

The ethics of investigating cultural and genetic diversity of minority groups

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Abstract (English language)

The use of genetic information for anthropological purposes requires an effort by the researcher to deal with the ethical issues that may arise. In some cases, these can lead to rather complex relationships between anthropologists and communities. The transparency of the research protocol is a fundamental requirement in order to establish a relationship based on trust and to conduct investigations in the most ethically sustainable way. In addition, researchers must take into consideration further aspects regarding the indigenous conceptions of corporeity, memory and history. A knowledge of these characteristics can help in the interpretation of results produced by the geneticists, and constitute a series of social, political and cultural responses. By involving the communities being investigated and engaging in a frequent and fruitful dialogue with their members will make it possible for anthropologists to learn more and also provide useful answers for the populations themselves.

Abstract (Italian language)

L'utilizzo delle informazioni genetiche per scopi antropologici richiede un impegno da parte dei ricercatori nell'affrontare le problematiche etiche che possono sorgere. In alcuni casi, esse possono condurre a relazioni particolarmente complesse fra antropologi e comunità. La trasparenza del protocollo di ricerca è un requisito fondamentale se si vuole stabilire una relazione basata sulla fiducia e per condurre indagini nella maniera più eticamente sostenibile. Inoltre, i ricercatori devono tenere in considerazione ulteriori aspetti riguardanti le concezioni indigene della corporeità, della memoria e della storia. La conoscenza di queste caratteristiche può aiutare nell'interpretazione dei risultati prodotti dai genetisti, e a costituire una serie di risposte sociali, politiche e culturali. Il coinvolgimento delle comunità indagate e dei loro membri in un dialogo frequente e fruttuoso renderà possibile per gli antropologi un maggiore apprendimento, e contribuirà a fornire utili risposte alle popolazioni stesse.

Introduction

The last two decades have seen a considerable increase in attention regarding the study of human genetic variation. The huge impact that this knowledge is having on the progress of biomedical research is universally recognized. Conversely, the importance of human genetic and genomic data as useful information for the study of the migration and demographic dynamics of human populations and their social relationships (e.g. see Pagani 2017 and Zeng, Aw, and Feldman 2018) is generally less known to the public. This kind of investigation, at the intersection of anthropological, historical and biological research, is commonly referred to as “molecular anthropology”. The birth of this discipline can be traced back to 1962, when the American biologist of Austrian origin Emil Zuckerkandl, in the course of the Conference “*Classification and Human Evolution*” held in Burg Wartenstein in Austria, coined the definition (Sommer 2008). Since then, the horizons of this discipline have expanded, continuing in the furrow traced by the pioneering studies that have been carried out since the 1970s by the Italian geneticist Luigi Luca Cavalli Sforza and his pupils and colleagues (Cavalli Sforza 2000; Cavalli Sforza and Bodmer 1971; Cavalli Sforza, Menozzi, and Piazza 1994; Mourant 1977; Rychkov and Sheremetyeva 1977; Sokal et al 1986; see also Jorde 1980 and related citations therein).

Molecular anthropologists are involved in finding answers to several questions regarding the historical origin of human populations, the period of their foundation, the migratory flows that have influenced their composition and their demographic trend over the centuries. Moreover, these researchers are also interested in the ways in which cultural peculiarities, marital habits and social structures can, over the generations, contribute to shape the genetic structure of human populations.

Today, as in the past, the comparative method is still *en vogue* in anthropological research. However, comparison cannot do without literature data and their accessibility. The increase in the production of genetic data depends on the degree of participation of donors of biological material belonging to the communities of anthropological interest that become subject to study from time to time. Therefore, human biological samples (tissues, single cells and subcellular components such as DNA, RNA and proteins) are the basic material on which this research approach depends. Participants voluntarily choose to contribute. Their physical involvement is limited only to the time of the donation of the sample, usually a small amount of blood or saliva taken with painless and minimally invasive collection methods. However, donor participation should be considered in a broader sense, looking not only at their agreement to sampling practices but also at what may happen later, to avoid underestimating the ethical, legal and social implications and the risks that both volunteers and researchers may encounter. In fact, the latter are increasingly in the position of having to face various challenges for their studies, even at

legal level. These challenges derive from the emerging ethical issues linked with the donation of biological samples for research purposes. Mostly, they depend on the so-called “dematerialization” of the body, the tendency to consider the body as a “carrier” of information that, once extrapolated, loses contact with it. This separation generates a conflict between the right to protect the corporeality of donors and the tendency of some researchers to consider biological samples as impersonal materials, without any form of link with donors (Tallacchini 2003). As stated by Stefano Rodotà (2006), these are pieces of ourselves, stored in biobanks where our identity is broken down. This “strong” statement contains an aspect of extreme relevance: the increasing informativeness of genetic and genomic data, not only regarding the donors, but also for their ancestors and descendants (DeSalle 2016). For this reason, molecular anthropologists must promote respect for donor rights and must also carefully consider the psychological aspects related to their participation as subjects belonging to the communities under investigation.

To cast more light on this issue, this paper looks at the studies produced by cultural anthropologists who, since the 1990s have focused on the work of geneticists, the results they produce and the interpretative schemes of the populations under study (e.g. see Kent, Santos, and Wade 2014 and Tamarkin 2014). This kind of ethnographic study can help focus on concepts that biological anthropologists can neglect. In Particular, regarding the nature of the genetic data that is returned to the populations studied, it is far from being neutral information. Interacting with pre-existing beliefs, knowledge and myths, it can represent an important political resource and an element that is capable of completely reshaping the past of a given population. The sensitiveness with which it is necessary to approach the community members is also justified by the fact that very often the investigated groups do not share the same concept of meaning around concepts such as corporeity, humanity, individual memory and collective history. As we will discuss, there have been several cases of genetic research that have been severely criticized by local populations, by lawyers who defend them and by social scientists. Very often, even within the horizon of informed consent, the indigenous social actors have perceived a violation of their rights and their value systems.

The importance of transparency

Researchers who want to conduct an anthropological research requiring the analysis of genetic information should know that they will have to “handle with care” their resources. This is particularly the case, when they deal with small socially identifiable communities, such as ethnic and religious minorities, or with geographically or culturally isolated populations.

Primarily, this is due to the fact that these are often virilocal communities with high rates of endogamy and consanguinity. For this reason, geneticists consider them as ideal case studies to analyze the effects of social practices and cultural factors on human genetic variation and for the identification of rare allelic variants (Ahmic et al 2018; Anagnostou et al 2017; Arcos-Burgos and Muenke 2002; Capocasa et al. 2013, 2014; Destro Bisol et al. 2008; Destro Bisol and Capocasa 2016; Peltonen et al. 2000).

Ethical questions can emerge from the analysis of the genetic structure of minority groups and can lead to rather complex relationships between anthropologists and community members. The transparency of the research protocol is a fundamental requirement to ensure that these relationships can grow on the basis of mutual trust in order to operate in the most ethically sustainable manner. Above all, it is a question of communication and how we describe the aims, the methods applied, the individual and collective risks and benefits and the modalities of participation. This form of transparency is both a right of donors and a duty of researchers, even more if the populations involved are characterized by peculiar cultural, linguistic, religious and territorial identities, which are different from those of researchers (Moodie 2010; Upshur, Lavery, and Tindana 2007). The first impact with local cultures often depends on the preliminary interaction with the political-institutional representatives of the investigated groups. In particular socio-cultural contexts, these personalities are highly respected and have a strong influence on the choices of the community members. Therefore, it is important for researchers to relate to respect their social position (McGregor 2010).

Clarity in the exposition of the research aims and transparency regarding the methods should be the premises for the collection of biological samples in a community. It is important to clarify that the donation of the sample is an individual choice, a voluntary act which should be carried out without any other purpose than to contribute to the realization of scientific research. Therefore, donation is a free act. However, each donor should be able to rethink and to withdraw their consent to participate in research that is different from the original one for which he had made his/her donation. However, the “withdrawal option” is just one example of the protections and rules that come into play in biological sampling procedures.

The protection of the rights of donors of biological samples and the regulation of their use for scientific purposes depend on the application and compliance with many international norms and specific national laws. It is not easy to draw a clear and comprehensive picture of the donors’ rights. In any case, we need to start from the *Universal declaration on the human genome and human rights* produced by UNESCO in 1997. Article 1 of this document states that “The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity”. In a symbolic sense, it is the heritage of

humanity. Moreover, Article 2 recognizes the uniqueness of the genome of each individual, which leads to the need to protect the individual.

In the same year, in the Spanish city of Oviedo, the Council of Europe drew up the *Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: convention on human rights and biomedicine*. This Convention emphasizes the importance of protecting the dignity of the human being, paying particular attention to the physical integrity of the individual. Furthermore, it emphasizes the consent of the donor, which must be obtained after giving exhaustive information concerning the purpose and nature of the research and the risks and consequences that may arise. Knowledge of Article 11 of this document, which prohibits any form of discrimination based on information deriving from the analysis of an individual's genetic heritage, is of fundamental importance for anyone conducting anthropological research through the use of genetic data. In 2003, the *International declaration on human genetic data* of UNESCO supported the importance of the protection of personal data, reaffirming how biological samples (and also the genetic data that can be extrapolated) can be collected and used only after obtaining consent from donors. Three years later, with *Recommendation R (2006) 4*, the Committee of Ministers of the Council of Europe emphasized the need to minimize risks to the individuals and their families when they are involved in biotechnological or genetic research. Particularly, Article 22 of the Recommendation states that “if the proposed use of identifiable biological materials in a research project is not within the scope of prior consent, if any, given by the person concerned, reasonable efforts should be made to contact the person in order to obtain consent to the proposed use”. As explained above, in addition to these international declarations, each country has adopted more or less specific regulations over the years. For example, in Italy, the protection of the rights of donors of biological materials is guaranteed by the “Law for the protection of privacy” (Legislative Decree No. 196/2003). However, this law does not distinguish between material and the informational nature of the biological sample, considering the same rules applicable both for the sample and the resulting extrapolated data.

An inadequate reading of these legal norms could hastily lead one to consider the anonymization of human biological samples as the only effective way to avoid violating privacy rules, thus legitimizing almost all research. However, this is not the case, mostly, because the anonymization of samples is an apparently simple procedure, which, in recent years, is becoming more complex to put into practice. In fact, several studies have shown how it is possible to identify, with a certain degree of precision, the donor or their family lineage, linking the genetic information with a series of metadata that can be found in online genetic databases, ancestry services and genealogical archives (e.g. see Gymrek et al. 2013 and Homer et al. 2008).

Therefore, those interested in participating in studies on their community have the right to demand a higher level of protection, in consideration of the increased risks of privacy violation and the current inadequacy of many of the security systems implemented by laboratories (Heeney et al. 2011).

On the basis of what has been discussed, we can state that the organizational requirements that every laboratory of molecular anthropology should satisfy can be essentially identified in the guarantee of transparency regarding the methods for analyzing biological samples, the protection of the confidentiality of the donors and the anonymization of samples and data. As we will discuss in the next section, these requirements are becoming increasingly necessary considering that biological materials are often collected for multiple research purposes and many of the possible investigations are not even predictable at the time of sampling.

From consent to participation: ethnic identity and possible misunderstandings

The research activity of molecular anthropologists cannot disregard informed consent. It is a tool that allows them to collect and analyze biological samples. At the same time, it allows the donor to express his right to decide the fate of part of his body. Informed consent has now become an ethical imperative. However, it is written before the start of the fieldwork and it cannot be effective in informing the participants about any new purposes that can materialize during the research. Thus, donors lose the right to be fully informed, since they cannot express their opinion on these new research areas, which instead could be possible if new consent can be requested each time the sample is used for a new study (Greely 2007). However, difficulties may arise in putting this approach into practice because carrying out all the operations necessary to obtain a new consensus is complex and it could be economically prohibitive for many research groups. Furthermore, in some cultures, decisions regarding the group are not taken by individuals but by subjects invested with specific decision-making authority. In these cases, a specific consent form, which we could define as “collective” or “community” consent, can help overcome most of the obstacles (Greely 2001; Hudson 2009). In this perspective, these circumstances totally change the classical concept of informed consent, shifting attention from the individual to the community.

These issues depend on some non-obvious assumptions: the idea that individuals involved are fully familiar with the language in which informed consent is written and that they are fully aware of what is meant by “genetic investigation”. In these cases, the use of cultural bridges is necessary, by we mean individuals from the indigenous community who are capable of translating and mediating between researchers and the interests of the local population.

Moreover, the latter should be informed concerning all the aspects of the research protocol and aims in order to be able to grant their consent, by organizing educational activities and public debates specifically aimed at these purposes.

Usually, the motivation behind participation is linked to the awareness of making a contribution to scientific progress and knowledge. Given that anthropological studies rarely produce immediate individual benefits for participants, what is most relevant to decision making is the potential gain in terms of knowledge for the whole community. For molecular anthropologists, the type of consent that seems to meet their needs is the so-called “broad” consent, a form where the research aims are specified only in a general sense. As stated by Grady et al. (2015), “broad consent is less specific than consent for each use, but more narrow than open-ended permission without any limitations” (34). In any case, research carried out using samples collected with the broad consent will have to follow the general principle according to which it will not be possible to put scientific results before the potential risks for the individual. Moreover, broad consent should provide the possibility for the participants to withdraw and to have the biological sample returned. However, it is difficult to hypothesize a real and complete application of this “opt-out option”. In fact, if the biological samples can be returned, the data extracted from them, once published and deposited in the specific databases, will be available for other research and therefore difficult to withdraw (Mascalzoni 2011).

The formulation and use of informed consent make it possible for participants to know who will handle their personal data, how they will do it and whether, and to what extent, someone else will be able to access it. Furthermore, with the consent form, researchers inform donors about the methods of anonymization of samples and data and the legislation regarding the respect of privacy.

Some fundamental principles should inspire anthropological research and human population genetic research in order to protect the efforts and work of the researchers. The practice of consulting the community is perhaps the most important and is the best way to directly involve the investigated population, through the implementation of a direct interaction based on the exchange of opinions. However, this community consultation should not be confused with the aforementioned community consent, even if the latter can only be requested after the consultation regarding risks, benefits and future implications of the research.

The involvement of the communities and the implementation of a frequent dialogue between participants and anthropologists is an aspect of fundamental importance if the latter are motivated to conduct their research in order to produce an advancement of knowledge which is also useful for the specific priorities highlighted by the community members. At this stage, anthropologists can meet the greatest difficulties. In fact, the study of ethnic minorities is often

complicated by the existence of profound differences in values and culture between members and researchers. These differences can lead anthropologists to rely solely on their cultural values in predicting the potential harm their approach can provoke, neglecting the principles and beliefs of the investigated community. In these circumstances, there is a risk of interpreting the research results in some way which conflicts with the historical, cultural and religious convictions of the participants (McGregor 2007). From this point of view, adopting a collaborative approach from the early stages of the project can help researchers calibrate and revise their research protocol in accordance with the needs of the community itself (e.g. the case of the Native Akwesasne; see Sharp and Foster 2002).

The investigation of small human groups is often characterized by the need to collect information concerning descendants and consanguinities between its members and those of geographically close communities. Usually, these data are collected through the administration of questionnaires containing questions regarding family trees and the kinship of participants. Genealogical information and individual personal data are necessary for the correct definition of the representative sample of the entire community. In fact, there are different methods to accomplish this important phase of the research protocol, the choice of which depends on the anthropological aims. For example, in anthropological studies based on the analysis of genetic unilinear markers (mitochondrial DNA and Y chromosome), samples can be selected on the basis of the so-called “grandparents’ rule”, according to which, only those donated by individuals who do not have a maternal grandmother in common (in the case of mitochondrial DNA analyzes, which is transmitted exclusively by mothers to all children) or a paternal grandfather (in the case of DNA analysis of the Y chromosome, which is transmitted only by fathers to male children) will be selected for genetic analysis. With this method, you can collect genetic data of unrelated individuals up to the second degree. It is very useful to obtain a picture of the genetic structure of a population, roughly comparable to what it had been before the “break-up of isolates” (Vogel 1992). This methodological example demonstrates how the use of genetic material as a historical and anthropological source cannot disregard the consultation of historical, demographic, genealogical and ethnographic information.

Shortening the distances between anthropologists and communities

For anthropologists, conducting research on the genetic structure of a population means relating to a group of individuals with a common history, identity and collective interests. Although researchers are aware of the importance of this interaction, many cases of misunderstanding with community members have occurred. Mainly, they were caused by the

lack of attention of anthropologists and geneticists regarding the priorities of the community members. The problem can be identified in the cultural perspective of researchers, in their ethnocentrism and in the consequential unbalanced relationships between observer and observed. These aspects have always accompanied anthropologists in their fieldwork, leading to a separation between researchers and donors, sometimes so marked that they leave the latter with a sense of mistrust and stigmatization. Rebecca Tsosie (2007) defined these negative impacts as “cultural harms”.

Most of the misunderstandings and difficulties ‘on the field’ may be due to little consideration of the history, customs and habits of the communities being investigated. According to Roderick McInness:

A geneticist's first impression of an indigenous culture is similar to viewing an iceberg: what you see isn't what you get. The obvious differences—the visible one-seventh of the iceberg above the water, are only a small fraction of all the distinct features of the indigenous culture. These surface features poorly represent the larger substratum of profound differences hidden beneath the surface (McInness 2011: 255).

Molecular anthropologists cannot presume they belong to a dominant culture and are dealing with a “subaltern” culture. However, they usually have greater scientific knowledge than the members of the investigated communities. This awareness permeates through almost all interactions between the two categories. Researchers should avoid spreading the message that, being the experts, they are the only ones able to teach something to others, boycotting any role of the participant's life experience and knowledge. Instead, they will have to find a way to involve the community members in the research project and in the interpretation of the results.

However, the interests of researchers cannot always coincide with those of the participants. When this happens, misunderstandings are just around the corner, leading individuals, if not communities as a whole, to withdraw their consent to research (Juengst 2004; Weijer 1999). Anthropologists should inform prospective donors of the possibility that the analysis of genetic data can lead to interpretations that could potentially contradict traditional community beliefs (i.e. the mythical origin of the community), or individual certainties, especially regarding kinship relationships. If this does not happen, participants will not be fully protected and informed at the time of consent. This ambiguity could lead to the withdrawal of the sample and data extracted from it, with consequent loss of valuable information (Mascalzoni 2011).

The complex relationships between research groups and investigated communities do not only concern the analysis of the biological samples of the living beings, but also those of their

ancestors. In fact, DNA testing of samples extrapolated from ancient human remains has led to ethical and legal disputes with potential consequences for community members, at least in three cases. Firstly, when the production of genetic evidence of ancestor/descendant relationships could be used to advance or reject land claims (Kaestle and Horsburgh 2002). Secondly, when ancient DNA studies produce narratives in contrast with the tradition and the mythical histories of community (Kaestle and Smith 2005). Thirdly, and finally, when analysis of paleogenomic data provides potentially stigmatizing results for the community members, as in the case of susceptibility to diseases (Bardill et al 2018).

Several approaches have been proposed to conduct research based on the analysis of human remains, taking into account the possible ethical, social and legal issues (Kaestle and Horsburgh 2002; Kaufmann and Rühli 2010). In September 2011, the Centre for Evolutionary Medicine at the University of Zurich released a code of ethics for evidence-based research with ancient human remains, focusing on three main issues: (1) the balance posthumous rights vs scientific progress; (2) management of sampling and processing with regards to the appropriateness vs level of invasiveness; (3) production, interpretation and publication of data (Kreissl Lonfat et al 2015). More recently, the Summer Internship for Indigenous Peoples in Genomics Consortium (SING) of the University of Wisconsin have provided a series of ethical recommendations for paleogenomics (Bardill et al 2018). The SING members started from the premise that any community-based research protocol should not consider ancestral remains as “artifacts” but as human relatives who deserve respect. Obviously, as highlighted by Jessica Bardill and colleagues, the deceased could not sign an informed consent. However, living community members should be consulted to assure that their point of view and their doubts on the research aims and methods will be taken into account. Increasing the engagement of community members, geneticists can establish trust relationships with them. Furthermore, following an inclusive approach, they can also receive information on the history and traditions of the investigated groups, that could be useful for the production of more robust scientific interpretations of the analysis of ancient DNA data.

Even taking into account the specificity of genetic material, it is worth to mention that it is not the only source of ethical problems. In fact, anthropologists face similar issues during their investigations based on the analysis of other markers of biological diversity, namely anthropometric, biochemical and physiological (e.g. see Fluehr-Lobban 2013; Kakaliouras 2012; Peña-Saint-Martin and Vera-Cortés 2018). As suggested by Trudy Turner:

The researcher must engage at a different level with his or her subjects. Engaging the community in the planning of a project and then ensuring that the community is

empowered are now parts of the process. And in some senses, with biobanks, community is the world community, and research is regarded as a public good. This continued engagement with the principles and the codes are designed to foster a sense of trust between what is now viewed as a research partnership (Turner 2012: S230-S231).

Cultural anthropology, genetics and socially identifiable populations

In recent decades, some ethnographers have emphasized the importance of including in their fields of investigation the study of the social, political and cultural uses of the investigation of geneticists by indigenous peoples (e.g. see Kent 2013, Tamarkin 2014 and Trupiano 2013). Several ethnographic contexts have shown that genetic investigations may have a huge political and social impact. In South Africa, population genetics has revealed a relationship between the Lemba community and the Jewish diaspora, generating an interesting process of rebuilding and rediscovering of the collective memory in the local population (Tamarkin 2014). In Brazil, a relationship between molecular investigations and the revival of ancient debates regarding the boundaries of national identity has been highlighted (Kent, Santos, and Wade 2014). There is also a growing number of cultural anthropologists who, starting from the 1990s, have tried to unveil the reasons behind the success of the models of “biosociality” (Rabinow 1996) in the non-expert public. The term “biosociality” refers to the generation of social relationships or the production of collective identities based on common biological or genetic conditions. Trying to answer the question “what do genes tell us about who we are?”, Stephan Palmié (2007) introduced the concept of ‘genomic essence’ to indicate that, to the non-expert, DNA appears as the substance that makes each individual “what he is”, constituting his naturally given foundation, independently from social or cultural manipulations.

Much of the ethnographic research conducted so far in this area aims to demonstrate the importance of the socio-cultural implications of genetic studies. Being reshaped by non-experts, they may be able to rewrite the contemporary parameters of social action through a reconfiguration of the collective past (Trupiano 2013). These studies are also intended to warn research promoters and scientists involved in the field: locally, the pervasiveness of genetic narratives shows that far from handling a neutral object, geneticists contribute, through their discoveries, to forging and directing the political choices of some social actors. The object of this ethnographic research is not represented by the scientific product resulting from genetic investigations. On the contrary, cultural anthropologists carefully show how these are handled on a symbolic level by local populations. In fact, once genetic studies become part of political

arenas, they begin to interact with a wide variety of pre-existing interpretative schemes. When the identity of a people becomes a political resource, DNA can be transformed into a symbol carrying naturalization processes that become important within the dynamics of identity trading. These debates encourage a reflection on what we can define as “return effects” of genetic studies, both on local populations and Western readers.

Some ethnographic case studies have demonstrated the importance of an analysis focused on the role of an “external view” (Fabietti 2013) for the construction of identity, considering the scientific production (of linguists, historians, physical and cultural anthropologists) both as an object of study and an analytical tool. Therefore, it would be of primary importance to develop a similar reflection also around genetic investigations. Although none of these studies has declared the intent to build ethno-cultural isolates, often scientific discourse, reshaped by local populations, can generate a complicity between knowledge and fiction, an evocative intertwining of science and ideological legitimacy competing to give rise to a rhetoric of separation (Zulaika 2000).

Although there are ethnographic studies conducted on the relationship between indigenous or isolated populations and the narratives produced by genetics (e.g. see Kent 2013, Kent, Santos, and Wade 2014 and Tamarkin 2014), those dedicated to the analysis of these issues within cultural contexts that possess a certain familiarity with the concepts of human genetics are more widespread (Simpson 2000; Solinas 2003, 2015; Trupiano 2013). These studies highlighted that genetic investigations on indigenous populations and ethnic minorities have given rise to a wide range of responses ranging from the most strenuous hostility to the active involvement of the community members.

Undoubtedly, one of the research projects that has fueled the debate, attracting the attention of anthropologists and social scientists, is the *Human Genome Diversity Project* (HGDP) promoted in the early 1990s by a group of geneticists led by Luigi Luca Cavalli Sforza (Kent 2013; Lock 2001; TallBear 2007). HGDP had a very ambitious goal: to build a database of the world human genetic variation (Cavalli Sforza et al. 1991). Far from questioning the undeniable scientific merits of the promoters of the HGDP, several voices (cultural anthropologists, lawyers of the indigenous populations and committees for the defense of the rights of the original peoples) tried to highlight some ethical-political issues related to this project. The first criticism of the HGDP concerned the proposal to primarily collect biological samples in partially isolated native populations. This was felt by the opponents of the project as a revival of a certain “emergency anthropology”, a scientific discourse able to immortalize the uses and ways of life of populations that, due to the increasingly unstoppable contact with the “cultural otherness”, were disappearing. HGDP did not aim to preserve a culture on the verge of disappearance but rather to

collect biological samples of endogamic populations with peculiar genetic heritages. These samples, pictures of almost extinct human groups, could be kept indefinitely. Thus, the objective of HGDP was to protect this genetic material from the consequences of globalization. Opponents of Cavalli-Sforza's pioneering project saw in these practices the phantom of the exploitation of indigenous peoples, considered more as interesting objects of study than as collaborators or interlocutors (Harry, Howard, and Shelton 2000; TallBear 2007). The geneticists involved in the HGDP were also accused of “biocolonialism”, a phenomenon that consists in the appropriation of traditional knowledge or genetic resources from populations settled in developing countries (Lock 2001).

In 2005, the *National Geographic Society* launched another genetic project with the aim to understand where our species originated and what are the migrations that have populated the Earth in ancient times: the *Genographic Project* (GP). The GP mixes marketing and scientific research strategies, those who underwent the test supported it both economically and scientifically, making their results available for genetic analysis. Undoubtedly, a successful strategy: at the beginning of 2017, over 800 thousand people from over 140 different countries had taken part in the project (Destro Bisol and Capocasa 2018). The GP promoters wanted to mark the differences with HGDP, particularly regarding the aspects linked to the community members' participation on the project. As reported in the FAQ Questions of the Genographic website, they affirmed that:

Ours is a true collaboration between indigenous populations and scientists. Helping communicate their stories and promoting preservation of their languages and cultures is integral. Before any fieldwork begins, we have been and will continue to seek advice and counsel from leaders and members of indigenous communities about their voluntary participation in the project (National Geographic, 2005, “FAQ Questions”, paragraph 3; in Wood, Hall and Hasian 2008: 442).

Despite these premises, opponents of GP, who had given HGDP very similar criticisms, described it as a substantial continuation of the previous project, reiterating the same mistakes (Rimmer 2007). One of the most relevant criticism of both projects regards the risk of biological racism and the generation of essentialist reification of ethnic identity and culture. Kimberly TallBear (2007) discussed the HGDP and GP controversies, also questioning the narrative proposed by the promoters of GP according to which these studies show that not only is racism socially deplorable, but also scientifically incorrect (see also Goodman 2018). This anti-racism would be built around the principle that we are all Africans and descendants of the so-called

“mitochondrial Eve” (Cann, Stoneking, and Wilson 1987). When geneticists use the word “Africa”, they do not refer to a physical place, but an ideological referent: Africa as a concept full of meaning, inevitably built around a Western narration, not without a colonial heritage. Africa as a place without time and history incorporating the Roussovian image of a golden age of brotherhood and representing a place of irrationality, hunger and ferocity: “Africa cannot be understood outside recent human and colonial history, not even by geneticists” (TallBear 2007: 414). Moreover, the idea that we are all Africans should not be learned uncritically because it hides a certain evolutionary heritage for which “Africans precede the modern white man on the evolutionary chain of humanity” (TallBear 2007: 414).

Some native communities were the first to become aware of some of these issues related to the collection and sequencing of DNA samples. Starting from this new interest, indigenous associations dedicated to the dissemination of genetic information and practices of scientists have arisen. For example, thanks to the efforts of Debra Harry, in 1999 the non-profit organization *Indigenous Peoples Council on Biocolonialism* (IPCB) was born in Nevada. This group supports the interests of indigenous peoples and its fundamental objective is to assist them “in the protection of their genetic resources, indigenous knowledge, cultural and human rights from the negative effects of biotechnology. The IPCB provides educational and technical support to indigenous peoples in the protection of their biological resources, cultural integrity, knowledge and collective rights” (see URL: http://www.ipcb.org/about_us/our_mission.html).

This association has dealt with very sensitive issues and borderline cases in which scientific research has denied or contradicted traditional narratives of natives regarding their mythical and ancestral origins (Harry and Dukepoo 1998; Harry, Howard, and Shelton 2000). Probably the most famous controversy regards the case between the Havasupai of Arizona and a research group of the Arizona State University (ASU), which began in 1989. It was an investigation to understand the possible genetic causes of the high rates of type II diabetes found in this community settled in the Grand Canyon. In this case, the blood samples initially collected for this specific purpose were also used for studies on the historical origin of these Native Americans, based on the analysis of genetic variability and on the degree of consanguinity, without asking for new consent (Rubin 2004). This secondary use of samples led to a court case involving the community and researchers, which began in 2004 and ended in 2010. The Arizona Court of Appeals obliged the ASU to return samples of DNA to the Havasupai and to economically compensate their community for the moral damage caused by having used genetic data for purposes other than those for which consent was given (Harmon 2010; Mello and Wolf 2010).

According to the IPCB promoters, attention must be paid to the ways in which social actors are involved in genetic research: native peoples are invited to acquire the basic knowledge that will allow them to make informed decisions about themselves, their people and the environment in which they live (Harry, Howard, and Shelton 2000). In fact, the most important challenge to give rise to ethical research is to consider the members of the indigenous peoples as working partners. It can be achieved only through a double action by scientists and community members: scientists must devote more attention to the involvement of local authorities in decision-making processes and to respect their traditional concepts; community members have to obtain information themselves about the proposed studies, so that their choices are not exclusively dependent on the researchers (Harry, Howard, and Shelton 2000).

Cultural anthropologists rarely pay attention to the ontological gap between the knowledge produced by genetic research and the indigenous conceptions of corporeity, identity, history and belonging. Several studies have shown that, although genetic investigations are based mainly on non-invasive techniques, biological materials taken from individuals involved in such studies are often of great importance within the system of values of indigenous populations (e.g. see Couzin-Frankel 2010 and Kent 2013). The recent developments of the Amazonian anthropology highlighted the centrality of the body fluids (i.e. blood and saliva) in the indigenous conceptions of humanity. Within a paradigm in which the distinction between the human and the non-human is defined, through corporeality, these physical elements become the main vectors of memory, differentiation between gender, sociality, and individual/collective attributes (Belaunde 2005; Guzmán 1997; Rival 2005; Viveiros De Castro 1998, 2003). Furthermore, we cannot neglect that the paradigm of segmentation, to which modern science belongs, is viewed with suspicion by many North American indigenous groups which underline the importance of inter-relationships within a holistic life system, “Regard their bodies, hair, and blood as sacred elements, and consider scientific research on these materials a violation of their cultural and ethical mandates” (Harry, Howard, and Shelton 2000: 21). Therefore, sampling biological materials from their ancestors and their process of immortalization represent a real conceptual challenge for these individuals. An emblematic case is that of the Yanomami, an indigenous group of the Venezuelan Amazon, which gave rise to a campaign to return the biological samples taken from the research group led by the anthropologist Napoleon Chagnon and the geneticist James Neel. Once they learned the fate of their samples, frozen and stored in public archives, they asked for them to be returned so that they could be destroyed by the elders. The immortalization of a body element represented for this community an unthinkable action: the only way to keep the world of the living separated from that of the dead was represented by the destruction of every part of the body and therefore also of their biological samples (Couzin-Frankel 2010). In addition to that

concerning the return of biological samples, Chagnon and Neel were also accused by journalist Patrick Tierney of having conducted their investigations without any respect for the welfare of community members. Particularly, Tierney accused them of having incited the Yanomami members to violence and to have falsified their research results (Tierney 2000). These accusations generated a media storm that forced Chagnon to terminate his academic activity prematurely. A few years later, following the investigations conducted by the American Anthropological Association, most of Tierney's accusations turned out to be false, so much so that he went from accuser to being accused of misconduct (Borofsky 2005). Recently, Chagnon (2013) gave his version of the facts in his book *Noble Savages: The Yanomamo and the Anthropologists*. The title of this volume clarifies, even before reading it, the ethical value, well beyond the facts themselves, that this story has represented for anthropological research.

However, things have not always gone so badly. In fact, it is not unusual to identify ethnographic cases in which the collaboration between the various social actors has generated mutual beneficial outcomes. A good example is the case of collaboration between the Uros, a population living on artificial floating islands of Lake Titicaca in Peru, and researchers of the Genographic Project. In this case, the incorporation of genetic research in the context of political debates provided concrete help to populations using their ethnic identity as a resource within territorial conflicts (Kent 2013).

Towards an extended discipline

James Peacock (1997) proposed three possible scenarios for the future of anthropological research: its extinction, its continuation as a “living dead” or its flourishing redirection into a prominent position in society. The latter alternative, the most appealing, can only be pursued by focusing efforts on a renewed emphasis concerning the relevance of anthropology to a wider audience, underlining the difference between the discipline and the academy (Lassiter 2005). It is an important change of perspective, where the classic unequal research models based on the rigid relational hierarchy between researchers and volunteers-participants-informants can and must be reviewed to promote greater equity (Fluehr-Lobban 2008). This change of perspective illustrates the major assonances between anthropology and other disciplines, such as sociology, psychology, history, pedagogy and even bio-medical sciences, where several collaborative research approaches are increasingly gaining ground (Jason et al. 2004; Nyden and Wiewel 1992; Staikidis 2006; Thomson 2003; Wallerstein and Duran 2006). Anthropology is extremely alive and provides different contributions to the development of participatory research protocols characterized by a more integrated interaction between researchers and community members

(Schensul et al. 2015). It is a way of conducting more sustainable and ethical research, also helping to achieve more robust, accurate and reliable studies.

Collaboration has its roots in the history of all anthropological branches. However, we can still observe a marked separation between the biological and socio-cultural aspects. According to Tim Ingold (1998), this separation originated from the notion of the human being as a complex object of study and, therefore, necessarily comprehensible only if analyzed from complementary but separate points of view. During the first half of the twentieth century, this separation took shape both in the British and American anthropological tradition, but through two different ways. In fact, in England, Bronislaw Malinowski and Alfred Reginald Radcliffe-Brown, placing emphasis on the fieldwork methods, limited their anthropological research to synchronic comparison, while in the United States, Franz Boas and his students contributed to the division of the discipline favoring the establishment of different university departments for cultural and physical anthropology (Barnard 2011). In contrast to this distance, Ingold (1998) proposed the dissolution of the disciplinary boundaries towards a study of human capabilities not as genetic or cultural properties, but as self-organizing dynamics of an evolving system whose understanding can only be reached through awareness that anthropology is a science committed to the dissemination of knowledge. Alex Mesoudi, Andrew Whiten and Kevin Laland (2006) reiterated the importance of achieving unity of intent in scientific terms, explicitly inviting socio-cultural anthropologists to join evolutionists and cognitivists in the construction of a unified science. Answering this invitation, Ingold (2007) confirmed the urgency and importance of the commitment to find a common, truly interdisciplinary working method, while not denying the difficulties still existing today on both sides, above all due to a certain mutual mistrust. This is based on a double prejudice: biological anthropologists saw their colleagues on the cultural side as lacking the necessary theoretical basis for the understanding of mathematical models and statistical analyzes proposed to explain cultural dynamics, while the latter considered the former as prisoners of the need to simplify.

Overcoming these limits of disciplinary integration is the real challenge behind making anthropology an extended discipline. Its cultural aspect is not characterized by a more speculative nature than the biological one. In fact, even for the latter, “plausibility and likelihood are often sufficient for the construction of hypotheses and even for longstanding and widely accepted theories” (Barnard 2011: 145). According to Alan Barnard (2011), the only real difference between them is represented by the fact that biological anthropologists need quantitative data, while cultural anthropologists need ethnographic information. However, both analyze and interpret their research materials by inference and deduction. For Barnard (2011), reaching the full realization of a truly interdisciplinary field aimed at studying the origins of man

would require a reorganization of university departments and, probably, also of research groups and funding agencies. In recent years, numerous steps have been taken towards reconciliation between biological and cultural anthropologists. Certainly, we cannot yet speak of shared approaches, but of dialogue and sharing of knowledge and scientific collaboration. Informed consent is at the center of this discourse. As already discussed, it is a familiar tool in the biomedical sciences and molecular anthropology, whereas in the social sciences and in cultural anthropology its use still today presents numerous difficulties. However, this reluctance contrasts with the indications that have long been coming from some of the most important and influential professional anthropological associations, such as the American Anthropological Association (AAA) and the Association of Social Anthropologists of the UK and the Commonwealth (ASA). Since 1998, the use of informed consent has been reported in the *AAA Code of Ethics*. Indeed, since November 2012, in the *Principles of Professional Responsibility* of the AAA Ethics Committee, the request for voluntary informed consent has been indicated as mandatory practice for both cultural and biological anthropologists dealing with living human communities. In this document, the AAA also provide a minimum standard to be followed for its drafting. A similar recommendation is also reported in the *ASA Ethical Guidelines for Good Research Practice*. In addition to the written consent, the ASA has also paid particular attention to cases in which the investigated communities are suspicious about the fact of having to sign a formal form, suggesting forms of oral consent as an alternative.

Concluding remarks

During the sixtieth annual meeting of the *American Society of Human Genetics* held in Washington in November 2010, Roderick McInness (2011) outlined an extremely significant point of view: culture is the silent language geneticists must learn. According to McInness, the influence of indigenous culture on the activity of researchers is a step, not yet completely accomplished, towards “culturally competent” research and respectful of beliefs, hopes and the desire to obtain benefits, even only in terms of knowledge, for the investigated communities. Unfortunately, the history of anthropological research concerning ethnic minorities tells us a tale in which the violation of privacy and the moral integrity of communities has sometimes brought more disadvantages than benefits. The misunderstandings that have arisen and the skepticism that community members have shown towards anthropologists and geneticists have led to difficulties in intercultural communication, which has often been underestimated, being seen simply as a price to pay for the progress of research.

Anthropologists often find themselves having to evaluate ethical, legal and social aspects so they can define an effective and efficient research protocol in order to avoid, as much as

possible, errors similar to those that we have been reported in this paper. In our opinion, this is a very important passage that depends on three main aspects. Firstly, researchers should be able to adapt their way of working to the needs of the communities under study. Secondly, they should be positively influenced by the culture of these human groups, learning details that may seem secondary, but which are in fact fundamental to avoid misunderstandings or even the risk of causing damage to the community members. Thirdly, and finally, according to Seta Low and Sally Merry (2010), they should never neglect their public engagement, whose importance also concerns emotional support during fieldwork and the promotion of respect for the human rights of vulnerable populations.

Certainly, in the transition towards a more engaged anthropology, something could be lost in terms of objectivity of evaluation. However, we believe that this is a fair price to pay if we want to go “on the field” aware of the possibilities that anthropology offers in terms of usefulness and knowledge sharing. In a more general sense, this change of perspective could have a strong impact on how the anthropologist's role in Western society is commonly perceived, both inside and outside the academy, as well as on the dynamics of interaction between researchers and the public. This is a passage that requires an extraordinary effort by anthropologists towards a shortening of the distances with the investigated communities. However, we are convinced that its completion will produce positive and beneficial effects both for researchers and community members and, more generally, for the future of anthropology.

Author contributions

MC and LV equally contributed in conceiving the paper and in writing the “Introduction” and the paragraphs “Towards an extended discipline” and “Concluding remarks”. The paragraphs “The importance of transparency”, “From consent to participation: ethnic identity and possible misunderstandings” and “Shortening the distances between anthropologists and communities” have been written by MC. The paragraph “Cultural anthropology, genetics and socially identifiable populations” has been written by LV.

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References

- Ahmic, Adisa, Belma Kalamujic, Anel Ismailovic, Lejla Lasic, Emir Halilovic, Irma Mujkic, and Naris Pojskic. 2018. Mitochondrial DNA diversity of the Roma from northeastern Bosnia, Bosnia and Herzegovina. *Homo – Journal of Comparative Human Biology* 69(6):347-356.
- Anagnostou, Paolo, Valentina Dominici, Cinzia Battaglia, Luca Pagani, Miguel Vilar, R. Spencer Wells, Davide Pettener, Stefania Sarno, Alessio Boattini, Paolo Francalacci, Vincenza Colonna, Giuseppe Vona, Carla Calò, Giovanni Destro Bisol, and Sergio Tofanelli. 2017. Overcoming the dichotomy between open and isolated populations using genomic data from a large European dataset. *Scientific Reports* 7:41614.
- Arcos-Burgos, Mauricio, and Maximilian Muenke. 2002. Genetics of population isolates. *Clinical Genetics* 61(4):233-247.
- Bardill, Jessica, Alyssa C. Bader, Nanibaa' A. Garrison, Deborah A. Bolnick, Jennifer A. Raff, Alexa Walker, Ripan S. Malhi, and the Summer internship for Indigenous peoples in Genomics (SING) Consortium. 2018. Advancing the ethics of paleogenomics: ancestral remains should be regarded not as “artifacts” but as human relatives who deserve respect. *Science* 360(6387):384-385.
- Barnard, Alan. 2011. *Social anthropology and human origins*. Cambridge: Cambridge University Press.
- Belaunde, Luisa E. 2005. *El recuerdo de luna: género, sangre y memoria entre los pueblos amazónicos*. Lima: Universidad Nacional Mayor de San Marcos, CAAP.
- Borofsky, Robert. 2005. *Yanomami. The fierce controversy and what we can learn from it*. London: University of California Press.
- Cann, Rebecca, Mark Stoneking, and Allan C. Wilson. 1987. Mitochondrial DNA and human evolution. *Nature* 325(6099):31-36.
- Capocasa, Marco, Cinzia Battaglia, Paolo Anagnostou, Francesco Montinaro, Ilaria Boschi, Gianmarco Ferri, Milena Alù, Valentina Coia, Federica Crivellaro, and Giovanni Destro Bisol.

2013. Detecting genetic isolation in human populations: a study of European language minorities. *PLoS One* 8(2):e56371.

Capocasa, Marco, Paolo Anagnostou, Valeria Bachis, Cinzia Battaglia, Stefania Bertoncini, Gianfranco Biondi, Alessio Boattini et al. 2014. Linguistic, geographic and genetic isolation: a collaborative study on Italian populations. *Journal of Anthropological Sciences* 92:201-231.

Cavalli Sforza, Luigi Luca. 2000. *Genes, peoples, and languages*. New York: North Point Press.

Cavalli Sforza, Luigi Luca, and Walter F. Bodmer. 1971. *The genetics of human populations*. San Francisco: W.H. Freeman.

Cavalli Sforza, Luigi Luca, Paolo Menozzi, and Alberto Piazza. 1994. *The history and geography of human genes*. Princeton: Princeton University Press.

Cavalli Sforza, Luigi Luca, Allan C. Wilson, Charles R. Cantor, Robert M. Cook-Deegan, and Mary-Claire King. 1991. Call for a worldwide survey of human genetic diversity: a vanishing opportunity for the Human Genome Project. *Genomics* 11(2):490–491.

Chagnon, Napoleon A. 2013. *Noble savages: my Life among two dangerous tribes-the Yanomamo and the anthropologists*. New York: Simon & Schuster.

Couzin-Frankel, Jennifer. 2010. Researchers to return blood samples to the Yanomamo. *Science* 328(5983):1218.

DeSalle, Rob. 2016. What do our genes tell us about our past?. *Journal of Anthropological Sciences* 94:193-200.

Destro Bisol, Giovanni, Paolo Anagnostou, Chiara Batini, Cinzia Battaglia, Stefania Bertoncini, Alessio Boattini, Laura Caciagli et al. 2008. Italian isolates today: geographic and linguistic factors shaping human biodiversity. *Journal of Anthropological Sciences* 86:179-188.

Destro Bisol, Giovanni, and Marco Capocasa. 2016. *Italiani. Come il DNA ci aiuta a capire chi siamo*. Roma: Carocci.

Destro Bisol, Giovanni, and Marco Capocasa. 2018. *Intervista impossibile al DNA. Storie di scienza e umanità*. Bologna: Il Mulino.

Fabietti, Ugo. 2013. *L'identità etnica. Storia e critica di un concetto equivoco*. Roma: Carocci.

Fluehr-Lobban, Carolyn. 2008. Collaborative anthropology as twenty-first-century ethical anthropology. *Collaborative Anthropologies* 1:175-182.

Fluehr-Lobban, Carolyn. 2013. *Ethics and anthropology: ideas and practice*. Plymouth: AltaMira Press.

Goodman, Alan. 2018. Conclusions: race as social fact and scientific fiction. *Journal of Anthropological Sciences* 96:255-256.

Grady, Christine, Lisa Eckstein, Ben Berkman, Dan Brock, Robert Cook-Deegan, Stephanie M. Fullerton, Hank Greely et al. 2015. Broad consent for research with biological samples: workshop conclusions. *The American Journal of Bioethics* 15(9):34-42.

Greely, Hank. 2001. Informed consent and other ethical issue in human population genetics. *Annual Review of Genetics* 35:785-800.

Greely, Hank. 2007. The uneasy ethical and legal underpinnings of large-scale genomic biobanks. *Annual Review of Genomics and Human Genetics* 8:343-364.

Guzmán, Maria A. 1997. *Para que la yuca beba nuestra sangre. Trabajo género y parentesco en una comunidad quichua de la amazonia ecuatoriana*. Quito: Abya-Yala.

Gymrek, Melissa, Amy L. McGuire, David Golan, Eran Halperin, and Yaniv Erlich. 2013. Identifying personal genomes by surname inference. *Science* 339(6117):321-324.

Harmon, Amy 2010. Indian tribe wins fight to limit research of its DNA. *New York Times*, April 21, U.S. sec. http://www.nytimes.com/2010/04/22/us/22dna.html?pagewanted=all&_r=0.

Harry, Debra, and Frank Dukepoo. 1998. *Indians, genes and genetics: what Indians should know about the new biotechnology*. Wadsworth: Indigenous People Council on Biocolonialism.

Harry, Debra, Stephanie Howard, and Brett L. Shelton. 2000. *Indigenous peoples, genes and genetics: what indigenous people should know about biocolonialism*. Wadsworth: Indigenous People Council on Biocolonialism.

Heeney, Catherine, Naomi Hawkins, Jantina de Vries, Paula Boddington, and Jane Kaye. 2011. Assessing the privacy risks of data sharing in genomics. *Public Health Genomics* 14(1):17-25.

Homer, Nils, Szabolcs Szelinger, Margot Redman, David Duggan, Waibhav Tembe, Jill Muehling, John V. Pearson, Dietrich A. Stephan, Stanley F. Nelson, and David W. Craig. 2008. Resolving individuals contributing trace amounts of DNA to highly complex mixtures using high-density SNP genotyping microarrays. *PLoS Genetics* 4(8):e1000167.

Hudson, Maui 2009. Think globally, act locally: collective consent and the ethics of knowledge production. *International Social Science Journal* 60(195):125-33.

Ingold, Tim. 1998. From complementarity to obviation: on dissolving the boundaries between social and biological anthropology, archaeology and psychology. *Zeitschrift für Ethnologie* 123(1):21-52.

Ingold, Tim. 2007. The trouble with 'Evolutionary Biology'. *Anthropology Today* 23(2):13-17.

Jason, Leonard, Christopher Keys, Yolanda Suarez-Balcazar, Renée Taylor & Margaret Davis, eds. 2004. *Participatory community research: theories and methods in action*. Washington DC: American Psychological Association.

Jorde, Lynn. 1980. The genetic structure of subdivided human populations. In *Current developments in anthropological genetics*. James H. Mielke and Michael H. Crawford, eds. Pp. 135-208. Boston: Springer.

Juengst, Eric. 2004. FACE facts: Why human genetics will always provoke bioethics. *Journal of Law, Medicine and Ethics* 32(2):267-275.

Kaestle, Frederika A., and K. Ann Horsburgh. 2002. Ancient DNA in anthropology: methods, applications, and ethics. *Yearbook of Physical Anthropology* 45:92-130.

Kaestle, Frederika A., and David G. Smith. 2005. Working with ancient DNA: NAGPRA, Kennewick Man, and other ancient peoples. In *Biological anthropology and ethics: from repatriation to genetic identity*. Trudy R. Turner, eds. Pp. 241-262. Albany: State University of New York Press.

Kakaliouras, Ann M. 2012. An anthropology of repatriation: contemporary physical anthropological and Native American ontologies of practice. *Current Anthropology* 53(S5):S210-S221.

Kaufmann, Ina M., and Frank J. Rühli. 2010. Without 'informed consent'? Ethics and ancient mummy research. *Journal of Medical Ethics* 36(10):608-613.

Kent, Michael 2013. The importance of being Uros: indigenous identity politics in the genomic age. *Social Studies of Science* 43(4):534-556.

Kent, Michael, Ricardo Ventura Santos, and Peter Wade. 2014. Negotiating imagined genetic communities: unity and diversity in Brazilian science and society. *American Anthropologist* 116(4):736-748.

Kreissl Lonfat, Bettina M., Ina M. Kaufmann, and Frank Rühli. 2015. A code of ethics for evidence-based research with ancient human remains. *The Anatomical Record* 298(6):1175-1181.

Lassiter, Luke E. 2005. Collaborative ethnography and public anthropology. *Current Anthropology* 46(1):83-106.

Lock, Margaret. 2001. The alienation of body tissue and the biopolitics of immortalized cell lines. *Body & Society* 7:63.

Low, Setha M., and Sally E. Merry. 2010. Engaged anthropology: diversity and dilemmas: an introduction to supplement 2. *Current Anthropology* 51(S2):S203-S226.

Mascalzoni, Deborah. 2011. Le biobanche di popolazione: i confini frammentati di una definizione tra individuo e gruppo genetico. In *Trattato di biodiritto*. Stefano Rodotà, Stefano Canestrari, Gilda Ferrando, Cosimo M. Mazzoni and Paolo Zatti, eds. Pp. 1216-1236. Milano: Giuffrè.

McGregor, Joan L. 2007. Population genomics and research ethics with socially identifiable groups. *Journal of Law, Medicine and Ethics* 35(3):356-370.

McGregor, Joan L. 2010. Racial, ethnic, and tribal classifications in biomedical research with biological and group harm. *The American Journal of Bioethics* 10(9):23-24.

McInnes, Roderick. 2011. 2010 Presidential address. Culture: the silent language geneticists must learn-genetic research with Indigenous populations. *The American Journal of Human Genetics* 88(3):254-261.

Mello, Michelle M., and Leslie E. Wolf. 2010. The Havasupai Indian tribe case – lessons for research involving stored biologic samples. *New England Journal of Medicine* 363(3):204-207.

Mesoudi, Alex, Andrew Whiten, and Kevin Laland. 2006. Towards a unified science of cultural evolution. *Behavioral and Brain Sciences* 29:329-347.

Moodie, Susan. 2010. Power, rights, respect and data ownership in academic research with indigenous people. *Environmental Research* 110(8):818-820.

Mourant, Arthur E. 1977. The genetic markers of the blood. *International Biological Programme* 11:9-46.

Nyden, Philip., and Wim Wiewel. 1992. Collaborative research: harnessing the tensions between researcher and practitioner. *The American Sociologist* 23(4):43-55.

Pagani, Luca. 2017. A Cover Story for a Nature cover: genetic signature of human expansions into Eurasia revealed by a panel of worldwide high coverage genomes. *Journal of Anthropological Sciences* 95:1-5.

Palmié, Stephan. 2007. Genomics, divination, “racecraft”. *American Ethnologist* 34(2):205-222.

Peacock, James L. 1997. The future of anthropology. *American Anthropologist* 99(1):9-17.

Peltonen, Leena, Aarno Palotie, and Kenneth Lange. 2000. Use of population isolates for mapping complex traits. *Nature Reviews Genetics* 1:182-190.

Peña-Saint-Martin, Florencia, and José Luis Vera-Cortés. 2018. Races, racism, and physical anthropology in Mexico. *Journal of Anthropological Sciences* 96:239-245.

Rabinow, Paul. 1996. *Essays on the anthropology of reason*. Princeton: Princeton University Press.

Rimmer, Matthew. 2007. The Genographic Project: traditional knowledge and population genetics. *Australian Indigenous Law Review* 11(2): 33-55.

Rival, Laura. 2005. Introduction: what constitutes a human body in native Amazonia?. *Tipiti: Journal of the Society for the Anthropology of Lowland South America* 3(2):1.

Rodotà, Stefano. 2006. *La vita e le regole: tra diritto e non diritto*. Milano: Feltrinelli.

Rubin, Paul. 2004. Indian givers the Havasupai trusted the white man to help with a diabetes epidemic. Instead, ASU tricked them into bleeding for academia. *Phoenix New Times*, May 27, www.phoenixnewtimes.com/2004-05-27/news/indian-givers/.

Rychkov, Yuri G., and V. A. Sheremetyeva. 1977. The genetic process in the system of ancient human isolates in North Asia. *International Biological Programme* 11:47-108.

Schensul, Stephen L., Jean J. Schensul, Merrill Singer, Margaret Weeks, and Marie Brault. 2015. Participatory methods and community-based collaborations. In *Handbook of methods in*

cultural anthropology, 2nd Edition. H. Russell Bernard, and Clarence C. Gravlee, eds. Pp. 185-212. Lanham: Rowman & Littlefield.

Sharp, Richard R., and Morris W. Foster. 2002. Community involvement in the ethical review of genetic research: lessons from American Indian and Alaska Native Populations. *Environmental Health Perspectives* 110(S2):145-148.

Simpson, Bob. 2000. Imagined genetic communities. Ethnicity and essentialism in the Twenty-First Century. *Anthropology Today* 16(3):3-6.

Sokal, Robert R., Peter E. Smouse and James V. Neel. 1986. The genetic structure of a tribal population, the Yanomama Indians. XV. Patterns inferred by autocorrelation analysis. *Genetics* 114(1):259-287.

Solinas, Pier Giorgio. 2003. *Arbores Americae*. In *Antropologia dell'occidente*. Pietro Scarduelli, ed. Pp. 69-101. Roma: Meltemi.

Solinas, Pier Giorgio. 2015. *Ancestry. Parentele elettroniche e lignaggi genetici*. Firenze: Editpress.

Sommer, Marianne. 2008. History in the gene: negotiations between molecular and organismal anthropology. *Journal of the History of Biology* 41(3):473-528.

Staikidis, Kryssi. 2006. Personal and cultural narrative as inspiration: a painting and pedagogical collaboration with Mayan artists. *Studies in Art Education* 47(2):118-138.

Tallacchini, Mariachiara. 2003. Paradigma dell'informazione e smaterializzazione giuridica del corpo. In *La terza rivoluzione scientifica. Bioscienze e coesione sociale*. Fabrizio Rufo, ed. Pp. 123-49. Roma: Edises.

TallBear, Kim. 2007. Narratives of race and indigeneity in Genographic Project. *The Journal of Law, Medicine & Ethics* 35(3):412-424.

Tamarkin, Noah. 2014. Genetic diaspora: producing knowledge of genes and Jews in rural South Africa. *Cultural Anthropology* 29(3):552-574.

Thomson, Alistair. 2003. Introduction - Sharing authority: oral history and the collaborative process. *Oral History Review* 30(1):23-26.

Tierney, Patrick. 2000. *Darkness in El Dorado. How scientists and journalists devastated the Amazon*. New York: Norton.

Trupiano, Valeria. 2013. *Gli usi della diversità genetica. DNA, parentele e politiche dell'appartenenza*. Bologna: il Mulino.

Tsosie, Rebecca. 2007. Cultural challenges to biotechnology: Native American genetic resources and concept of cultural harm. *The Journal of Law, Medicine & Ethics* 35(3):396-411.

Turner, Trudy R. 2012. Ethical issues in human population biology. *Current Anthropology* 53(S5):S222-S232.

Upshur, Ross, James Lavery, and Paulina Tindana. 2007. Taking tissue seriously means taking communities seriously. *BMC Medical Ethics* 8:11.

Viveiros de Castro, Eduardo. 1998. Cosmological deixis and Amerindian perspectivism. *The Journal of the Royal Anthropological Institute* 4(3):469-488.

Viveiros de Castro, Eduardo. 2003. La imanencia del enemigo. *Amazonía Peruana* 28-29:41-72.

Vogel, Friedrich. 1992. Break-up of isolates. In *Isolation, migration and health*. Derek Roberts, Norio Fujiki, and Kansi Torizuka, eds. Pp. 41-54. Cambridge: Cambridge University Press.

Wallerstein, Nina, and Bonnie Duran. 2006. Using community-based participatory research to address health disparities. *Health Promotion Practice* 7(3):312-323.

Weijer, Charles. 1999. Protecting communities in research: philosophical and pragmatic challenges. *Cambridge Quarterly of Healthcare Ethics* 8(4):501-513.

Wood, Rulon, Damon M. Hall, and Marouf Hasian. 2008. Globalization, social justice movements, and the human genome diversity debates. A case study in health activism. In *Emerging perspectives in health communication: meaning, culture, and power*. Heather M. Zoller, and Mohan J. Dutta, eds. Pp. 431-446. New York: Routledge.

Zeng, Tian Chen, Alan J. Aw, and Marcus W. Feldman. 2018. Cultural hitchhiking and competition between patrilineal kin groups explain the post-Neolithic Y-chromosome bottleneck. *Nature Communications* 9:2077.

Zulaika, Joseba. 2000. *Del Cromanon al Carnival. Los vascos como museo antropologico*. Donostia: Erein.