

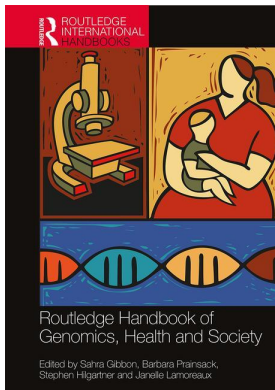
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Publisher: *Routledge*

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Handbook of Genomics, Health and Society

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Genomics in emerging and developing economies

Publication details

<https://www.routledgehandbooks.com/doi/10.4324/9781315451695-28>

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Published online on: 09 Apr 2018

How to cite :- Duana Fullwiley, Sahra Gibbon. 09 Apr 2018, *Genomics in emerging and developing economies from*: Handbook of Genomics, Health and Society Routledge

Accessed on: 28 Sep 2021

<https://www.routledgehandbooks.com/doi/10.4324/9781315451695-28>

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Genomics in emerging and developing economies

Duana Fullwiley and Sahra Gibbon

Low and middle-income countries have become a site of increasing research interest and investment with the transnational expansion and spread of genomic knowledge and technologies (Kumar 2012, Seguin et al. 2008). This reflects a dynamic terrain in which genomics is being harnessed to address a range of healthcare challenges. With initiatives such as *MalariaGEN* (Malaria Genomic Epidemiology Network 2008) this includes not only infectious diseases, but also the growing financial and social burden of common diseases as these intersect with genomic susceptibility amid larger environmental forces and economic precariousness (Fullwiley 2011, H3Africa 2013). At present genomics is increasingly situated as a pathway to global health, framed as a useful tool to understand the genetic patterning of ailments affecting all of humanity in its diversity (Bustamante et al. 2011, Popejoy and Fullerton 2016). These developments demand critical and engaged social science attention (Beaudevin and Pordie 2016, Taussig and Gibbon 2013). Central to this analysis is how countries, regions, and populations themselves are amassing ‘genomic profiles’, where the unique characteristics of their populations are now thought to be of exceptional value. The ways that peoples, tribes, races, and ‘nation-state’ groupings came to be conceived of in population genetic terms have diverse genealogies tied to how their value is perceived today in practice. These issues of genomics in developing economies link transnational research and investment to the questions of inclusion and social justice that social scientists have explored in Europe and the United States (Fullwiley 2008, Nelson 2016, Reardon 2012, Lee and Prainsack *this volume*), albeit in new ways.

Some social science literature is emerging on how notions of inclusion and population specificity are unfolding outside Euro-American contexts (Benjamin 2009, Fullwiley 2011, Gibbon 2015, Sleeboom-Faulkner 2010, Wade et al. 2014, Whitmarsh 2008). In this chapter we further these conversations by focusing on two regions of the world, Latin America and Africa, to show how diverse histories of colonialism as well as entrenched structural inequalities inform the limits and possibilities of genomic research and medicine. We present case studies of research on identifying disease biomarkers in cancer genetics and pharmacogenomic research related to warfarin dosage in Brazil and a wide range of technologies used in sickle cell programmes in Senegal, as well as the H3Africa initiative (which is currently funding major genomics studies in Benin, Botswana, Ethiopia, Mali, Nigeria, South Africa, Uganda, and Zimbabwe). In Senegal the most common technology to assess sickle cell markers in clinical care and research is

still basic electrophoresis, while several specific pharmacogenetic and population health investigations have taken place collaboratively between scientists in France and Senegal. Researchers working in varied sites under the rubric of H3 Africa employ or plan to use ‘genotyping chips used in genome-wide association studies, sequencing of all the genes in the human genome (called exome sequencing) and eventually, whole genome sequencing’ (H3 Africa 2013). In late 2016 the genome sequencing company Illumina announced the development of a special sequencing chip specifically for the project, called the ‘H3Africa Consortium Array’.¹ At stake in all of these instances is how questions of human diversity, global inclusion, equity and ethics are actively shaping how genomics is proceeding in these contexts.

Genomic medicine and research in Brazil: the historical legacy and contemporary relevance of population diversity

The notion of Brazil as a ‘racial laboratory’ has fascinated and facilitated the interests of both foreign and Brazilian scientists since the mid-nineteenth century with the themes of race and racial mixture integral to thinking about the country’s historical formation (De Souza and Santos 2014). As a result Brazil has long been constituted as both a valuable site and source of genetic data. Visits and exchanges by North American geneticists from the 1930s were central to the development of national and international fields of genetic research and medicine (Sequeiros et al. 2015). As Ricardo Santos and colleagues suggest, Brazil was constituted as a ‘significant site of cognition’ in the production of knowledge related to population genetic variation after World War II (2014). Like other areas of the ‘global south’ (Anderson 2012) Brazil was both a resource and domain of investigation regarding new methods and approaches where, as part of a broader internationalisation of science, it was constituted as an ‘idealised’ field site for inquiry into and understanding of human biological variation. While ‘miscegenation’ meaning the ‘mixing of different racial groups’ was often seen as foundational to scientific inquiry, both ‘mixture’ and ‘purity’ could be examined in relation to the so-called ‘race question’ (Santos et al. 2014); themes which also have a long history in Brazil of being linked to public health (Lima 2007). In the twenty-first century the dynamics between genomics, population variation and nationhood have continued to be generative not only in Brazil but also within the wider context of Latin America in countries such as Mexico and Columbia (Wade et al. 2014). While an emphasis on ‘tri-hybrid’ genetic ancestries (European, Indigenous, and African) has been commonly used to parse admixture across the region, the use of stable parental population categories and in some cases an emphasis on more ‘regional’ homogenised specificity, point to the diverse articulations of what Wade et al. refer to as ‘mestizo genomics’ (2014). In Brazil particular colonial and post-colonial histories of race classification and discrimination, a national and nationalising discourse of race mixture and a contemporary focus on multiculturalism in areas of health and education shape the meaning and significance of molecularised categories of population difference (Kent et al. 2014).

The fields of genomic research and medicine relating to cancer genetics and pharmacogenomics in Brazil are informed by this historical legacy and also by the recent contemporary global medical and scientific relevance attributed to human genetic variation. The work to identify cancer-susceptibility variants or develop pharmacogenetic targets and understand the various contributions of environment and biology to disease aetiology or drug response (Suarez-Kurtz 2010, Palmero et al. 2009) is directly linked to the ability in Brazil to ‘include and account for genetic heterogeneity’ (Gibbon et al. 2011). Yet population mixture is also dynamically constituted in ways that bring into view unity and diversity or national uniqueness and transnational utility. In the context of Brazilian cancer genetics an emphasis on addressing rising rates of

cancer through examining genetic variation in terms of ‘needing to know and characterise...the particular aspects of our population’ (INCA 2009) would appear to lay claims to genomic sovereignty (Benjamin 2009). At the same time this articulation of specificity creates potentials for different kind of leverage. Whilst facilitating an articulation of national need linked to certain population characteristics it can also be situated as a resource within a global and globalising discourse about the scientific or medical value and utility of identifying diverse patterns of human genetic variation.

Pursuit of these fields of genomic medicine in Brazil reflect therefore the broader international and transnational terrain in which a focus on population difference and diversity has shaped and continues to shape post-genomic research (see Lee, *this volume*). As a result, an ability in Brazil to address what is framed as extensive diversity has engendered a range of heterogeneous research collaborations, networks and consortiums. In the case of pharmacogenetics this includes participation in international multi-centric studies of warfarin dosage (Santos et al. 2015). Similarly, Brazilian cancer genetics is constituted and made possible through a range of international collaborations with researchers and leading institutes in the United States, Portugal and France, supported directly and indirectly by both global charitable and pharmaceutical research investment.² In both cases claims relating to the diversity of the Brazilian population engage and facilitate trans-national scientific interest.

Nevertheless, attempts to ‘universalise’ the data from this research raise more or less explicit concerns or critiques. Many Brazilian researchers discover that their research findings are only relevant to a wider international research community when translated into specific taxonomies and categories of difference. In the case of pharmacogenomic studies in Brazil this has led to the exclusion of samples from populations classified as ‘brown’ or ‘*Mestizo*’ from multi-centre studies which are seen as too indeterminate to fit the required racial framework that is often demanded within a ‘political economy’ of publications (Santos et al. 2015, see also Montoya 2007). By contrast an explicit research interest in European genetic ancestry (framed in some publications in terms of a ‘Caucasian haplotype’) in Brazilian cancer genetic research would appear to bring about an apparent alignment between specific high profile ‘global’ population genetic research categories or priorities and an urgent need to understand or explain Brazilian regional disparities in cancer incidence, given variable admixture. Yet this co-exists alongside a recognition, amongst this research community, of the still ‘unknown’ nature of genetic variants and cancer risk in Brazil, which must be understood in terms of a continuum of national population diversity as this concerns correlations between genetic ancestry and skin colour (Gibbon 2016). In both cases we see how in variable ways articulations of difference and similarity or specificity and diversity are alternately incorporated, reframed and sometimes explicitly rejected as part of process described by Santos et al. in terms of ‘racialising to deracialise’ (2015).

Alongside an engagement with genetic variation, a range of other rationales and justifications also underpin the pursuit of these particular fields of genomic research in Brazil, informed by concerns with social justice and health care inequities.

Underserved communities, inequities and the judicialisation of health

The way that a notion of ‘under-served’ communities is articulated in Brazilian genomics, as well as in broader arenas of Brazilian public health, has generally not been orientated to the needs of specifically racialised groups. Despite an emerging multi-cultural agenda that intersects with genomic research in Brazil and across Latin America (Wade 2017) there is not currently the same delineation of such populations as there has been in the United States, where an

explicit focus on the needs of ‘Latina’ and ‘African American’ communities has been foregrounded (Fullwiley 2008, Lee this volume, Joseph 2014, Reardon 2012). While there is an emphasis in Brazil on regional specificity linked to different colonial histories of migration this does not map directly or easily onto a notion of ‘under-served communities’. Instead the question of inequities is marked by wider concerns with national and cross-regional social or economic inequities in health care resources more broadly.

While there is therefore articulation and recognition of inequalities in public health by those working across a variety of genomic research fields in Brazil these do not always align with race. In the case of pharmacogenomics, explicit efforts to ‘de-molecularise’ race and genomics are underlined and pursued in an effort to address and ameliorate inequities in public health policy. It is argued that these would be exacerbated through a ‘racialised’ application of pharmacogenomics by imposing ‘arbitrary’ race categories that do not account for the heterogeneity of the Brazilian population, with potentially dangerous consequences in the case of the warfarin dosage (Santos et al. 2015). Cancer genetics by contrast is constituted by Brazilian cancer genetics researchers as a form of ‘neglected’ preventative public health that entails actively engaging with ‘under-served’ communities and families (Gibbon 2015). As Melo et al. demonstrate, the question of inequities and genetic medicine in the context of public policy debates concerning rare genetic disease is coloured by concerns about extending universal access to drugs and public health care services (2015).

Efforts to address health care inequities through the promise of genomics as preventative medicine are particularly significant in a context such as Brazil where the public health system is precarious, uneven and under resourced (Paim et al. 2011). While this association contributes to the visibility and also legitimacy of genomic research, this is an ethically complex endeavour, especially where the boundary between research and care is thin. While the inter-dependencies between terrains of care and research are a characteristic feature of ‘translational’ research in cancer genetics more broadly in Euro-American contexts (Cambrosio et al. this volume), these intersections also generate particular ethical dilemmas in developing country contexts (Traore et al. 2015). While some see this as a form of ‘hidden innovation’ in Brazil that is enabling of both national and transnational research (de Souza *unpublished thesis*), aligning clinical practice and research at the interface with public health and national or transnational networks has varied outcomes. Whilst informing as it mobilises calls for genomics as public health, it also propels patients into research in search of scarce medical care and resources with specific consequences (Petryna 2009).

High technology medicine and related interventions are now increasingly entangled with the growing judicialisation of health in Brazil (Biehl 2013, Diniz et al. 2012). The constitutional commitment to provide health care for all by the Brazilian state has led patients, families and patient organisations to pursue and strategically instrumentalise (mostly free) legal rights to medications and also other health care sources, including the use of genetic testing in diagnosis. With hundreds of thousands of judicial cases it has become a significant means in Brazil by which access and inclusion to technologies and medicines associated with genomic research and interventions, are now adjudicated; a situation made particularly evident in relation to ‘rare’ genetic disease (Gibbon and Aureliano forthcoming).

A recent special issue of the leading Brazilian anthropology journal *Vibrant*, examining questions of identity in the context of novel developments in the life sciences highlights the need to consider how questions of social vulnerability, inequality and legitimacy are entangled with novel fields of genomics (Do Valle and Gibbon 2015). With the likely deepening and further entrenching of social differences at a time of economic and political crisis, such issues will continue to be a feature of the terrain across which genomic research and medicine in

Brazil will necessarily have to traverse. This raises questions about how individualised ethical frameworks for consent which have been developed for pursuing genomic research and medicine outside of the region are translated and made relevant in contexts such as Brazil. This is particularly true when questions of inequity, human rights and social justice have and continue to be more immediate concerns (Penchezadeh 2015) and where there are different histories of both bioethics and social medicine (Goldim and Gibbon 2015). While novel articulations of bioethics are emerging in North America and Europe in response to the shifting parameters of research regarding data sharing and public participation (see Prainsack this volume), there are also particular concerns in pursuing ‘broad consent’ in the creation of biorepositories in developing country contexts, as explored below. It remains to be seen to what extent diverse histories and experiences, such as those outlined in Brazil, can shape evolving discussion of ethics in an era of global and globalising genomic research.

Uses of ethnicity and tribe in Africa for science

In contrast to the country of Brazil, European colonists often saw African populations throughout the continent as fixed in time and rooted to specific spatial geographies where ethnicity was naturalised as race (see Pales and Linhard 1952; cf Tapper 1999, chapter 3). Ideas of group mixing, although acknowledged, were at times written off or ignored for scientific and mapping projects that consisted of surveys of ABO, MN, and RH blood groups along with sickle haemoglobin for ‘comparative’ *raciologie* (Fullwiley 2011: 171). In the French West African colonial capital of Dakar, these serological studies conducted by the anthropological mission, the *Musée de l'homme* and the National Blood Transfusion Centre were explicitly *not* about health. Rather the objective was to use biomarkers like the sickle cell trait to establish that what had been considered cultural and linguistic ethnicity was in fact also “biological” race (Fullwiley 2011: 168; Pales and Linhard 1952: 85). In other contexts, such as colonial Zimbabwe (then Rhodesia), population-based sickle cell frequencies were used to arbitrate land and resource disputes based on imagined purity and autochthony (Tapper 1999: chapter 3). In what is now Ivory Coast, different dynamics of ethnic consolidation took place that had implications for housing, economic labour casts and, in the postcolonial era, for the humanitarian distribution and triaging of anti-retroviral HIV treatments (Nguyen 2010: 124–125).

The admittedly messy dynamics that underlie the production of singular bloc ethnicities happened in contexts where mixing and human diversity were surely realities. Nonetheless, the tendency of colonial medicine and anthropology was to highlight ossified notions of ethnicity, race, and even tribe when describing African peoples as study subjects. In both colonial and post-colonial states the trend has been to construct and to speak about relatively singular groups, while this often happens through global dynamics whereby African people are active agents in constructing or edifying ethnic identities as a result of exposure to European power (Nguyen 2010: 124–125; Matory 1999: 79–81). What is interesting is that after the wave of independence movements beginning in the 1950s, when many new nation-states emerged, a continued pattern of labelling arose to delineate populations – albeit now in terms of the nation-state. These ascriptions were often synonymous with, or superimposed onto, prior notions of ethnicity or tribe. That is: concepts of population remained tightly yoked to geography, whereby new stakes for claiming ancestry for political reasons (linked to land and market shifts) created new value for African peoples’ biology (Crane 2013; Peterson 2014). At times this confluence of factors bolstered older ideas of biological and genetic sameness in new terms (Fullwiley 2011: 5–7).

New nation-states, ancestry, disease, and the value of African populations

One clear example of this development is that starting in the early 1980s geneticists discovered that three African and one Middle Eastern sickle cell populations differed in the genetic markers (haplotypes) inherited with the gene for sickle haemoglobin (hbS). French researchers obtained samples in Africa from patients in several cities that were chosen for their Pasteur Institutes and other markers of scientific promise that might afford contacts with local physicians working on the disease. With funding from the multinational pharmaceutical company Sanofi, the scientist leading the research attended conferences in the sites of interest, whereby she made arrangements to access samples that her team would analyse after transporting the biological material back to France (Fullwiley 2011: 179–185). The African haplotypes discovered and characterised by this team were named for the polities of ‘Senegal’, ‘Benin’, and ‘Central African Republic, CAR’. The results that came of these initial studies shifted how the vast array of sickle cell phenotypic difference would be conceptualised the world over. Each haplotype was correlated with a general degree of severity, versus mildness.

The HbS haplotype mapping that established ethno-national ideas of ‘mild’ versus ‘severe’ sickle cell ushered in two important moments for genetics in Africa. The first was that, despite earlier cartographic studies of human variation and bloc ethnicity via sickle cell frequencies in the late colonial period, the new haplotype studies were framed in terms of genetic ‘origins’ and ‘ancestry’ now tied to new national borders. Yet even though these genetic signatures conceptually signalled notions of old human biological descent, Parisian researchers followed the logic of a 1980s Francophone-informed geopolitical map in calling the African sickle cell haplotypes by names such as ‘Senegal’ and ‘Benin’. In this process, ethnicity often receded to the background in favour of ethnicised nation-state labels, even though patients in Nigeria might have the ‘Benin’ type and patients in Gambia could have the ‘Senegal’. This expansive frame where nation-state, region, and later ‘Africa’ as a whole could be conceived of in genetic terms would persist. The second was that researchers in Senegal began to protest unfair treatment of African researchers in this and later ‘collaborations’ where they were not mentioned in journal publications (Fullwiley 2011: 138). Subsequent efforts to conduct such studies in Senegal were met with clear demands for fairness, calls to build infrastructure and to create training opportunities. In the 2000s sickle cell researchers in Senegal refused to merely serve as ‘*envoyeurs de sang*’ (blood senders) who mail samples to scientists in the North (ibid.: 190).

Health politics and North–South research to meet local needs

In Senegal where the disease was thought to be the most ‘mild’ on the continent, sickle cell centres and eventually country programmes focused on improving patients’ quality of life through minimal medical interventions in part out of scarcity. Also at work was a science narrative intimating that the exceptional ‘genetics’ of Senegalese people had alleviated some fraction of the disease burden. Although newborn screening programmes have been piecemeal, country specialists have shown that early intervention and follow-up care increase survival and basic indices of thriving, socially as well as biologically (Diagne et al. 2000, Diop et al. 1999). With this country success story of sickle cell made “mild” through a hybrid of genetic localisation, economic scarcity and medical making-do, the head of the national programme requested that the state finance a comprehensive care and research centre for populations outside of the capital beginning in the late 2010s. The goal was to research and track success – and to save lives with minimal intervention. After several failed promises for state funding, specialists eventually secured funds from the foundation arm of the third largest pharmaceutical company in France,

Pierre Fabre. Since 2013 the *Fondation Pierre Fabre* and specialists at the Gaston-Berger faculty of health sciences in Saint-Louis, Senegal are conducting a long-term study on neonatal drug and care regimens that they hope to eventually institutionalise at a population level. In short, private financing, humanitarian philanthropy, development market logics, and population health converge in a research-care hybrid for a national “population” group that is seen to possess unique genetics that favour better health. Local specialists refer to mild sickle cell as a “saving grace,” a biosocial boon that must be documented for research and public health efforts.

If researchers in Paris were informed by the francophone imperial map to define the sickle cell haplotypes in sub-Saharan Africa, a similar linguistic set of colonial and post-colonial relations inflect how initiatives under the rubric of the Human Health and Heredity (H3Africa) project are emerging across the continent today. H3Africa, which launched in 2010, is a US National Institutes of Health and UK Wellcome Trust joint initiative that has as its mission to support genomic research in Africa and to set up research infrastructures across the continent. Its goal is also to investigate the interplay of genomic and environmental factors that determine disease susceptibility and drug responses in African populations (H3Africa Vision 2013), which are theorised to benefit the whole world. Thus far, the majority of projects are in Anglophone countries. To date, the structural legacies of British colonialism has limited actual inclusion from researchers from countries with French, Spanish, or Portuguese as their official languages. Out of the 27 projects currently funded as part of the consortium, all but three are headed by PIs from Anglophone countries. This will surely affect how genetic variation is described down the line. At present, and since the launch, H3Africa researchers have globalised ‘Africa’ as an entity; a place where humans’ unique genomic characteristics are keys to science.

H3Africa’s organisers hopes and founding philosophies are manifold as concerns diversity, inclusion, fairness, and notions of African population biology. These were evident in pronouncements made by scientists from the start. One was that real relationships and “capacity building” would be a defining feature of the initiative. At the highly publicised press conference signalling the first round of \$38 USD million in funding, Dr Bangani Myosi, Head of the Department of Medicine at the University of Cape Town, reiterated concerns held by sickle cell scientists in Senegal years prior. Denouncing what he called ‘a colonial mode of doing science’, he told the international audience that collaborations must be ethical in terms of halting extractive practices based in asymmetrical power relations. This would also require envisioning how to address the inability to exploit research findings in resource-poor settings that resulted in samples – and the final achievements of published science – nearly always being taken abroad (Wellcome Trust, Transcript 2010).

Myosi went on to discuss the African ‘genetic origins’ of common and rare diseases. Francis Collins, head of the National Institutes of Health, doubled down on this notion of African populations’ ancestral utility and potential health gift to global humanity. After detailing the age and unique structures of genetic diversity of African populations, he laid out the vexing issue of trying to assess common disease risks and concluded: ‘Africa will answer the question’ (Wellcome Trust, Transcript 2010).

Thus the ethical treatment of African scientists would be crucial to harnessing the power of African genomes for humanity. To address both, building the necessary infrastructure would be paramount. This concerned establishing biorepositories and laboratories where samples could be stored and shared for eventual intra-African research collaborations, as well as global ones. Just how the imagined tens of thousands of African people who would be asked to join the research would understand what storing and sharing DNA and tissue samples via a biorepository would mean raises a second layer of ethical exigencies the consortium must now address. These include biobanking, export of samples for global secondary uses, and ‘broad consent’ to store and re-use

samples in the first place. Issues of ownership and governance of DNA and biological tissues are also at stake. To date, many of the research guidelines in African countries that might be used to assess the ethics of these practices were developed in response to clinical trials, epidemiological studies, or broader health research – not genomics (De Vries et al. 2017). This is disconcerting because genomes allow for myriad research queries and analyses that go far beyond those of more traditional clinical trials or epidemiological projects. The implications of such broad potential use of genomes should not be underestimated or played down in discussions of broad consent and the facility it allows researchers to exploit genomes with today's technologies.

These issues are not specific to genomic research in Africa. Appeals to join genomic research are also currently taking place much more generally. New rules around broad consent and data sharing, detailed in revisions to The Common Rule, received public comments and underwent debate in the United States in 2016, the implications of which many study participants may not fully grasp (Skloot 2015). Issues of commercial uses, privacy, and re-identification are but a few of the concerns that discussions around true informed consent of DNA samples must address in Africa, Latin America, the United States, and elsewhere. It will be up to scientists involved in these projects to do more to think through past structural inequalities, histories of resource extraction, and issues of equity as they ethically engage and educate people whose DNA is the basic necessity that permits human genetic research in the first place.

Notes

- 1 In their press release Illumina promises that 'H3Africa data will inform strategies to address health inequity and will lead to health benefits in Africa and beyond'. See 'H3Africa Consortium Array Available Soon': New cost-effective chip offers unprecedented content for African genomic research. www.illumina.com/company/news-center/feature-articles/h3africa-consortium-array-available-soon-.html (Accessed May 19, 2017).
- 2 This includes US organisations such as the Susan Komen Foundation with programmes of sponsored research on addressing 'Latina' populations and 'ethnic diversity' in cancer genetic research.

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