status", "may suggest falsely that there is

greater analytical difference between the two than there is really is" (Lee, 2009 p

1185). Indeed, as stated previously, it is accepted within the medical genetics community that there is no biological (genetic) basis for using the terms "race" or 'ethnicity" in scientific research. It would seem then that the utilization of the terms "race" and "ethnicity" in scientific research only reinforces the use of the artificial socially constructed definitions of race and ethnicity. Epstein (2007) discusses the debate in terms of using race or ethnicity. He writes that:

> In the second half of the twentieth century as scientific evidence mounted that the so-called continental races – such as Africans, Caucasians and Asians-simply cannot be demarcated by any scientific means and that the terms do not correspond to any sharp genetic divisions in the human species, many analysts proposed that the term 'race' in all its invidious history, be discarded. Some people have proposed that ethnicity understood as a marker of cultural difference with no specific biological referent, can perfectly well replace race in our conceptual vocabulary. While admirable in some respects these strategies are impractical in the short run insofar as they ignore the incredible salience of racial categories in the politics of everyday life (p27.).

With regard to the use of the terms race and ethnicity both authors rightly point out that scientifically redefining the terms in isolation will have little impact, because of their constant usage in other areas of society. Furthermore, it is important to incorporate the usage of race and ethnicity by other institutions such as government and healthcare, and to understand the impact redefining these

terms may have. In her paper "Racial and Ethnic Categories in biomedical Research; There is no Baby in the Bathwater", Mildred Cho (2006) discussed the issue of racial categorization in biomedical research. She stated that there is "no clinical or scientific utility to racial and ethnic categories unless one is studying perceived race or ethnicity or self perception." (p.499) She went on to say that "what defines these individuals and groups is not what we call "race" or "ethnicity" because there is no consistent definition of racial or ethnic categories" (Cho,2006 p.499). Cho is alluding to the notion that society develops these "race" categories to fit the situation at any given time.

Literature Review Summary

The literature review began by providing evidence that has illustrated racial categorization manifest in society based on socio-political events. It then went on to discuss the way in which race and ethnicity has been utilized within medical practice and, additionally, the way in which race and ethnicity are defined by examining government census in North America. Finally, the issues of generalization within research and race based medicine were focused on as more contemporary examples. This literature review sheds light upon the fact that the notions of race and ethnicity are fluid and impacted by socio-political events. Furthermore that there is evidence that the patterns associated with defining race overlap that the race categorization methods of Blumenbach, Cartwright and Linnaeus's can be seen today. In terms of the questions regarding the use of the terms race and ethnicity that were queried at the beginning of this

thesis the literature review reveals that there is no agreement about how to utilize these terms and that within research using a race as a proxy for actual genetic evidence can be dangerous.

In the next section, I will analyze biomedical publications that use the terms race and ethnicity using the recommendations as a guideline for the criteria of my search. I will then discuss the results of my search to examine whether the guidelines have been incorporated into the most recent publications. The thesis will then discuss current challenges that face researchers and academics regarding race categorization. Finally the thesis will conclude by examining how well the recommendation have been incorporated and offer further recommendations based on the results of my research.

Chapter 3: Methodology/Justification for Criteria

In order to investigate to what degree the current recommendations for the use of the terms "race" and "ethnicity" within biomedical research publications have been utilized a content analysis was undertaken. In this content analysis, 205 papers published from the year 2010 to Jan 6, 2012 were examined to reveal whether current recommendations regarding the use of the terms "race" or "ethnicity" in biomedical research have been adopted. In order to conduct the search and identify papers, an online database of biomedical publications (www.pubmed.com) was utilized. Pub med is a free database service of the United States national library of medicine that includes over 19.5 million searchable citations going back to the year 1865.

There was a 4 stage search, identification and evaluation procedure:

Step one: search of the Pub med medical database that fit the following criteria/limits: humans, clinical trials, English, 2010 to January 6, 2012, all text, "race" and/or "ethnicity" in the title or abstract of the publication. A total of 205 papers were identified for analysis using these limits/criteria with the process being illustrated in the flow chart below. All 205 papers were downloaded as PDF files and saved for review.

Step two: Each downloaded article was subjected to another review using the same criteria to ensure that each article 1) used human subjects; 2) used race to describe the race or ethnicity of the subjects and was not an acronym or referring to a sport; 3) that had race or ethnicity in the title or in abstract. Articles that used these terms for different purposes were eliminated. After this review 205 articles remained in my data set.

Step three: An excel sheet was created with sixteen categories for analysis which were: 1) Author, 2) Title, 3) Journal Name, 4) Year of publication, '5)

Race or 'Ethnicity' in the Abstract, 6) Basis for assigning the population term, 7) Why is this population used?, 8) How is race used as a variable, 9) Type of Data Source, 10) Data Source, 11) Organ System, 12) Impact Factor of journal, 13) Paper topic, 14 Which condition?, 15) Is race defined?, 16) Is there a medical outcome associated with race?. Within these categories two were coded: 1) Organ Systems (as has been traditionally done in pathophysiology textbooks), 2) Basis for assigning the population term. 3) Including a category that analyzed the publications medically by organ system,

Step four: The downloaded articles were examined and the data extracted, entered into an excel spreadsheet and descriptive statistics performed.

Justification of Criteria/Limits for Pubmed Search

Type of article- **Clinical Trials**

Clinical Trials were selected as they were the more likely to collect data that associate a medical outcome, treatment difference and or healthcare disparity as well as collecting data on race. Using the search limit of Clinical Trials also lessened the likelihood that publications that deal with the term "race" in a completely different context would be returned. Examples of this are papers that refer to "race" the athletic endeavor.

Subjects in Clinical Trials - **Humans**

Humans were a criteria to ensure that the subjects in the clinical trials were human and not animals.

Languages- **English**

The author of this research only speaks English. English was chosen to avoid having to use translation with inherent bias.

Published from- **2010 to Jan 06, 2012**

According to my literature review, the year 2010 and Jan 06, 2012 represents a time period where the uses of the terms "race" and 'ethnicity' were not investigated. Furthermore this time period reflects a reasonable delay between the publication of guidelines/recommendations and recently published work.

Text options- **All text**

The text selected included free text and text offer for cost. This study did not have to pay for any text as they were all accessible through McGill, Concordia and McMaster online libraries.

Search criteria: "**Race" and/or "Ethnicity" in Title or Abstract of manuscript**

The title or abstract of an article represents critical areas of topic focus in a scientific manuscript. Limiting the search to these two areas ensured capturing papers where race and/or ethnicity were a focus.

A Breakdown of the Analysis Sheet:

To determine to what degree the recommendations for the use of the terms "race" and "ethnicity" within biomedical publications were utilized from 2010 to the present, a series of data categories based on the recommendations were generated, data from each article extracted and entered into an excel spread sheet (partially reproduced in Appendix 1). The categories for analysis were broken into three general themes: 1) Basic features of the study; 2) Reasons for utilizing specific populations; and 3) the Role of race and ethnicity within the study.

Basic Features

The first section is called basic features. This section analyzed each article for four pieces of information regarding the study it reported: Author, Title, Journal Name and Year of publication.

- *Author*: this section notes the author or authors of the publication[1]

- *Title*: The title of the article is of importance because the intention of the research can be revealed in title

- *Journal name*: This portion notes the journal the research came from. The medical specialty or subject matter of the journal was also determined and used in analysis. In this analysis, the total number of journals was

analyzed vs. the total number of publications. The journals that appeared more than once were extracted and examined for impact factor and content

- *Impact Factor -* The impact factor offers a way in which to measure the number of times an article was cited. According to this calculation a high impact factor is 5 and beyond. Impact factors are calculated out of 10.

- *Year of publication* The year of publication was from 2010 to Jan 06, 2012

Justification for using race/ethnicity as populations

The second section studies the reason the research was conducted using the terms race and ethnicity. This section is comprised of three categories: Are the terms race and ethnicity in the title or abstract? What is the basis for using the population? and why was this specific population used?

- *Race/Ethnicity in the Title or Abstract*: The abstract provides fundamental information about the publication. It not only provides the background of the paper but also offers a rationale for the study. The abstract will also provide the hypothesis and limitations of the study. The hypothesis may reveal why the author has decided to study a certain race and how it relates to the premise. It may also shed light on its founding idea. The limitations, if mentioned, are also noteworthy because they may reveal how widely the findings can be applied to populations beyond the

specified races, or ethnicities. In addition to hypothesis and limitations, the publications were analyzed for subject of focus. For example: Disease acquisition, gaps in healthcare, reactions to drug or treatment, and/or how a population reacts to a medical process.

- *Basis for assigning the population*: This section examines how a population's label originated or how it was determined. For example, was the population labeled self - reported by the participants or was it determined because of a geographical location?

- *Why this specific population?* This section examines if the underlying reasons for studying a specific population are identified. When the population is chosen, is there any indication of why other populations are not being studied?

The role of race or ethnicity

This section examines the various ways the terms race or ethnicity are utilized within each publication

- *Is race or ethnicity used as an independent or dependent variable?*

  This portion examines if race or ethnicity was utilized within publications as a covariate or an outcome.

- *Sample Origin*

This portion examines whether the study reveals the methodology behind gathering statistics about individuals.

Publication defined by Organ.

This portion examines which organ of the body the study applies to. There are twelve in total. This establishes the focus in terms of disease for the data set.

Disease - This portion discusses what disease if any the publication mentions.

- *Is race defined?*

   This section of the analysis examined whether the terms "race" and/or "ethnicity" were defined within the publications when referring to the mentioned populations.

- *Are races that fall outside of the scope of the study accounted for?*

   This portion examines the ability of the study to discuss why it has included specific races and not others.

- *What are the races mentioned?*

   This section examines what specific races are mentioned within the publications.

- *Is there a medical outcome associated with race made in the article?*

This portion examines whether a medical outcome is associated with a race or ethnicity within the publications.

Chapter 4 Results

The following table shows the collected results from the comparison of the

studies to the categories created based on published recommendations

Table 1 data from the identified 205 articles

Data Category	Result	Comment
Journal Name	Total number of papers vs. the total number of journals	The total number of publications returned for this search is 205. The total number of journals is 189. The journals that have been cited the most within this search are the following: • Personality and Social Psychology • American Heart Journal

		• Cancer Epidemiology • Biomarkers • Clinical Journal of the American Society of Nephrology • Ethnicity and Disease • International Journal of Radiation Oncology Biology Physics • The Journal of Pediatrics

		• Pediatrics.
Subject content of the most cited journal within the search	The content within the eight journals covers the following subjects :	• Personality and Social Psychology This journal subject content is: social cognition, attitudes, group processes, social influence, intergroup relations, self and identity, nonverbal communication, and social psychological aspects of affect, emotion and language
	Mental Health	
	Oncology/Cancer	
	Biological Markers	
	Kidney Disease	• American Heart Journal The journal subject content is: cardiology cost-effectiveness, design of clinical trials, reports of
	Pediatric Disease	

	Epidemiology	negative clinical trials, and the changing organization of medical care.
		• Cancer Epidemiology Is a peer-reviewed, open access journal that publishes original research articles, review articles, and clinical studies in all areas of cancer epidemiology?

		• Biomarkers
		This journal presents the biomarkers of disease- covering measurement of endogenous substances or parameters indicative of a disease process and the use of pharmacodynamic and genetic markers in evidence-based laboratory medicine and treatment. In addition it examines the biomarkers of exposure, response

		and susceptibility • Clinical Journal of the American Society of Nephrology This journal is devoted to the study of Kidney Disease. Educating patients about treatment and self assessment. • Ethnicity and Disease This journal provides information on the

		causal relationships in the etiology of common illnesses through the study of ethnic patterns of disease.
		• International Journal of Radiation Oncology Biology Physics This journals content includes but is not limited to experimental studies of combined modality treatment, tumor sensitization and normal tissue

		protection, molecular radiation biology, particle irradiation, brachytherapy, treatment planning, tumor biology, and clinical investigations of cancer treatment that include radiation therapy.
		• The Journal of Pediatrics
		This journal's content serves as a resource for pediatricians who manage health and diagnose and treat disorders in infants, children, and

		adolescents.
		• Pediatrics This journal offers clinical observations, nutrition, surgery, dentistry, public health, child health services, human genetics, basic sciences, psychology, psychiatry, education, sociology, and nursing.

Impact factor of Journal	The impact factor for each journal is: • Personality and Social Psychology - 5.076 • American Heart Journal - 4.651 • Cancer Epidemiology - 4.123 • Biomarkers	The highest impact factor for the journals within this search is: 5 and the lowest is 1. Out of eight publications the majority are 4.

	• Clinical Journal of the American Society of Nephrology - 4.361	
	• Ethnicity and Disease - 1.030	
	• International Journal of Radiation Oncology Biology Physics -4.105	
	• The Journal of Pediatrics - 4.115	
	• Pediatrics - 5.391	
Publication year	The data was taken from 2010 onward.	The data retrieved: 2010: n= 78/ 38% 2011:n= 115/56%

		2012: n= 12/6%
"Race"/"Ethnicity" in Title/Abstract	Race and Ethnicity in title: Race and Ethnicity in abstract: Both:	 Race and Ethnicity in title - 22% Race and Ethnicity in abstract - 59% Both - 37%
Focus of the publications by year and area	The following subjects were mentioned as the specific focus of publications from the date 2010 onward: Epidemiology/ Health Disparities/ Treatment Health Economics	 Epidemiology: 17% Health Disparities: 44% Treatment: 30% Health Economics:9%

Basis for assigning the population/ Why this specific population?	From 2010 and onward: 38% of the publications did not mention why they referred to the specific population or how the label emerged, 62% of the populations mentioned that they were using a specific group because of comparison to another group, or prevalence of the disease. No publication mentioned why they were not using other groups	No mention: 38% Mention: 62% Reason for not using other populations: 0%
Data Source	In 205 publications the data source is. Primary - 56% Secondary - 28%	Primary Source is defined clinical trial recruitment, Secondary Sources are hospital records, census and prior research databases. Self reporting

	Self Reported - 16%	is based on categories that have been laid out by the researchers and researcher participants chose.
Publication by organ system	Publications were analyzed by the following: Musculoskeletal Neurological Mental Health Metabolic Health Economics Gastrointestinal Infectious Disease Cardiovascular Respitory	The following are the results: Musculoskeletal - 2.9% Neurological - 8.2% Mental Health - 2.9% Metabolic - 17.9% Health Economics - 9.1% Gastrointestinal - 2.4% Infectious Disease - 9.7% Cardiovascular - 14% Respitory - 8.7%

	Skin	Skin - 0.9%
	Blood Disorders	Blood Disorders - 2.4%
	Urinary and Renal	Urinary and Renal - 4.8%
	Reproductive	Reproductive - 3.9%
	Pharmacology	Pharmacology - 1.4%
Are other races accounted for?	No publication in this study states why other races are not used	
Is race defined?	Definition of Race – In all 205 papers there has been no definition of race.	In addition there has been no information about why other races were omitted from studies. In 100% of the publications race or ethnicity are mentioned in the title or abstract and none of them define the terms.
What are the races	There were 22 different	Specific race or ethnicity

or ethnicities mentioned?	races or ethnicities referred to between within papers published between 2010 - 2012 in this data set.	by percentage.
		Hispanic - 32%
		Non- Hispanic - 5.3%
		Caucasians - 10.6%
		African Americans - 29%
		White - 51%
		Non-white - 0.9%
		South Asian - 1.9%
		Other - 11.6%
		Black - 38%
		American Indian - 2.9%
		Asian - 28%
		Pacific Islanders - 1.9%

		European - 4.8%
		Latino - 2.9%
		Mexican - 0.4%
		Eskimo - 0.4%
		Alaska Native - 1.4%
		Native - 3.4%
		Chinese - 5.8%
		Filipino - 0.5%
		Korean - 0.5%
Association with medical outcome?	66% of the publications make an associate a medical out come with race.	Two out of three publications associate a medical outcome with race, while never defining race.

Analysis of the results

This search returned many different journals. As a result the journals that appeared more than once were extrapolated. This was calculated based on the total number of papers returned (205) vs. the total numbers of journals (189). There were 9 journals that appeared more than once in this search. The subject matter within these journals entailed: psychology, cancer, biomarkers, kidney disease and pediatrics. The journals that appeared more than twice within this group were *Cancer* and *Ethnicity and Disease*.

Impact Factor: The highest impact factor within the most common journals of this study was 5 and the lowest was 1. Of the nine journals extracted, 80% of them had an impact factor between 4 and 5. The journal that appeared most within the 205 publications was *Ethnicity and Disease*. This journal provides information on Epidemiology, genetic, health services and biology. It also has a very low impact factor at 1. This may be a result of the search criteria using clinical trials exclusively. Journals that are devoted specifically to clinical trials have higher impact factors.

Publication year: This research analyzes publications from the year 2010 onward. The percentages of publications from the years examined were: 2010- 78/205 (38%), 2011- 115/205 (56%) and 2012- 12/205 (6%). It is important to keep in mind that the search included publications from 2010 to Jan 06, 2012 and that a comparison of the number of publications per year has thus little meaning in such a short time period. However, it should be noted that over half of

the publications are from 2011. This increase could be a result of the impact of the Human Genome project or the emergence of personalized medicine but a longer temporal examination would have to be undertaken to ascertain this.

Is Race or Ethnicity in the title or abstract of the publication? This data set reveals that over 50% of the publications refer to the terms 'race' or 'ethnicity' in both their title and abstract.

Publication Focus: The publications were divided into four categories based on their focus. The categories are well-accepted groupings of the types of health research generally examined in clinical trials. The categories are as follows: Epidemiology, Health Disparities, Treatment and Health Economics. Papers were defined as Epidemiology if their main focus was how common a disease occurs within in one population versus another. Health Disparities focus was defined as papers focused on access and provision of healthcare service. Treatment focused papers examined drug effects in populations. Lastly; Health Economics papers were defined as those showing the economic impact of any and all of the above categories.

Accounting regarding population labels: None of the 205 publications examined, justified the use of a labeled population or explained reason why other populations (racial groups) were not discussed or included. Based on this information, two categories emerged from the data: 1) Authors that did not mention the basis for assigning a label; and 2) authors that at the very minimum explained why the choice of a particular group was useful in conjunction with the

study. In 205 publications, 38% did not mention why they referred to the specific population or how the label of the population emerged. In contrast 62% of the publications mentioned that they were using a specific group because they were going to compare it to another or wanted to study the prevalence of disease, but these publications never defined how they arrived at the definition of the population's label. However, no publication mentioned why other populations were not used. For example, a publication called the "Racial Influence on the polycystic ovary syndrome: a black and white case control study" stated that its clinical trial would be based on differences between White and African American populations in terms of pharmacogenomics (Ladson, 2011) but never bother to state what evidence the researcher had arrived at making the specific comparison. This lack of information may reflect convenience for the author instead of legitimate science or theory.

Data Sources: By discussing Data Sources as a category for analysis, I wish to determine how or if race or ethnicity is defined within publications. Understanding the origin of the source may help explain how the data was measured and illustrate the lack of consistency in terms of how race data is collected. The data sources that each publication used (if stated) were categorized as Primary, Secondary and Self-reported. "Primary Source" refers to studies that recruited original patients and were able to record race data in person. In this study 115/205 (56%) of publications examined mentioned that data from subjects was taken in clinical trial recruitment, which requires face to face contact with an investigator. "Secondary sources" refers to studies that utilized hospital records,

census records or prior research databases. In this study, 57/205 (28%) reported using secondary sources to compile information about subjects. The last category "Self-reporting" meant that if race or ethnicity was defined it came from a choice or description provided by the subject themselves.

The majority 172/205 (84%) of the publications do not discuss how they defined race. They only state that they engaged in clinical trial recruiting or that they used a secondary source. In 33/205 (16%) of the publications they say that race was defined by the individual, however the individual had to choose from categories that were imposed by the investigator. In none of the cases of self-report was it discussed how the choices were generated or if they were validated. Using a secondary source is only acceptable if the method of defining race in the primary data is recorded, however in this sample of papers the methodology of recording race is never mentioned. Inappropriate and inconsistent methodology may add to inaccurate information about individuals and groups being recorded and lead to specious conclusions and problematic interpretations.

Publication by Organ System: The next section discusses publication by organ system. Table 1 shows the categories in detail. Two of the highest categories within this data set were Metabolic (17.9%, n=205) and Cardiovascular (14%, n=205). Examples of Metabolic disorders are Obesity and Diabetes. Diabetes and Obesity are two disorders in which higher incidence and prevalence have frequently been associated with certain racial and ethnic groups (however poorly the groups are defined). The other organ system that is heavily represented

within the publications is Cardiovascular, which is defined through hypertension, high blood pressure and heart disease/attack. Differences in Cardiovascular Diseases are also connected to racial and ethnic groups as exampled through the emergence of the drug BiDil that has been developed specifically for African Americans. It is interesting to note that these diseases are most often associated with race (even though it is not defined often) and they have the highest representation within this search.

Is race used as an independent variable?: Looking at how the terms race and ethnicity were utilized as variables, 100% of the papers used race or ethnicity as an independent variable (covariate). This reflects that unless the study were specifically looking at racial identification it is unlikely that race would be used as a dependent variable.

Is Race or ethnicity defined and is it associated with a medical outcome?: The terms "race" and/or "ethnicity" were not defined in any of the 205 publications examined. This is especially problematic since as 135/205 (66%) of the publications examined race or ethnicity is associated with a medical outcome.

What Races are represented?: There were twenty-two representations of races or ethnicities in these publications. The most common representations are: Hispanics (32%, n=205), African Americans (29%, n=205) and Black (38%, n=205). Table 1 gives a more detailed account. It is interesting to note the inconsistency of these references regarding the terms Black and African American. As a result of the lack definition within these publications, certain

questions may come to mind such as: are the authors talking about two different populations? Are black people and African American different in terms of genetics? What about black Hispanics? In this study none of the papers examined ever defines race, or discusses what method they use to generate categories and in some papers races or ethnicities that are not mentioned initially were brought in to the publications later and are not accounted for.

Limitations

There are some limitations in this study to be considered. This study only used one database (Pub med). The search criteria/limits utilized could have been too broad or too specific. Future research should utilize optimum search strategies to ensure representative samples for similar examinations with multiple reviewers. Lastly, as a result of the relatively recent publication of the guidelines it may take some time for the impact of guidelines to manifest.

Chapter 5: Discussion

The goal of this study was to examine whether the recommendations set out by a multi-disciplinary team in 2008 had been applied by a set of recent publications. Such a study is not without relevance or potential direct applications. Indeed, my own interest in the topic of the representation of race and ethnicity in biomedical research emerges from the potential danger that could result from using undefined population labels within medical research. A summary of the potential consequences which heightened my interest are: hindering study replication and progress, harm to patients as a result of creating health disparities and leaving terms to be interpreted by various individuals (Race, Ethnicity ad Genetics Working Group, 2005). There is overwhelming evidence according to which:

> Investigation that fail to recognize and acknowledge the full range of mechanisms through which designations of race and ethnicity, and ancestry can correlate with personal traits and health outcomes threaten to reinforce widely held stereotypes. Yet genetics research also has the potential, by delineating the complex origins of traits and the close biological affinities between human groups, to help dispel these stereotypes. (p.519)

The data presented here suggests that there is a lack of accountability over all with regard to this subject. More specifically, in terms of defining the population, analyzed papers do not discuss why other populations were not chosen and accounting for and do not mention other races or ethnicities. Scientists therefore

need to open up to some recommendations and guidelines (Soo-Jin Lee, et al 2008) that need to be followed when using race/ethnicity within biomedical publications.

There is no scientific basis for any claim that the pattern of human genetic variation supports hierarchically organized categories of race and ethnicity*.*

This statement is based on the historic evidence that the concept of race has been intentionally interpreted to create human inequities and support racist ideologies. In the literature review these discriminatory practices were illustrated by the examples of Blumenbach and Linnaeus. The Race, Ethnicity and Genetics Working Group (2005) offered further examples that illustrate the development of the ideology of race as a social interpretation based on superficial and arbitrary physical variation. The group states:

> As Europeans encountered people from different parts of the world, they speculated about the physical, social and cultural differences between human groups. The rise of the African slave trade, which gradually displaced an earlier trade in slaves from throughout the world created a further incentive to categorize human groups to justify the barbarous treatment of African slaves. (p.522)

Racial categorizations/classifications were utilized as a tool to control slaves. Still today they are manipulated to create false differences to reinforce racism.

Margaret Cho states that "Scientists and Clinicians do not intend to imply hierarchy when they use racial classifications, but it is naive to think that hierarchy can be surgically removed from the concept of race. Hierarchy was an integral part of the concept as originally defined" (2006, p.2, Cho). Therefore, researchers need to be accountable in their use of racial and ethnic groupings within biomedical research publications, and also be aware of the consequences that using the terms inaccurately may have.

The consequence of the improper use of these categories within biomedical research is undeniably a human rights issue. Sandra Soo-Jin-Lee (2008) and her colleagues discuss the inalienable rights of human beings to illustrate the conflict with historical practices of racial classification. They write:

The equality of rights of all human beings is an unquestionable, moral claim that   cannot be challenged by descriptive, scientific findings. As a normative   commitment, equality is fundamental to our conception of human rights, and is not open to debate. Classification by racial and ethnic categories has, at   particular moments in history, been used to further racist ideology. In view of   concerns that linking of emerging genetic data and race/ethnicity categories may   promote racist ideologies, we emphasize that there is no scientific basis for any   claim that the pattern of human genetic variation supports hierarchically ranked   categories of race or ethnicity. Furthermore, we abhor any use of genetic data to   reinforce the idea of between-group difference in order to benefit one group to   the detriment of another. (p.404)

This recommendation calls for the acknowledgement of the way poor scientific practices and misclassification may impact populations. Researchers need to be educated about past wrongs and make reparations by coming to an agreement about not being part once again of such a misuse of the scientific method.

The data presented here from 205 publications that use the terms race and/or ethnicity in their title or abstract shows that none of them define the groupings they use and that, nevertheless, 2 out of 3 papers associate a medical outcome based on these groupings. This illustrates a lack of understanding of the research methodology. This misstep could lead to the racialization of a disease, where the disease becomes only identifiable by a specific population group. Additionally, this may create unintended secondary outcomes such as discrimination and stigmatization within institutions beyond medicine. It would seem that this practice was repeated as recently as September 2012. Dr. Tamara Hannon led a study that supports difference between white and black teenagers in terms of blood pressure based on racial differences. The study states that

> It's known that blood pressure increases with increasing levels of adiposity. It is also known that as children grow, their blood pressure also increases, and for that reason blood pressure in children is assessed by age and by size, which is different from [adult assessment]," lead investigator Dr Tamara Hannon (Indiana University School of Medicine, Indianapolis) told heartwire. "What's not known is that for children of

different races, age-matched kids at similar levels of obesity, black kids

tend to have higher blood pressures at lower body-mass indices when you

compare them with others. So there appears to be a race difference that

we think is physiologic (taken from www.theheart.org)

At the very least, these types of studies need to provide more information about

how researchers defined their populations groups or why they used the groups

the way they do. It is not insignificant that high blood pressure becomes

associated with black people; because this gives credence to the idea that we

can make diagnosis or set treatment pathways based on visual representation.

The education on terms of cultural competence for researchers is essential to put

a stop to the racialization of disease.

Separate genetic/biological from cultural/environmental factors

The human genome project has expressly stated that "Human beings are

essentially the same. Human genetic sequences are 99.9% identical: of the 0.1%

of the human genome that varies from person to person only 3% to 10% of that

variation is associated with geographic ancestry (Revisiting Race in a Genomic

Age, Koenig et al, intro p.1). With the emergence of the human genome project

there has been renewed interest and haste to determine differences between

populations. However, in most cases, the greater differences are seen within

groups rather than between groups. Soo Jin-Lee (2008) et al state that:

"Research in human genetics has highlighted that there is more genetic variation

within than between human groups, where those groups are defined in terms of

linguistic, geographic, and cultural boundaries" (p.404.2). Soo Jin- Lee (2008) goes on to point out that differences between individuals can be measured in terms of other variables such as geography or socioeconomic status which are more reliable than using race or ethnicity. They (2008) state that,

Patterns of variation, however, are far from random. We recognize that human population history, including major migrations from one continent to another as well as more short-range movements, has led to correlation between genetic variation and geographic distribution. This finding is particularly true of indigenous peoples; populations characterized by a high degree of interaction with neighboring groups adhere less to these patterns (p.404.2).

Grouping people based on geography and differences within groups as opposed to between them may make the process of population grouping more valid and consistent, because differences are be based on genetic information that is connected to geographic movements and interaction with similar groups. Population groups differences are then based on more concrete historical facts and are less influenced by social construction.

Avoiding reliance on one type of information for the descriptors of race/ethnicity

The recommendations from the working group state that there are a number of factors that contribute to an individual's overall ancestry. Geographic ancestry

should be incorporated into a full picture of an individual's genetics. Soo-Jin Lee et al (2008) argue that: "An individual's 'geographic ancestry' or 'bio geographical ancestry' can be taken to mean the sum of all the geographic locations inhabited by an individual's biological ancestors. Often, however, genetic data reflect just a small subset of these ancestors. For example, knowing a person's Y-chromosomal lineage is at best a partial view of an individual's ancestry" (p.404-2).

Using race as a proxy for genetics is problematic because it cannot be relied upon to illustrate a total picture of ancestry and even less when it is used without explanation about what process the author went through to establish the categories or population labels. Using race and ethnicity to identify differences between individuals' health status/outcomes infers that other factors such as geography or socioeconomic status do not play a role in these outcomes. For this reason disparities between socially constructed groups should be sought through socially constructed solutions (not through the search for a genetic explanation). Jin-Lee et al (2008) comment on this. They state that "We see value in recognizing both bio geographical and cultural ancestry that underlies an individual's and group's identity, particularly in the context of addressing health disparities" (p. 404-2).

In the papers examined in this study, 22 different "races" or "ethnicities" were mentioned with no definition of the groups or discussion of how the groupings related to the disease process or therapeutic outcome. None of the publications

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attempted to control for education, socio economic status, housing status as co-variants or biases in their groupings. The goal of biomedical research is to develop hypothesis and carry out experiments to test them in such a way that others can replicate them or that the data can be applied to other populations or individuals. As a result of the inconsistency of the use of groupings by "race" and "ethnicity" any attempt at replicating studies would seem futile.

Researchers need to be aware of the social constructions and change overtime

It is imperative that researchers become aware and accountable for the fact that the definitions of racial or ethnic groups are borne out of systems based on hierarchies that reinforce the dominant classes. This has been widely recorded and represented in historical literature. Barbara Koenig (Marks, 2008) asserts that the original conceptualization of race:

> "arose at the conjunction of two historical moments: the scientific revolution (privileging the study of nature and particularly its classification) and the age of colonialism (establishing hegemonic economic relations with the unfamiliar and commonly fluid, political and social entities." (p.21)

To use these obviously fluid conceptualizations of race or ethnicity as a basis for grouping humans seems fatally flawed. It must be established that grouping and identifying individuals is a complex process.

Genetic data cannot reveal an individual's full geographic ancestry

precisely, although emerging research has been used to identify

geographic ancestry at the continental and sub continental levels. Genetic

clusters, however, are far from being equivalent to socio-political racial or

ethnic categories. Diverse populations identified as 'Hispanic', for

example, are heterogeneous and have distinct ancestries and social

histories. We recognize that social experiences and conditions inform

racial identity, making such identity a poor proxy for genetic ancestry.

(Soo-Jin Lee, 2005 p.404-2).

Soo-Jin lee discusses the example of the term "Hispanic" to illustrate the

heterogeneous nature of this racial group. When used to describe populations or

individuals, researchers refer to the term "Hispanic" in a way that inadvertently

reduces people associated to this group to having entirely homogeneous

qualities. Our own research has demonstrated the same lacunae when it comes

to the term Black and African American. Within the 205 publications examined

here the three population terms that appeared most commonly were: "Hispanic"

32%, "African American" 29% and "Black" 38%. Beyond the previously described

lack of definitions of groups there is an inconsistency regarding the use of the

terms Black and African American. The concept of African American is a highly

politicized one. This term emerged because African Americans believed that the

term "black" did not encapsulate the diversity of their culture. When biomedical

research does not define their population terms, in this case "black" and "African

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American" can mean one thing to an individual or community and another to an institution (healthcare in this case).

Discussion or Outcomes within biomedical research should not link genetic explanations with arbitrary socially constructed groupings

Authors in biomedical research should exercise caution in when using genetic explanations to equate for differences between groups. For example, the potential of excelling academically or athletically or a tendency towards violence is used to discriminate people in relation to education and crime statistics. Associating these characteristics with certain groups and not with others without any evidence reinforces stereotypes. This tendency to extrapolate social conduct from some supposed genetically determined traits is clearly illustrated by theories on the racial ordering of intelligence. "Despite the weak scientific basis for such ordering, the consistent return to the rhetoric of racial hierarchies of IQ reflects the powerful role that science has historically played in promoting racist ideologies" (Soon-Jin Lee 2008, p.404-2)

Author Troy Duster discussed the impact of the improper use race and ethnicity in Biomedical Research. While, according to him, social forces that conceptualized race in the 18th and 19th century are fairly obvious, the influence that contemporary social forces exert is harder to recognize. He predicted that:

> "the next decade will witness an outburst of behavioural genetics research, buttressed by the molecular re inscription of race tying crime to

biological processes and then correlating those biological processes to race" (Wolf, 2006, p.484).

This is a warning to researchers using race or ethnicity in their publications: inaccurate methods could serve as a tool for discrimination in the future. As a result, researchers should be thinking about the impact of their research not just medically but about what it may mean socially. There are many institutions in society that are influenced by scientific outcomes and classification systems. For instance, researchers need to be concerned about how their methodologies will be interpreted by the mass media. Offering come advices, Soo- Jin Lee (2005) et al write that:

> Current evidence suggests that for most complex behavioural traits, contribution of any one gene to normal variation is small and these traits may be more fully explained by variation in environmental factors. We therefore caution against making the naive leap to a genetic explanation for group differences in a complex behavioural trait, where environmental and social factors clearly can and do play major roles. (p. 404-2)

The common warnings in these recommendations are that human beings are complex and the representation of them in research may influence the definitions and assumptions about the groups more that investigating them as they report.

Researchers who use racial/ethnic categories should be accountable for the use and assignment into categories

In this content analysis there are three categories based on the recommendation/ guidelines that discuss accountability in terms of population labels. They are: 1) Basis for Assigning population; 2) Why was this population chosen; 3) Are other races accounted for. This by no means equates accountability for or assignment into categories. Over 30% of publications do not mention any rationale for why they used a certain population. Even more surprising, when a publication did state why it was using a population, it was never clarified why other populations were not utilized. Accountability should entail discussing rationales for use, explanations for labels and how other populations fit into the framework. As author Robert M. Sade (2007) states, a "fundamental scientific problem with the idea of doing research stratified by race is the claim that the very concept of race is biologically meaningless. Race is a social construct not a scientific classification. Therefore, there should be a requirement to furnish a scientifically valid definition of the population under study" (2007, p.2). Based on the results of this investigation and Dr. Sade's assertion one could come to the conclusion that often researchers believe that the methodology surrounding race does not have to stand up to the same scrutiny as other variables utilized within investigations.

Searching for solutions, some researchers seem to feel that self-reporting is a viable option to deal with inclusion/exclusion into racial groups. Of the 205 publications examined, self-reporting occurred in 16% of them. In the self-reporting studies participants were asked to choose from options/categories chosen by the primary researchers or secondary sources. The participants are forced to choose based on the category they most identified with. If participants

identify with none of the categories offered, they are then forced to choose a category referred to as "other" which was never defined within my investigation. The "other" category is used in over 10% of the publications examined. The concept of self-reporting then is misleading as it infers that the participant has more power to identify themselves than they actually do and it erroneously suggests more accuracy in reporting race or ethnicity. An example of the issues raised by self-reporting can be found by examining census surveys. The census is relevant as an example in this discussion because often biomedical research uses secondary sources such as census or hospital records. The census is a data collection tool that has the goal of systematically acquiring and recording information about the members of a given population. In the article "Beyond Black and White Metropolitan residential segregation in multi-ethnic America", author John Iceland explores racial segregation in America. Iceland discusses the Office of Management and Budget's (OMB) census framework in the Data and Methods section of his article. He states that,

> In 1977 the office of Management and budget (OMB) issued its Statistical Policy Directive 15, which provided the framework for the federal data collection on race and ethnicity to federal agencies, including the Census Bureau for the 1980 decennial census. The OMB directed agencies to focus on data collection for the four racial groups – White, Negro or Black, American Indian, Eskimo, or Aleut; and Asian or Pacific Islander and one ethnicity – Hispanic, Latino or Spanish origin. The questions on the 1980 and 1990 censuses asked individuals to self-identify with one of these four

racial groups and whether they were Hispanic or not. (Iceland, 2004

p.253)

It is interesting to note that the directive to use specific race categories from the OMB assumes that the OMB has sufficient knowledge regarding the race/ethnicity of the people in America. Furthermore, it infers that the OMB has the ability to classify and prioritize certain groups within the census. This deters from the goal of the census, which is to gain an understanding of the demographics of individuals defined by residence. As a result of this inherently flawed model of collecting race and ethnicity data, not only are any direct findings regarding race highly dubious; the inaccuracies will be repeated, complicated and amplified by other researchers using the census data in secondary investigations. Above all, the priorities for grouping individuals for research purposes should be grounded in accountability for the use of the label in the first place. The definition of a label and why it is necessary are issues that should be addressed at a bare minimum.

Data on group characteristics should not be ascribed to individuals

This next recommendation deals with the concept of Generalizability. This concept within biomedical research pertains to the degree to which outcomes found in a certain population (sub-population) are thought to be applicable to the population at large and/or other populations. Soo-Jin Lee (2005) discuss that

Although a broad range of associations between genetic markers and human traits - including diseases - is emerging, any accompanying correspondence with race or ethnicity is statistical. Although certain relatively rare genetic diseases, such as Tay-Sachs, are found in higher frequencies in some human populations, the result of population bottlenecks or environmental pressure, these diseases are also found in other populations. (p. 404-2).

Additionally, the Race, Ethnicity and Ancestral Working Group (2005) point out that

genetic research that involves making population comparisons can inaccurately stereotype racial and ethnic groups, both by implying that such groups are clearly delineated and by associating health outcomes with all individuals in those groups rather than with only those individuals who exhibit the outcome. (p. 526).

Generalization of data regarding the health needs or potential of disease in individuals or groups is based on assumptions and not valid medical data. Soo-Jin Lee et al (2005) discussed that this behaviour leads to essentialism. They argue that

Overemphasizing the genetic contribution to complex human disease or behavioural traits can promote not only racism, but also a naive genetic essentialism - the notion that genes determine health status or behaviour.

Such essentialism is particularly dangerous in clinical translation, where a focus should be maintained on the individual rather than the group. (p. 526)

Even without proper definition of populations, research outcomes and/or results can influence health policy and service provision at a community level. As a result this could leave healthcare workers to interpret the definition of populations within the publications and determine how they relate to their own patients.

Acknowledge all stakeholders in the outcomes

Biomedical researchers should consider stakeholders at all levels. This includes public health in regards to research that impacts their policy, at a clinic in terms of service provision by staff and also in terms of reporting their work institution like the media. Soo- Jin - Lee (2005) et al discusses how the interpretation of research at a local level often warps the outcomes. They assert that:

> Scientific data are often quickly politicized and incorporated into specific policy agendas without extensive explanation of the scientific research and its details. Often lost in the announcement of scientific findings is discussion of the limitations of the research. Our hope is that scientific data about human genetic variation might undermine spurious popular beliefs about the existence of biologically distinct human races and beliefs that support racist ideologies (p. 404-3).

It has become clear that the outcomes from biomedical research are not only accepted at face value (albeit flawed) but then interpreted to suit specific agendas. A major concern that arises is when research findings are interpreted inaccurately and announced to an audience. At this point, the possibility of correcting or reinterpreting misinformation is narrow. This could be remedied by including instructions on how to interpret the data within a research publication. The publication should clearly state what the findings mean, but more importantly outline the limits of the conclusions and inferences that can be made from the data. This would greatly enhance the translation of research findings to the public. In their paper "Race and ancestry in biomedical research: exploring the challenges, Caulfield et al (2009) discuss media representations as a very important challenge. They state that:

> There are certainly examples of news reports that include a thorough examination of the challenges associated with using race in biomedical research, but media representations often simplify the science and use of concepts such as race without explaining how the social category relates to the research outcome. (p.8.5)

The media plays a large role in disseminating health information to the public. Because of this, researchers must acknowledge and address issues that may arise when they report their findings, such as: interpretation, limited time or space within a news cast or newspaper and the tendency of media to substitute accuracy with representations that appeal to target demographics.

Ensure a consistent message to laypeople (knowledge transfer)

As discussed throughout this investigation the conceptualization of racial and ethnic groups are often interpreted by many people and institutions in society differently. This is because the definitions of these terms are framed by personal experience, politics, social events and prevailing power structures. Margaret Cho (2006) writes about the controversy surrounding the use and/or definition of these terms/groups:

> There are deep divides over the use of racial and ethnic categories in biomedical research and its application in both medical and non-medical contexts. On one side of a roughly described dividing line are practitioners who need to use every piece of information at their disposal to solve pressing, real-world problems in real time, such as making clinical diagnosis or identifying perpetrators of crime. On the other side are scientists and policy makers committed to meeting a scientific and social need for accuracy and thus trying to avoid miscategorization. (p. 497).

Understanding the great impact that representations of (racial) groups of people can have, how can consistent and valid messages be transmitted to the public? Any plan to provide consistent messages via the dissemination of research results should include education about the process of scientific inquiry in terms of its goals and objectives. This is especially true with regard to biomedical research where the way in which research outcomes are interpreted and applied impacts individual health, social policy and health economics. A good place to

start regarding consistency in terms of this information would be to ensure

mandatory culture historical education for researchers using these terms and

additionally educating the public or allied agencies about how to interpret

research. Soo-Jin Lee et al (2008) discusses the importance of education points

out that funding education is critical to building that consistent and valid

message. They write:

> Education is critical in providing both the foundation - basic scientific
>
> literacy - and the historical context through which to understand human
>
> genetic variation as data from studies are released. We believe that
>
> expanded public education at all levels will enhance understanding of
>
> human genetic variation and interpretation of any correspondence with
>
> categories of race and ethnicity. We recommend that the teaching of
>
> genetics include what we recognize today as past uses of science in
>
> promoting racism. Finally, we encourage increased funding for the
>
> development of such teaching materials and educational programs that
>
> focus on the social impact of scientific discoveries as well as the impact of
>
> social values and beliefs on the conduct of science (2005, p.404-2)

The social implications of the message of either an investigation or its outcomes

seem to be as important as the research results themselves. If there is pressure

for researchers to be accountable, they will be more likely to incorporate this

thinking into their investigational plans. However, this may well require training

researchers and thus would take some time to work its way into the general

practice. Alternatively, if funding was contingent on providing a clear messaging plan that included making results accessible to laypeople, the research community would have little choice but to conform. Unfortunately, unless educating laypeople, media, and other health care providers that are impacted by these medical outcomes is attached to a financial or publishing incentive the situation will likely remain the same. However, delivering a consistent message to laypeople is essential and education about the scientific process and the history and current practices regarding race classification should be incorporated into that message.

Challenges outlined by Researchers

The original question of this research query was to establish the degree to which recommendations for using race and ethnicity within biomedical research have been applied to biomedical articles published from 2010 to Jan 06, 2012. This discussion has attempted to contextualize the results from the investigation within an explanation for each recommendation. This investigation reveals a lack of accountability by researchers in using the terms race and ethnicity within their publications. More specifically, in the 205 publications examined: The populations that were represented within publications were never defined and other variables such as environment, socioeconomic status, lifestyle choices or geography that could have been used to identify difference between groups (co-variable) were not considered or at least not discussed. The population labels that are used for groups are inconsistent and lack definition, pattern or

agreement between publications. Finally there is no rational offered within any publication for the inclusion or exclusion of populations. These results reflect that the recommendation made by the Soo Jin Lee et al (2008) have been ignored or need time to be integrated into practice.

While the recommendations seem clear it must be acknowledged they are cannot be implemented without challenges. Susan M.Wolf outlines the challenges as they impact researchers, funders, journal editors, research participants and the community at large. The following is a summary of Wolf's review of the sociological, legal and medical aspects of using the terms race and ethnicity in biomedical research. Gaps in healthcare services and outcomes between groups are referred to as healthcare disparities. It is important to carry out research to identify the gaps and to which groups they apply. Researchers and academics believe that studying the perception of race in terms of healthcare is essential. Researchers are not blind to the misuse of the terms race and ethnicity in healthcare, but find it essential in terms of examining inequities in the healthcare system. Dr. Margaret Cho asserts that there in danger in the use of any racial grouping because there has been no agreement on how to use the terms or groups. In her paper "Racial and Ethnic Categories in Biomedical Research: There is no Baby in the Bathwater," Cho states that "The problem with using race or ethnicity as a measure is that it is really used as a proxy for an as-yet undetermined mix of genetic, biological and environmental factors. While this may be perceived as good enough for use in daily clinical practice, it reinforces inaccurate perceptions about "racial" and "ethnic' groups (p.1). Using race as a

proxy for genetics and many other factors is inaccurate and often reinforces

historical medical racism used on some groups. Furthermore, that because of the

fluidity of race and ethnicity that "There are categories far more relevant to

research and clinical care such as categories based on environmental factors or

more precise to ensure distinctions in ancestral origins" (Wolf, 2006, p484)

Cho believes that the only acceptable reason for using race categories is when

"studying whether the perceived race of patients correlates with health

disparities" (Wolf, 2006, p.484). There is agreement amongst some researchers

that outside of investigations regarding health disparities, the terms race and

ethnicity have no scientific or clinical relevance. Dr. Raj Bhopal agrees with Dr.

Cho in terms of the utilization of race and ethnicity in areas of epidemiology and

public health. Although he advocates for their use in these two areas of research

he states that "the concepts of race and ethnicity have long been abused" (Wolf,

2006, p.484). In terms of health disparities he asserts that "Epidemiological and

public health research can identify health problems facing minority populations

and suggest interventions. Abandoning racial and ethnic classifications would a

setback to public health efforts" (Wolf, 2006, p.484). An interesting approach to

the study of the use of race and ethnicity in biomedical research is to examine

how it impacts individuals at a community level. Dr. Morris Foster analyzed

health practices using qualitative methods in African American and Native

communities. Dr. Morris asserts that while there is some evidence "that racial or

ethnic identity categories can affect how a community member interacts with the

health care system beyond the community" (Wolf, 2006, p.484) his findings

indicate that the use of the race or ethnicity did not play a large role in actual health practice within the community. Morris concludes that "racial and ethnic categories are not fundamental social or biological units of analysis" (Wolf, 2006, p.484). Furthermore, he states that "the dominance of racial and ethnic categorization in biomedical research is directly linked to qualitative approaches that depend on aggregating large numbers of individuals into a small number of analytic categories to attain significance" (Wolf, 2006, p.484). The similarity of qualitative research methods and biomedical research that utilize race categories is that both use artificially created categories.

Biomedical Journals also have taken on the challenge on reexamining the use of race and ethnicity in the articles that they publish. Dr. Margaret Winker, editor of the *Journal of American Medical Association*, makes the observation that "researchers routinely report their results by race or ethnicity, regardless of the relevance of these categories and their explanatory value" (Wolf, 2006, p.485). Winker believes in the use of race and ethnicity within biomedical research when used properly, however she asserts that "researchers should explicitly address how they have assessed and analyzed race and ethnicity" (p.485). Winker is one of many journal editors that have been trying to shift the inaccurate practices amongst researchers.

The emergence of personalized medicine through the emergence of BiDil has brought much debate about biomedical researches inability to define its terms consistently. Lawyers and professors Erik Lillquist and Charles Sullivan have not

found any rules that explicitly regulate the use of race and ethnicity within biomedical research. They also found that race based medicine is discriminatory because it defines people according to a concept that is indefinable. Their particular focus is regarding clinical trials, specifically BiDil. As discussed previously, BiDil is a heart drug specifically developed for African Americans with heart disease. Lillquist and Sullivan, find this particularly problematic because: "Race- based clinical trials may lead to denial of potentially life-saving treatment to individuals on the basis of race"(Wolf, 2006, p.485). Their contention is that there should be more pressure on researcher to use genetics instead of race, especially in the case of race based medicine. In their article "Race and ancestry in biomedical research: exploring the challenges," Caulfield et al also discuss the use of race and ethnicity in biomedical research as part of an interdisciplinary workshop examining challenges affecting: policies, commercial and regulatory consideration, the media and the ambiguous nature of the terms "race" and "ancestry". They assert that decisions to utilize race or ethnicity in biomedical publications are often framed by commercial or regulatory responsibilities and "that reward or require the use of racial categories in particular ways that may not serve constructive purposes" (Caulfield, 2009 p.8.3). Often regulatory imperatives, will direct the source and variety of the data collected. This is problematic because a census for example looks at only social categories and demographics with virtually no way to link to health status or access to care, never mind genetic identity.

Another issue concerns the vernacular used. Caulfield et al. remark that "market

forces will push toward terminology that captures a larger population and have

more immediate public recognition. Narrowly defined terms such as ancestry are

likely to have less public recognition than race" (p.8.5). Therefore, the precision

that is usually exercised within biomedical research is overshadowed by market

and regulatory responsibilities. From this perspective, media is seen as a

resource in terms of health research. The representation of research within

media is often simplified to suit news reports to the extent that the report bears

little resemblance to the original research. Caulfield et al point out "Although the

relationship between media representation and public perceptions of biomedical

research is complex there is some evidence that the media can influence social

perceptions and attitudes even about race" (2009, p.8.5). The mandate of the

media outlet can also have an impact on how information about race and health

care research is received. For example, a conservative news station may report

stories about certain populations using stereotypical framework and unfounded

conclusions to reflect their ideology. Caulfield et al go on to discuss the

importance of the unification and input from all institutions and stakeholders in

terms of the meaning and use of the terms. They state that "the relevance of race

and of race categories far exceeds the arena of scientific discourse and becomes

the concern of government regulation, media accounts and language debate,

science cannot independently dictate its meaning or invent new terms to replace

it" (2009, p.8.5). This is a reason for these institutions to work together because

they all contribute to the social construction of racial identity. All of these factors

need to be considered and included "as part of an iterative process directed at clarifying the import of human genetic variation in the long term and using of using genetic insights to help eliminate rather than reinforce, disparities in health status" (p. 85).

The inclusion or exclusion criteria that biomedical research utilizes in terms of population groupings have the potential to impact institutions, individuals and populations. The challenges outlined within this discussion frame the use of these concepts as having the potential to have medical, legal, criminal and financial impacts for all. This reinforces the call for education to be involved at every level and a unified, multidisciplinary approach to using these terms within biomedical research.

Chapter 6: Conclusion

This thesis used a content analysis method to review 205 publications that used the terms "race" and/or "ethnicity" in the title or abstract. The study examined clinical trials specifically in order to elicit publications that would associate a medical outcome with race. First, the investigation offered a discussion about the conceptualization of race and ethnicity throughout history and how these racist and discriminatory practices overlap to current times. Finally, the literature review discussed the current issues that face race classification in biomedical science. The catalyst for this investigation was the potential consequences for the improper use of racial terms and groupings which not only came with risks but the potential to hinder study replication and thus slow scientific progress. It was also important to investigate the degree to which the recommendations that were developed to ensure that these terms and groupings were being incorporated and used accurately.

However, the results in this investigation suggest that despite published guidelines for the use of the terms race/ethnicity, researchers and editors are neither using nor enforcing the use of them. One may think that racism has utterly disappeared from modern scientific literature, but the powerful influence of racial categories can be seen in the publications examined. At their core, these categorizations resemble the old classifications that Blumenbach and Linnaeus used to create racial hierarchies. It is imperative that the scientific and medical community act responsibly and take a leadership role in the proper use of racial

and ethnic grouping. The ongoing utilization of race as a political tool is only emboldened by the use and misuse of racial groups by biomedical researchers. In the paper ""Race" and "ethnicity" in biomedical research: How do scientists construct and explain differences in health?" Catherine Lee (2009) states: "the history and development of the women's movement and the Civil Rights Movement have helped to politicize these categories, making them more significant for ordering political action and understandings of difference" (Lee 2009, p 1186).

Lee is reinforcing a point that has been made previously in this thesis, that categories of individuals are political and when they are reproduced within scientific research without proper definition they have the potential to be interpreted at that level. Lee (2009) goes on to state "Health officials have seen and treated these categories as static, self-evident, and easily recordable" (Lee, 2009 p, 1185). Moreover, the potential risks of misclassification of race leading to inappropriate clinical decisions seems to outweigh the benefits of many current medical associations attributed to racial or ethnic groups. As presented this leads some researchers to feel that there is no place for the concepts of race in biomedical research. Mildred Cho discussed the issue of racial categorization in biomedical research stating that there is "no clinical or scientific utility to racial and ethnic categories unless one is studying perceived race or ethnicity or self perception." (Cho, 2006 p.499) She goes on to say that "what defines these individuals and groups is not what we call "race" or "ethnicity" because there is no consistent definition of racial or ethnic categories" (Cho,2006 p.499). As

stated numerous times within this discussion, Cho is alluding to the notion that society constructs these "race" categories to fit the situation at any given time. As the appropriate definition of groups is essential to the fields of sociology and anthropology this area may represent an opportunity for cross discipline knowledge transfer. If biomedical science can improve its adherence to recommendations about the use of race and ethnicity it ultimately may become a positive tool in overcoming the social and political impacts of race and ethnicity on individuals. The main issue in the utilization of these terms is that "race" and "ethnicity" have been connected and politicized in reference to economic, social and political aspects of society. The dilemma becomes then how do we stop using them or use them in a unified way even though the definition varies depending on geography, culture and language. In his book, *Inclusion, The Politics of Difference in Medical Research*, Steven Epstein (2007) argues that ''everyday political relevance of gender and racial identification in the US only increases the likelihood that these categories will be emphasized in biomedical classification'' (Epstein 2007, p. 192). Epstein is alluding to the growing need for society to categorize and classify individuals based on increased social events. The Race, Ethnicity and Genetics Working Group discussed the social interpretation of physical variation. The group's members write that "Given our visual acuity and complex social relationships, humans presumably have always observed and speculated about the physical differences among individuals and groups" (2005, p.522).

We are socialized to note physical differences, this is illustrated in history. Our contemporary media and other institutions have continued to base our existence on physicality. For example, society identifies individuals and populations based on skin colour. Our interpretation of skin colour is not the same as in Brazil for example, where "skin colour is not closely associated with the percentage of recent African ancestry a person has, as estimated from an analysis of genetic variants differing in frequency among continent groups" (Parra et al 2003, from the Race, Ethnicity and ancestry working group, p.522). The interpretation of the connection between skin colour and ancestry is becoming less effective as our population becomes more and more visually diverse. There is an ongoing debate over how best to understand race generally. It is a complicated matter that defies easy definitions and generalizations. Yet, when race is used in biomedical publications it is assumed that there are clear and validated definitions as required by the scientific method. Caulfield et al (2009) discusses the diversity in understanding race in terms of biology and social context. They write that:

> Racial definitions can fluctuate according to social context, geographical location, historical period and personal experience. Indeed. It is not uncommon for the same individual to report their racial identity differently in different contexts and at different points in their lives [15-17]. For these and related reasons many scholars view racial identity as primarily a social construct [18-22], and one that can misdirect the categorization of participants in biomedical research. Others see racial identity as

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correlated with a mix of social and biological risk factors that should be

recognized and disentangled, even used to advantage, in an effort to

explain and address health disparities (p.2)

Clearly race and or/ ethnicity are ever changing concepts and are impacted by

socio-political events overtime. As a result of the fluid nature of these concepts

academics or social scientist believe that meaning emerges out of specific social

and historical context. Race and/or ethnicity in the social scientists mind are

mostly or entirely based on social grouping environment, language, culture and

custom. In contrast, it would seem that biomedical researchers view race mostly

as being attached to biology. Race, or more specifically skin colour, is used as a

surrogate marker for genetic similarity. This despite the clear pronouncement

from geneticists that there is more genetic variability between people of the same

"race" that of different "races". However, the data that is collected from us over

and over within society that often proves our identity or citizenship is defined by

where we come from and what our physical description is. I believe the common

discourse, though undecided, attempts to define race from both perspectives:

physical and social. Race has been conceptualized historically based on socio-

political events and those ideas or representations are so pervasive in their

power that they define our definitions currently. Understanding this, we need to

acknowledge that the discourse about race and ethnicity is complex, in that we

define individuals in a multi-faceted manner. We, in society define people in

terms of physical appearance and then incorporate characteristics or behaviours

that we have been socialized to believe to complete our perceived identity of others.

This is not to say that we do not try to fight against our stereotypes about individuals when they serve as barriers, but none the less we have been programmed through media and other institutions to frame unknown individuals in this way. Ascribing group characteristics to individuals is one of the ways that we navigate in society. Our socialization of individuals is a combination of essentialism and constructivism. Academics, researchers and more believe they agree with one theory or the other, however on a daily basis people are defined based on visual representation that is reinforced by social events. The sooner that we, in society, admit how vulnerable we are to socialization, the quicker that we can come to a agreement about what race means in terms of medicine and other institutions. Socio-political events shape and influence the definition of race and race classification within a society, as a result concepts of racism develop from power structures that are exclusionary to those who fall outside of the dominant social group. From the eighteenth century race has been used to support biologic inferiority/superiority, which is then extrapolated to support dominant beliefs regarding ability, temperament and behavior. Although the concept of race is constructed, the identity that emerges is tangible.

The sample of publications examined within this research reinforces some of the concerns that generated the guidelines for the use of race/ethnicity in biomedical publications. Biomedical researchers continue to use the terms 'race ' and

'ethnicity' and group people by these categories without defining them, yet still

continue to make associations about these groups of people and medical

outcomes. Thus, the priority going forward should be education, an agreement to

understand who the stakeholders are and to encourage research that includes

the identified groups as throughout the research process.

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