**Anne Hambro Alnæs** 

**Abstract** This chapter examines and discusses certain similarities and differences between established national art collections and evolving public biobanks. Such a comparison has the merit of sharpening our awareness concerning the rights and duties pertaining between collectors and donors. Tracing the way in which some works of art have been acquired in the past, and considering more recent examples of bioprospecting, it becomes evident that collecting exists along a continuum from people's altruistic donations, via deposits, to commercial acquisitions, as well as illicit appropriations hardly discernable from confiscation and theft. Comparing collections of biologicals with art galleries shows that analogies are polysemic and depend on being interpreted in line with some, but not with other connotations, if they are to add to our understanding. Both national art galleries and depositories of biologicals represent iconic and indexical representations of considerable value for future scientific research and as archives for posterity. It is up to future researchers to unlock the as yet unknowable information embedded in present biological depositories. This chapter aims at shedding light on which rules for preserving, dissolving, selling, or abandoning different kinds of collections should prevail. Analogies have a didactic potential, which at the same time carry normative implications.

### Introduction

The uniting theme of this book is how to develop analytical tools to understand, define, and discuss ways of conceiving and managing depositories of human biological material. As the Norwegian law on "biobanks" implies (Norway 2003), the potential of such material is threefold: to increase diagnostic competence, to develop innovative therapy, and to enhance research endeavours to further medical

A.H. Alnæs

Section for Medical Ethics, Faculty of Medicine, University of Oslo, Oslo, Norway e-mail: ahambro@online.no

knowledge for future generations. These three kinds of biological depositories, subsumed under the term "biobank", render it somewhat difficult to capture the essence of these fledgling institutions (i.e. their ontology) with a single expression or analogy, as there always will be features in what is sought compared, which draw in different directions. However, the aim of an analogy is *not* to demonstrate a homologous relationship between the known and the unknown, but rather to discover differences in likenesses, and similarities between what *appear* to be different features. If not, the analogy would cease to serve the purpose of functioning as a heuristic tool.

In the present chapter, I want to explore the connotations elicited by existing nomenclature, "biobank", and to compare these with the implications and undertones embedded in art collections. These may be, I suggest, better suited to convey the creative potential of the different *kinds* of value as well as a number of immaterial *values* that are at stake in the expanding "wealth" of stored biological material. Perhaps a term like "biogallery" could serve as a heuristic device to bring forth other practical as well as ethical dimensions in the wake of establishing biological depositories?

When discussing the merits and disadvantages of the term "biobank", we must of course realize that we have already long passed the time of its birth, and the joining of "bio" and "bank" cannot now easily be undone. The choice of inputs to this metaphor was, I will argue, non-arbitrary and inherently a priori value laden. However, the point is not to replace the common use of the term "biobank" which is well ingrained; rather to examine whether alternative terminology could sharpen our awareness about the non-obvious, and perhaps dubious, associations emanating from the term biobank (henceforth without inverted commas). By suggesting a notion like "bio-gallery" I intend to compare the repository of human biologicals to public art collections. National Galleries are the property of a nation's citizens, which, according to most institutional statutes, cannot sell its pictures or sculptures, or exchange them for other art valuables in the open market. These are in a double sense priceless, even though the cost of insuring them when they occasionally go on tour to other galleries temporarily necessitates evaluating individual works of art in economic terms.

People's concerns about biobanks are partly due to an uneasiness some experience about the possible commodification or misuse of tissues derived from our bodies. Biologicals convey information about our "inner" selves, which many do not wish to make available to others. The possibility of identifying genes predisposing individuals to a variety of diseases, and cross-linking this information with other data, such as health care files and insurance policies, causes anxiety and raises questions about consent, benefit sharing, the regulatory power and possible politicization of ethics boards and data protection. However, as Søren Holm (Holm 2007) provokingly points out, if doctors are allowed and expected to pass on information about a would-be insurer's health record to the company in which he wants to be

<sup>&</sup>lt;sup>1</sup> A useful term to cover the plethora of biological materials, introduced in the early 1980s. See Landecker 1999: 204.

insured, there is no principled argument which should make it legally and ethically unacceptable to inform these companies of that person's genetic predisposition.

The use of analogies, metaphors and metonyms affords a way of probing into something unknown. This is a bold step to take for representatives of the exact sciences, such as medicine. Analogies are often used as rhetorical devices to reassure people that the "newness" of a concept is not at all threatening, but instead, rather close to something everyone is familiar with – only dressed up in new clothes. Hofmann et al. point out that, if the purpose of an analogy is to instill a certain conduct, the closer the two analogy components are, the more persuasive the comparison will be (Hofmann et al. 2006).<sup>2</sup> If we on the other hand prefer to use analogies as a way of exploring something unfamiliar, then a modicum of distance between the familiar and what is sought explained has greater potential. However, I will claim that analogies which make us see new connections are able to combine the two purposes just mentioned, even though analogies at times may be cognitively and emotionally demanding. Analogies, metaphors and models rarely involve a unidirectional transfer of meaning from source domain to target domain, but rather affect each other in a two-way, reciprocal manner. Metaphors that "work" consist of an imaginative bringing together of words and ideas stemming from different domains. As a result, and in hindsight, this subtly changes and expands their original meaning. Lakoff and Johnson describe the imaginative merging of words as "cross-space mapping" (Lakoff and Johnson 1980).

An expression such as the "living dead" can serve as an example: it is built on the Christian promise of eternal life after death in this world, a notion familiar to most people in the Western cultural sphere. It has since been transported into the secular realm to refer to patients who are neither alive, nor quite dead (according to traditional standards), i.e. those *liminal* persons evolving in organ donation situations, in the era of transplantation medicine.

For those involved in transplantation medicine, the "living dead" is a far less offensive term than "cadaver-donor" (commonly used in transplantation literature under the acronym CD); besides, it is better suited to capture what many still regard as the mysteries and miracles of transplantation medicine. The innovative effect of the living dead metaphor is that the decisive factor for being declared dead have changed (from cardiovascular to brain death), just as the criteria for being considered alive nowadays no longer depend exclusively on maintaining a heart beat, but rather on blood circulation to the brain.

If the analogy between national art collections and central depositories of biologicals is to have any leverage, we first need to agree whether possible similarities between works of art and human biological material<sup>3</sup> may have any argumentative

 $<sup>^2</sup>$  For this, see also chapter "Mapping the Language of Research Biobanking: An Analogical Approach".

<sup>&</sup>lt;sup>3</sup> The German pathologist Gunter von Hagen did something which can be compared to Duchamp's historical elevating of the urinal as a work of art. Through a plastinating preservation technique he developed, von Hagen exhibited a collection of dead persons' bodies in postures from every-day life, such as sitting at a desk, running or driving a motor bicycle. He also displayed aborted embryos.

hold. A patient's blood and tissue samples are clearly not the result of artistic visions. In the world of medical research, cells and tissues have to be extracted, isolated, preserved and developed through the re-working and analysis by laboratory technicians, pathologists or haematologists. It is only the reworking and interpreting of what was our bodies' physical materials which makes them scientifically valuable and hence, in a certain sense, comparable to works of art. In the hands of experts, otherwise perishable biological tissue is metamorphosed into specimens to be inspected and analysed for their morphological properties and biomedical patterns. It is the adding of fixants and transformation by various biomedical techniques, that prevents biologicals from degrading into non-informational waste.

The fact that the establishment of national galleries is generally linked to the era of nation building does not render the concept obsolete for comparison purposes. On the contrary, the shifting patterns of national boundaries, e.g. the rebirth of countries which until 1989 formed part of the Soviet Union, such as the Baltic countries, show how establishing national identity through carefully targeted media-footage, e.g. about the uniquely heterogenic or homogenous character of one's population, remain an inherent aspect of nation building. Collecting and organizing the genetic pool of one's countrymen (as took place in Estland and Iceland) may similarly be seen as capturing the vitality of a dormant, but nonetheless national, resource. Indeed, this can be understood as the post-modern equivalent of the way people in previous centuries regarded their painters', composers' or writers' works as symbols of national identity.

For the reasons mentioned so far, it is timely to imagine alternative scenarios for how biological collections should be conceived and managed, before the national, or transnational policies (such as EU-legislation) governing them become immutable and fixed in issues of national prestige. When I use the word "imagine" it is to emphasize the importance of sharpening one's antennae for what may lie around the next innovation bend, instead of deducing and solving problems solely on the basis of other institutions' experience. As a well-known phrase reminds us: all comparisons are odious, which means that we must be wary of exaggerating the similarities at the expense of important dissimilarities between the associative components in analogies and metaphors, such as *biobank* or national *bio-gallery*.

#### Overview

In the following I shall first present some arguments for why I consider biobank a somewhat unfortunate way of referring to collections of human biological material subsumed in the term biologicals. Second, I will point out some perhaps unobvious (a) similarities and (b) differences between the familiar (art collections), and what is sought explained (the depositories of biologicals). Third, I will probe into the various kinds of relationships that exist and are reproduced between valuable objects, their collectors and custodians, and the "consumers" of these objects. I refer to "consumers" in a double sense: (1) figuratively, as when people visit and view works

of art, or art historians who research and write articles and books on the basis of works of art; or (2) in the case of biologicals, literally, in connection with biomedical researchers and the recipients of therapeutic substances such as e.g. blood or bone marrow. Fourth, before concluding, I shall consider various kinds of opposites to capture different paired ways of parting with and acquiring objects of value.

### Problems Related to Terminology

First, why am I to a certain extent sceptic as regards the term biobank? Fundamentally, it is because we here are dealing with a neologism which masks its unacknowledged metaphoric construction and therefore risks narrowing our view. An indication of tropes' seductive and persuasive power can be seen in the way politicians use metaphors. On a more general level, when we hear speakers using metaphors we see the issue being discussed from the speaker's point of view. We are enticed into following his or her arguments and hence tend more easily to agree to conclusions drawn.

The term biobank was clearly not created ex nihilo. I presume that the concept was born with intended alliteration, like in *b*lood *b*ank, *b*ody *b*uilding and in *b*ed and *b*reakfast. Catchy coining makes new expressions easier to remember (compare biobank to e.g. "biogenetic storehouse", "biotank" (ref. "think tank") or "biotarium" [reminiscent of other well-known concepts like "planetarium" or "arboretum"]). Moreover, the coupled *b*s in blood bank and biobank facilitate the design of visibly pleasing and easy to remember logos, to be used in recruitment campaigns.

In a cautioning commentary to Hofmann et al.'s article about the analytic usefulness of analogies, López (2006) points out that the French Commité Consultatif National d'Éthique (CCNE 2003) was careful not to use the term biobank and instead studiously referred to "collections of biological material and associated information data" (my emphasis). By examining the construction behind taken-forgranted metaphors such as biobank, we can appreciate how politicians as well as representatives of biocapitalism – such as the pharmaceutical industry – use neologisms to subtly persuade the public into accepting *their* point of view (here: the primarily positive potentials of biobanks).

Neologisms, especially those created in the absence of existing forms, are often constructed *experimentally* and aim to capture what initially is seen as the essence of the new entity. However, joining the financial sphere of "banking" with the universal givens of biology, as in the prefix "bio", can be seen as a devious way of placing biologicals within the realm of market economics and imposing a profit-maximizing way of thinking. This association proximity risks foreclosing alternative ways of perceiving the ontology, goals, dangers, constraints and opportunities that lie in the accumulation and management of biological material and data. One of them is the important question of altruism which has little to do with the principles of banking.

Titmuss' celebrated work on blood donation (Titmuss 1970) illustrates the importance of counting on, rather than discounting the appeal that altruism still has for

many people. Biotechnological development has of course 'since' vastly expanded the therapeutic and research promise contained in blood and blood products, and the realization of this potential has necessitated big economic investments which would not have occurred unless investors were given some control over investments and believed that these would generate profit. As a result, what started out as gifts has been reworked and developed into objects circulating as commodities, thus negating the sharp borderline which Titmuss argued existed between gifts and commodities. Describing this situation Kopytoff remarked that there has always existed a universal tug-of-war between the tendency of all economies to expand the jurisdiction of commoditization, and of all cultures to restrict it (Kopytoff 1986). The commoditization of human biologicals, e.g. blood, semen, ova and the recent possibility to "rent-a-womb", is no exception, and exemplifies how these issues are enmeshed in profound bioethical and moral webs of meaning.

Whereas altruism arguably is not a relevant concern for understanding financial banks, it is crucial for the constitution and management of collections of biologicals. These presuppose people's generosity and willingness to contribute without any other benefit sharing than a furthering of scientific insight and development of new medicines, achievements which possibly only future generations may "profit" from. Spreading doubts about people's altruism on a general level (e.g. as a Marxian form of false consciousness) risks, in my view, to backfire onto the more specific level of recruiting contributors to biobanks. This downplaying of any altruistic motivation reflects a Hobbesian belief in a "nasty and brutal world" in which people neither desire nor are able to behave unselfishly. Titmuss' analysis of blood-donation practices strongly suggests that an a priori negative view on people's altruism is mistaken. Indeed, his evidence showed that the number of voluntary blood donors in the UK actually decreased when blood donations were remunerated in cash. Titmuss' informants maintained that exchanging blood for money constituted a trivializing commodification, which to many donors acted as a disincentive. Applied to the discourse on biobanks, it is not inconceivable that contributors are similarly motivated by altruistic concerns in contributing to the general welfare of society, i.e. reflecting a communitarian approach. It should be pointed out though, that alternative definitions of altruism complicate the picture. According to some theoreticians, altruism is restricted to acts that involve placing the interests of others well ahead of one's own, i.e. excluding all acts in which self-interest is involved. In Titmuss' understanding, though, a degree of self-interest does not necessarily disqualify or preclude altruistic motivation. Donating a kidney to a close relation is to a certain extent also in the donor's self-interest, because the latter's wellbeing may depend on the ailing relative staying alive and being relieved from suffering.

In a more narrow understanding, altruism is motivated by a regard for the well-being of others for its own sake. However, according to a third point of view, self-interest and altruism are not necessarily always incompatible. Altruistic acts can for instance also be a way of increasing self-esteem, while at the same time intentionally benefiting others. This is perhaps not an uncommon mix of motivations among those who donate their art to public collections; for in addition to augmenting their own self-image, they may perhaps also enhance their public esteem and social

status, which again can be used as an entrance ticket to a country's cultural and established élite. According to a narrow altruism concept, this kind of motivation conceivably renders such donation acts slightly less selfless.

My other misgiving about the term biobank has to do with the way it gerry-manders trust. Future contributors to biological depositories will – presumably unconsciously – transfer society's generally positive attitude towards blood donation to biobanks, thereby reducing and/or postponing possible resistance towards such depositories. To quote Pierre Bourdieu, by playing on the linguistic resemblance between "blood banks" and biobanks, the latter gain "symbolic capital" from the former (Bourdieu 1977). According to Bourdieu, such symbolic capital serves as the subtle but necessary means through which the production and reproduction of social institutions is achieved, smoothing over possible resistance.<sup>4</sup>

As a consequence of the scandals of HIV (contaminated blood which caused the death of many haemophiliacs), people's previous blanket trust in blood banks has to a certain extent been eroded. It turned out that blood supplies were not only composed of blood from healthy altruistic citizens, but that stores were pooled with blood *purchased* from donors recruited in countries lacking sufficient control to eliminate HIV contamination. As a result, even receiving blood transfusions in connection with surgery has become a health risk in several countries.

A third reason for my unease with the biobank term is due to its additional and unfortunate connotations. Casting biobank contributors in the role of financial depositors, for instance, risks overshadowing the role of *altruism* which was, and still is, a crucial criterion motivating donors of blood and bone marrow (as it certainly also is for many donors of paintings, sculptures and other works of art). The role of "depositors" is on the other hand more in line with prevailing ethical principles of autonomy, enabling contributors to be framed as "participants" in "partnerships", i.e. in what appears to be reciprocal relationships with the collectors.

When we add the many negative connotations that now also stick to commercial banks, such as exploitative interest rates, corruption, risky investment schemes and bankruptcies (sic), it would probably have been well advised to have had a deeper discussion of the neologism<sup>5</sup> biobank, before choosing terms for legislation.

#### Similarities Between Biobanks and Art Galleries

It may still seem facetious to draw an analogy between national art galleries and the contents of a country's biological depositories. For what does a Renoir painting have in common with biological specimens, genetic information twins, or statistics on blood types and HLA-matching?

<sup>&</sup>lt;sup>4</sup> For more on symbolic capital, see below.

<sup>&</sup>lt;sup>5</sup> Random House Dictionary, second edition, 1991 does not contain the word, nor does the Encyclopaedia Britannica of 2007.

First, both national art galleries and depositories of biologicals function are archives. They are, respectively, storehouses of our cultural heritage and storehouses of biomedical information about a country's citizens in need of experts' handling. They can be interpreted as testimonies of identity, on a national or personal level.

Second, such collections have a number of organizational features in common:

- (a) Biobanks and art museums both collect their material according to established rules of inclusion and exclusion. Only pictures of acclaimed quality are deemed worthy of hanging on the walls of National Galleries. Art works are selected according to qualitative criteria such as skill, originality, and the artist's reputation and position in the history of art. The institutions containing biologicals are similarly run according to prescribed rules and regulations, whether they be collections of pathology slides from cancer patients, registries of people who have declared themselves willing to become bone marrow donors, storages of frozen blood products in blood banks, or institutions containing data on a given population's individual DNA profiles (such as those existing in Iceland and Estland).
- (b) Both types of collections depend on recruiting voluntary donors. Affluent art collectors are courted by gallery directors and fund raisers, in the hope of acquiring their art treasures either as altruistic donations, or as bequeathals. In the case of biobanks, recruitment consists of finding people who will consent to the transfer of their bodily tissues to institutions dedicated to either diagnostic, therapeutic or research purposes. I intentionally use the perhaps fuzzy term "transfer", to indicate that the character of the exchange of biomedical entities remains unclear. Are they *gifts* with or without strings attached, *donations* given altruistically, temporary *deposits* which can be withdrawn at any time, or more or less voluntary *extractions* carried out at hospitals or in doctors' surgeries?
- (c) Just as banks attract new (and keep old) customers by inferring reliability and confidentiality, so biobanks depend on the general public's long-term trust as regards these institutions' ethical soundness. Contributors expect openness about biobanks' motives and expected findings, as well as the risks and benefits befalling donors. In a similar way, the exhibition policies of art galleries are open and available to be seen and critiqued by reviewers and the general public.
- (d) Art collections, diagnostic records, biological samples and genetic profiles all represent iconic and indexical representations of considerable value. Bone marrow "banks" are virtual depositories in that they contain indexical information about potential donors' immunological profile. The costs of cross-matching and transporting vials of haematopoietic tissue are covered by the national health care system of the recipient. In a similar way, when works of art are sent abroad or to other galleries in the country, on temporary loans, the Ministry of Culture finances insurance expenditure and transport, pending on formal request and approval.
- (e) The most significant feature linking art collections and biobanks is that they both must be understood as systems of *communication*, and as encoding meaning. We read "meaning" into pictures and sculptures through training the eye to see beyond the colours, shapes and lines, and to recognize and interpret topics

and scenes through our cultural heritage. In a similar way pathology slides, MR-*imaging*, X-rays and PET *scans* are meaningless squiggles and clouded patterns to the medically uninitiated, but convey information about disease and irregularities to the specialist.

## Some Differences Between "Biobanks" and Art Galleries

As institutions, biobanks and art galleries also differ in several important respects. First, National art collections are accessible to the general public, whereas health records, genetic profiles and other biologicals are encoded sources of information available only to accredited officials and researchers.

A second distinction has to do with the contributors' legal rights to destroy what they have stored, compared to art collectors' disposal rights. As already mentioned, contributors to biobanks can demand that their own biologicals be withdrawn and eliminated. Under certain circumstances, such as bankruptcy, the custodians of these depositories may be forced to demolish their entire collection, even without the contributors' permission, to prevent sensitive information from falling into wrong hands or being misused. Life insurance companies could for instance use knowledge about clients' genetic predispositions as a way of raising premiums.

National galleries on the other hand, are enjoined to at all costs preserve and maintain whatever is entrusted them. Thus, an artist who has deposited or donated a work of art to a National Gallery cannot, even if s/he thinks the work is out of date or badly executed, demand that the Gallery destroy it.

The rights of private art collectors as regards their acquisitions are perhaps less clear. Collectors who buy at auctions are customers who choose to invest their money in paintings, instead of in expensive buildings or other forms of property. The Japanese businessman and art collector Ryoei Saito, who bought van Gogh's "Portrait of Dr. Gachet" at the then record-price of \$82 million, stipulated that when he died, the masterpiece was to be cremated with him. It is perhaps only thanks to the economic decline of Mr. Saito's paper manufacturing firm, which forced him to sell van Gogh's masterpiece (and Renoir's *At the Moulin de la Galette*), which prevented them from being irrevocably destroyed.

A third seminal difference has to do with the financial running of these two kinds of institutions. National Galleries are usually non-profit institutions aimed at benefiting the general public, educating children and students, and providing bases for art curators and researchers. National Galleries are primarily financed by governmental grants, which cover the costs of employees' wages, the acquisition of new works of art, expenditure and insurance premiums.

Depositories of biologicals, of which there may be several in a given country, can – but need not – be governed by commercial interests.<sup>6</sup> Research biobanks, which e.g. aim at isolating viruses and locating gene sequences that heighten

<sup>&</sup>lt;sup>6</sup> According to current Norwegian legislation, those who seek permission to establish a biobank are duty bound to inform the Ministry about economic interests and possible profits.

targeted people's risk of acquiring various diseases, prepare the ground for the development of new medicines and vaccines. However, the process of getting new pharmaceuticals from the laboratory, through a period of trials, to hospitals and doctors' offices, is arduous, time consuming and costly and usually in need of commercial backers. Investors who place capital in such ventures are motivated by the possibility of patenting their products and reaping profit.

A fourth difference is of course that works in art galleries are valuable and appreciated also due to the deep *emotions* which they evoke about the human condition. We feel pity on seeing Munch's portraits of TB-infected children, horror at witnessing Goya's rendering of an execution scene, and delight at seeing Breughel's "Children's Games". Paintings kindle our interest in ways of living in the past and open our eyes to problems in contemporary society.

In contrast, depositories of biologicals are the object of medical professionals' enquiring and unemotional gaze, something to study (research institutes), or a source from which to provide therapy for patients in need (of e.g. bone marrow). However, breakthrough discoveries and intellectual insight stemming from research on biologicals may evoke scientists' pride and the general public's admiration, which shows that achievements in the field of biomedicine are not entirely without emotional value.

A fifth disparity lies in the use of money, when forming collections and depositories of biologicals. While works of art can be bought as part of a National Gallery's policy to complete or expand its collection – through Governmental grants or sponsorship – when and if desirable works become available on the market, in most jurisdictions it is illegal to pay for raw biologicals. Collections of biologicals depend on recruiting willing donors or by passing laws which make the collecting of various medical data mandatory.

# The Relationship Between Collectors and Collectables

Collections of art and the way these are formed and run can perhaps provide a tool with which to scrutinize the different relationships that evolve between the differently positioned actors and the materials about which they compete.

Despite the laws that have been passed in several but not all countries, biobanks as yet mostly function somewhat ad hoc and according to trial and error, whereas National Art Galleries are well-established institutions. However, it is precisely such a diachronic perspective which may enable us to profit from the way art galleries over time have solved some of the problems that now beset contemporary collections of biologicals.

The contested ways in which much art has been collected across centuries, can now serve as a background against which to gauge the way contributors of biologicals should be recruited. National Galleries, on their side, might perhaps today profit from emulating biobank practice, i.e. by having an ethical committee which can be consulted, for instance as regards possible conflict of roles. Is it e.g. ethically and

politically warranted that a National Gallery's Board-chairman functions as a private art collector at the same time s/he is in charge of a nation's main art collection, as was the case in Norway from 2003–2007? Or is a more stringent separation of roles called for so as to avoid any conflict of interest? All kinds of collecting implies a coveting eye, strategic conduct, and a set of motives, which are not necessarily always transparent to those whose valuables are sought (see for instance the Moore case, discussed below). An important issue is therefore to consider the relationship between collector and contributor, and to uncover whatever hidden purposes may accompany the collecting process both as regards art and biologicals.

As briefly mentioned, we have not yet satisfactorily settled what kind of transfer takes place when human biological material is removed from people's bodies and transferred to depositories. The role, rights and duties of the contributors and managers are also somewhat unclear. Are the contributors to biobanks *customers*, as in saving banks, or *citizens* expected to do their duty for the common weal, both, or something in between? And who are the possessors and true managers of biobanks: The Health Ministry, the officially appointed national bioethics committee or the combined forces of medical and biotechnical researches and the pharmaceutical industry? The manner in which these transfers take place has implicit consequences for the way depositories of biologicals are to be managed.

I want to draw attention to the contributors' understanding of the exchange taking place and the very different rationalities guiding collectors' practices. Contestable degrees of ownership are involved when valuables "move house" from their erst-while owners, and are categorized and given institutional "labels". This applies equally to works of art and to biologicals, except in cases when the biologicals have been anonymized and therefore cannot be traced back to the donors. What happens to known donors' and depositors' rights when an institution changes its legal statutes (such as happened when Norway's National Gallery changed from being a national institution under Ministerial leadership, to a free-standing foundation)? Can contributors, whether in art galleries or in bio-depositories, be forced to accommodate to a given institution's new structure, or do new agreements and informed consent procedures need to be re-negotiated?

As will be seen, collecting exists along a continuum that stretches from people's altruistic donations, via deposits, to commercial acquisitions, to illicit appropriations, hardly discernable from confiscation and theft. Expanding our view to the way art collections have been formed in the past may sharpen our awareness about the overtones now present in the gathering of other valuables, such as biologicals.

In the subsections which follow, I start with the known (art galleries), in an attempt to shed light on the unknown (depositories of biologicals).

### Altruistic Donations

On one side of the continuum we find the selfless givers of both art and biologicals who donate without strings attached. When Olaf Schou donated his collection of

116 paintings by Munch and other seminal Norwegian artists to the National Gallery in the early twentieth century, they were intended to be shown, or stored, entirely according to the director's discretion. Munch, who normally did not like to part with his paintings, was willing to sell his works to Schou, knowing that they eventually would be donated to the National Gallery.

The altruistic donations of both biologicals and art become complicated and emotionally taut when the person or institution destined to become the recipient, for various reasons, is prevented from accepting the proffered gifts.

An ethically delicate situation may for instance arise when an artist wishes to donate one or several works, and the intended recipients consider them to be of insufficient quality, or the artist poses conditions as regards the way the work(s) must be exhibited. Sometimes the artist wanting to give away a painting or sculpture does so for an ulterior motive, namely to enhance his/her CV by including a sentence such as "the artist is represented in the National Gallery". If the Gallery accepts the donation, the artist is bereft of the pecuniary income s/he might have derived from a sale on the open market, on the other hand it enhances his/her "symbolic capital" (Bourdieu 1977).

Within the field of biologicals, a pure, uncorrupted form of altruistic donation takes place when the next of kin of a person suffering sudden death, consent to letting the deceased's organs be used for transplantation purposes. In Norway, families know they will never receive any external form of gratitude or recognition. The only kind of verbal – and therefore symbolic – reciprocity lies in the brief thank you letter from the National Transplant Unit to the family who gave their consent. The next of kin's donation is therefore based on altruism, although, if the dead person had pre-signed a donor card (which has only been possible in Norway since 2001), or in other ways made his/her positive attitude to donation known, it is the *deceased* who should rightfully be seen as the true altruist. However, compared to people who will their paintings or sculptures to a National Gallery instead of letting their family inherit the valuables, organ-donor cardholders do not in any way reduce the value of their estate. Their organs cannot be of any use to their survivors, nor can solid organs be preserved for future sale, which, besides, would be illegal.

Even if organs for transplantation are in short supply, legislation and ethical considerations sometimes make it necessary for the health care in charge of the donation to refuse the next of kin's "offer" of their deceased relative's organs. While conducting fieldwork at a hospital (Hambro Alnæs 2001) to study next of kin motivations in connection with organ donation, a doctor-informant told about a case in which the family had been adamant about their newly deceased's desire to have his organs used for transplantation purposes. The trouble was that the would-be donor did not qualify as brain dead, i.e. there still remained some blood circulation to the brain. For ethical reasons, the doctor was not willing to keep his patient on the mechanical ventilator, as it was uncertain how much time was needed to fulfil the legal requirements of brain death. In this case, the doctor felt compelled to decline the family's offer, a response which the family experienced as deeply humiliating. (Patients

<sup>&</sup>lt;sup>7</sup> Strictly speaking, they consent to transferring objects to patients in need, which they do not, and have never owned. They (only) donate *on behalf of* their dead relative.

suffering from diseases such as diabetes or cancer are excluded from becoming donors [except in cases of totally encapsuled brain tumours], even if the deceased and/or his or her next of kin were in favour of organ donation).

Countries which include a protocol called "Donation After Cardiac Death (DCD)" (as opposed to donation after *brain* death), defend their practice as a way of satisfying the expressed wishes of the person about to die, as long as there also exists a foregone agreement with the next of kin. However, such DCD-protocols are contingent on expanding the medico-legal criteria for donation, an issue which remains ethically fraught for many health care employees. The donation of organs, in other words, involves not only givers and recipients, but also mediators (doctors, nurses, transplant coordinators) whose skills and communicatory competence are of the essence for the transfer of these highly sought after and valuable biological gifts.

A willingness to donate biologicals or works of art is, in other words, not necessarily contingent on any duty to receive what is offered. Artists and art collectors cannot count on having their works accepted. This, of course, goes inherently against the sociologist Marcel Mauss (1990) well-known analysis of the universal rules involved in the exchange of gifts which – as he observed among pre-modern Maori – consisted in the duty to give, to receive and to reciprocate.

### **Deposits**

Deposits can be altruistic, such as when rare and extremely valuable musical instruments are given on *loan* by collectors to promising young artists who cannot afford purchasing them. Sometimes these loans are done anonymously, through an intermediary; sometimes the owners are well-known companies who wish to enhance their status by supporting and encouraging young artists' careers. These deposits can be likened to a right of use, or ususfructus, a form of temporary possession – which precludes the right to sell – as opposed to ownership.

Some painters similarly lend their works of art to galleries as deposits, an arrangement which can be seen as an alternative to costly storage with the added advantage that they will be seen by the public under the protection of guards and relatively safe from theft. Depending on agreement, the artist can in principle temporarily or permanently withdraw his/her work so as to take part in other exhibitions.

The borderline between donations and deposits is not always crystal clear, either in connection with works of art or biologicals. For the curators of National Galleries, the conditions attendant upon donations can even give cause to legal problems. One such incident occurred when the director of Norway's National Gallery wanted to re-hang its pictures as part of the new profile he wished to present to the public after the "new" National Museum<sup>8</sup> was established in 2003. This involved splitting the priceless Langaard collection, which had been donated on condition that the works

<sup>&</sup>lt;sup>8</sup> Based on the amalgamation of four national art institutions.

of art be exhibited as a unified collection in a single room. The heirs were provoked, and threatened to withdraw the entire collection. Compared to Mr. Schou's donation, the strings attached to the Langaard collection make the latter seem less of an unconditional gift, more like a deposit.

As regards biologicals, the principle of donations under restricted conditions seems most in line with present Norwegian biobank legislation. Current law specifies that the contributors of biologicals can withdraw their material at any time, and without giving any reason, as long as the samples are not anonymized or already used in a publication which has appeared or is about to go into print. Thus, while the contributors of biologicals cannot exert traditional property rights over their material once it has been sampled, they have retained significant dispositional rights, an arrangement which empowers contributors in accordance with the principle of autonomy.

Contributors of biologicals need to be approached again if their material is to be used for research which differs from the project they consented to originally. By their withdrawal the contributors can demonstrate their disapproval, e.g. if they consider the new protocol unethical. An exception, however, is when the projects in question are part of a national overview such as e.g. Norway's personalized registry of all cancer diagnoses, or the national registry of all diagnosed causes of death. In these cases, the need to secure epidemiological data overrides the autonomy of the individuals who provide the bases for these registries.

If the donors of biologicals maintain the right to withdraw their material at any time, then surely their contributions resemble deposits more than gifts, and Langaard more than Schou. Biological contributors' rights at present seem to fit better within the more self-interested frame of "biobanks" than within the domain of altruistic gifts. If they haven't been anonymized, biological deposits appear to be reversible and retractable. This situation differs from the unconditional altruism evident in the donation of organs. The next of kin in organ donation situations are called on to act as communitarian-minded *citizens*, whereas the contributors of samples retain *customer*-rights.

Why the contributors of other kinds of tissues, including blood, should have different and stronger rights, needs further explaining. Reserving oneself against the use of one's donated blood in certain research projects corresponds to a view that a person's tissue – after it has been detached and treated with fixants – continues to represent a person's inalienable identity. This metonymic way of thinking, i.e. founded on association by contiguity, is the principle behind sympathetic magic, which seems a far cry from the rationalities otherwise guiding biomedicine. But practice does not seem to be fully consistent. If blood donors learn that their donation might go to treat wounded soldiers in a war of which they disapprove, the donors can all the same not withdraw their blood. Bone marrow donors, on the other hand, can decide not to go ahead with their planned donation, even when the recipient has already started his/her often gruelling de-construction of immunological defences, in preparation of transplantation.

<sup>&</sup>lt;sup>9</sup> See Jakobson 1956.

#### Power

Whereas the depositories of biologicals presuppose recruitment strategies, the job of leaders of National Galleries lies in encouraging private collectors to relinquish their art treasures to enhance the public weal. They are collectors *on behalf of* the general public. Although both, seemingly, act in the role of supplicants, they do so from positions of power. While power is notoriously difficult to define (Barth 1993), most people know how powerlessness is experienced.

From the point of view of the Greek nation, the acquisition of the Elgin Marbles was the result of an unethical exercise of asymmetric power, a point of view which can be said to resemble Mr. Moore's opinion on Dr. Golde's appropriation of his lymphokines (see below). For several decades now the Greek Government has argued that the Parthenon Marbles should be returned to their "homeland", as they are the most profound symbol of Greek history and identity. The British Museum argues that Thomas Bruce, the seventh Earl of Elgin and ambassador to the Ottoman Empire, had purchased the sculptures and frieze legally. The Greeks, however, claim that Elgin took advantage of the Ottoman occupation of Greece, by obtaining a vague and untraceable *firman* (license to purchase) from the Sultan. To begin with, the Sultan gave Lord Elgin permission to remove the freestanding sculptures; however, Elgin used the volatile political situation to help himself to the monumental frieze forming part of the main temple as well. The British Museum rejoinder has been that the marbles would have eroded and been lost for posterity if Lord Elgin had not purchased these monumental sculptures and brought them to London. According to the British Museum, the Marbles were legally bought, and now morally owned by the museum.

For the collectors of biologicals, this example of power wielding from the early nineteenth century serves as a reminder that informed consent consists of more than signing a document and that consent of this kind is only valid if the contributors fully understand and agree to what and why they give. From a different perspective, the Elgin Marbles also exemplify the importance of salvaging valuables from destruction. There is little evidence that the Greeks at the time of the purchase attached any significance to the ruins of the Parthenon. This and other examples from the art world may also serve as a cautionary note for collectors of biologicals to keep samples and data in professional storage, even when their immediate value is not evident. Neither the donors nor the collectors of biological specimens can foresee what scientific insight may evolve from such collections. Unless the storage of biologicals represents a public health hazard, the duty to responsibly preserve what can arguably be seen as a biomedical resource is not different from a national museum's duty to store and maintain the works of art in their collection, either within the Museum itself or in storehouses elsewhere. Donations of both kinds of valuables are per force based on the donors' implicit trust that they will not be misused or squandered and that custodians will ensure that the deposits are treated according to appropriate ethical rules and accountability.

Let us consider the power dimension in connection with the recruitment of contributors of biologicals. Such recruitment usually takes place at hospitals, blood

banks, and/or in doctors' surgeries. Doctors' offices and hospitals are spaces in which the situation can be crudely defined as: patient in need of therapy or guidance seeks doctor's care and advice. When GPs or hospital doctors ask their patients to participate in research protocols, this approach has been criticized for being slipped in between other health concerns and as being insufficiently explained. In medical consultations, the asymmetric distribution of power stems partly from doctors' virtual monopoly in interpreting medical facts, risks and proposal of therapy. Access to medical information on the Internet has not changed the situation drastically: patients – according to some professional (personal communication) – still lack the education and insight to differentiate between robust arguments based on complex knowledge and more spurious, un-evidenced articles; so the "homework" the patient does ahead of his meeting with the doctor, is often riddled with misunderstandings in need of time-consuming clearing up.

As regards bone marrow donors, recruitment is layered. Blood banks carry out the initial, preliminary drafting, which is followed by a more comprehensive enrolment process, if the potential donor after a period of reflection is still willing to participate. Enrolment involves HLA-typing, medical examinations and a thorough explanation about what being a bone marrow donor entails for the donor, such as sometimes having to donate several times (e.g. if the first transplantation is not successful), the necessity of having injections to stimulate the production of stem cells, and the possibility of having to undergo general anaesthesia if peripheral blood donation is unsuccessful. Informing about bone marrow transplantation would be one-sided unless the donor also understands the life-saving benefits bone marrow transplantation represents for the recipient. However, such information can hardly fail to place an enormous responsibility and moral pressure on the potential donor, hence rendering it extremely difficult to cancel donations at the last minute. Although the two-step process may appear to be a way of diminishing the asymmetry between the "brokers" of bone marrow, i.e. the doctors and the donors, the situation can equally well be interpreted as exemplifying a form of symbolic violence (see below).

The exercise of power is particularly contestable when trust is assumed but violated. Since cell lines are such a contested issue and the primary goal of several research biobanks, I want to revert to two now famous instances.

The well-known HeLa cell line, named after an African-American Baltimore housewife, Henrietta Lachs, was developed on the basis of her cervical cancer tissue which had unusual cell division properties. Over the years, copies derived from this patented cell line were first given to researchers free of charge, later sold to scientists and laboratories for considerable amounts. Nobody at the time asked the patient for permission to use her tissue, and despite later requests from her husband and children, Lachs' survivors never received any economic remuneration.

The famous Mo-line (later renamed "RLC") was the result of what in hindsight came to be seen as the result of an ethically questionable relationship between patient and therapist. Mr. Moore suffered from hairy-cell leukaemia. During several months of treatment and before advising his patient to have his spleen surgically removed, Mr. Moore's doctor, David Golde, discovered that his patient

produced unusually large quantities of lymphokines. These, he knew, could be used to develop a potentially profitable cell line. During eight months following splenectomy, Dr. Golde repeatedly called his patient in for follow-up consultations which he used as a pretext for taking further blood-, bone marrow-, skin- and sperm samples.

Mr. Moore's suspicions were raised when Dr. Golde requested him to sign a document in which he granted the University of California rights to any cell line or product made from his blood, a document he refused to sign. Mr. Moore instead hired a lawyer, and a ten-year Odyssey from court to court ensued. Mr. Moore claimed that Dr. Golde had taken tests on false premises, without first seeking his consent or informing him about the potential economic profit. Mr. Moore's repeated court appearances were by many understood as being primarily motivated by a desire to be awarded a share in the economic benefits ensuing from what he saw as "his" cell line. In addition, Mr. Moore claimed that Dr. Golde's manipulation of him had blocked his opportunity of donating tissue to "enable *other* researchers to make the most of these discoveries".

Seen from a power perspective, it can be argued that given his serious illness, Mr. Moore lacked adequate informed consent *competence*. As Dr. Golde had been silent on the question of possible economic gain, Mr. Moore was implicitly led to believe that the numerous tests he was required to take were to provide him with the best diagnosis and therapeutic possibilities. Dr. Golde's conduct can thus be seen as setting the stage for a *therapeutic misconception*, which occurs when a patient believes his tests are taken to enhance curative possibilities. As became clear, Mr. Moore's samples were part of a different agenda. Dr. Golde needed to secure sole access to, and control over, Mr. Moore's exceptional lymphokine-rich spleen, in order to file for patent rights and subsequently reap the economic profit from the cell line he planned to and succeeded in developing (in collaboration with his research assistant Shirley Quan).

Mr. Moore's well-organized effort to ensure some form of benefit sharing between the contributor and scientist came to nothing. The successive law suits focused on distinguishing between on the one hand the raw material (Mr. Moore's spleen), which would have been useless if it hadn't been developed as a research vehicle, and on the other hand the re-worked tissue which through Dr. Golde's intervention and scientific prowess resulted in an entirely different entity, of great biovalue. Some saw the courts' rulings as condoning confiscation, others as ensuring that research efforts should not be stymied by demands from the person whose biologicals are used. Denying Mr. Moore rights to the dividends of the Mo-cell line was seen as a way of empowering the research community, which in turn could benefit the general public. Mr. Moore's demands to exercise autonomy over his own tissue were seen by the court as a legally irrelevant topic of contention.

The conflict stood, and stands, between intellectual property right advocates who claim that the scientific endeavour depends on rewarding innovators and tempting investors; and those who are concerned about the need to protect the equivalent of a biomedical "commons"; the latter wish to protect certain kinds of human tissues and information about tissues and genes from commodification. The conflict in many ways mirrors the competitive struggle that took place in England from the twelfth

to the nineteenth century, over the so-called enclosure, i.e. the land over which the community held disposition rights. The manorial lords gradually succeeded in privatizing the "commons" in order to increase their own amount of full-time pasturage, at the expense of grazing rights for villagers' livestock.

The power relations between collectors, donors and recipients are contextual, contingent on timing, context and the often unequal distribution of knowledge between the interactants about the objects' real value. After Mr. Moore unsuspectingly had let Dr. Golde take samples from his spleen, and agreed to splenectomy, he was de facto rendered powerless. Dr. Golde had the raw material from which to produce biovalue, exemplified in the ensuing Mo-cell line.

In comparison, doctors hold less power in necro-donation cases. However strongly the requesting doctor is motivated to secure organs for donation, the outcome in each case depends wholly on consent from the bereaved family and/or prior confirmed statement from the deceased patient. Potential bone marrow donors are in a similar position of power vis-à-vis the requesting doctor and the patient in need of such therapeutic HSCs. Donors can withdraw their offer to donate at any point in the process without incurring any negative repercussions from the medical establishment or doctors.

Art collectors' power sometimes resides in their superior knowledge compared to those who apparently voluntarily give, or sell their objects for a pittance. As mentioned above, the Parthenon Marbles were not seen by the Greeks as valuables at the time Lord Elgin negotiated his deal with the Sultan. Nevertheless, for the Greek nation, the frieze, particularly, represents a key symbol (Ortner 1973) of Greek identity and nationhood. After lengthy legal battles, the Paul Getty Museum has recently returned a substantial number of art treasures to Greece and Italy because of incriminating evidence about how these objects had been "found", acquired and exported to the US.

The exercise of power is thus closely linked to the unequal knowledge of positioned interactants. A way of reducing this gap in connection with the collection of biologicals is to empower the national bioethics boards, and for the government to support the spread of knowledge to the general public, even, or especially, when existent legislation is scrutinized and critiqued. Part of the officially appointed Norwegian Biotechnology Advisory Board's (*Bioteknologinemnda*) role in Norway is to increase the transparency of the biomedical community by e.g. arranging regular public meetings where national and international experts come together to discuss contentious issues within research and health politics.

# Appropriations-Extractions-Confiscations

These are not synonyms to be used interchangeably, as their appropriate use depends on context and crucially on the differently positioned actors' knowledge and motivations. There exists a significant difference between coercing people into handing over objects which they themselves value and wish to keep, and the transferral

of objects when one of the partners knows he is dealing with something of great potential value, whereas the other believes s/he is giving away trivialities, as the Moore case and the Elgin Marbles exemplify.

Dr. Golde's treatment of Mr. Moore constitutes an example of what has later been critiqued as "biopiracy" and "bioprospecting" (Nelkin and Andrews 1998).

In the world of art collecting, the Soviet Union's justification for appropriating the war booty stemming from World War II represents a noteworthy example of declared confiscation. The Soviet army seized 300,000 works of art, among them a rare Gutenberg Bible, paintings by Matisse, Renoir and Manet, and the Trojan gold treasure discovered by Heinrich Schliemann. Some 50 years after the peace agreement (1995), this trove of art resurfaced from hiding and was openly appropriated by the Russian State as *compensation* for the devastations caused by the German army, even though many of the works consisted of paintings and art objects stolen by the Nazis from innocent Jews. According to the *Duma's* ruling, only victims in countries who fought against the Germans had the right to claim restitution of cultural valuables.

In Western Europe, the Austrian government's treatment of the Rothschild art treasures, confiscated by the Gestapo and their Austrian accomplices after *Anschluss* in 1938, affords another example of extraction euphemized as "donations". In 1947, Louis Rothschild's niece Clarice was given custody over the crates of art treasures, which had been systematically categorized and stored in a salt mine outside Salzburg. This was not, however, the same as reclaiming the family's stolen goods. Even though the Rothschilds were war victims, the Austrian government decided to apply a law introduced after the World War I as a pretext for preventing Rothschild's private collection from leaving the country. After much legal haggling, export licenses were provided over a period from 1947 to 1950, but only in exchange for "donations" to Austrian museums and galleries. Ironically, the labels informing visitors about these exhibits now read: "dedicated by Clarice Rothschild, in memory of Alphonse Rothschild".

This first instance of art appropriation exemplifies an extreme case of cutting of strings between the rightful heirs on the one hand and the paintings and other art treasures now forming part of Russia's art collections. In the second case, the Austrian Government used an old law as a bargaining tactic to pry loose some of the Rothschild treasures from the heirs of their erstwhile owners. The cases illustrate what Callon has aptly called "disentangling" processes (Callon 1998).

Callon first employed the word "entangled" to describe the character of organs from brain-dead patients. These perishable valuables cannot be stored outside the body, and must be reattached to the blood vessels of the recipients within the course of a few hours. The transfer of organs is also restricted by their immunological profile, to prevent the graft from being rejected by the recipient. Consenting to donation presupposes relinquishing ownership and disposition rights, which in its turn depends on cutting the symbolic strings attached to these organs.

Callon's "entanglement" and "disentanglement" terms can be used to critique disposition rights over other kinds of biologicals. As just mentioned, the next of kin relinquish all rights when they consent to organ donation. In connection with

other non-anonymized biologicals, however, the contributors maintain dispositional rights, for instance the possibility of withdrawing their material if they do not wish it to be used in a particular research protocol. This is noteworthy, considering that most contributors in donation situations regard their deceased's heart, lungs and cornea or other organs as significantly more inalienable than a vial of blood.

The doctors helping themselves to Mr. Moore's and Henriette Lachs' "raw material", without prior consent, can be seen as an illegitimate cutting of strings. This may not be quite the equivalent of appropriation, confiscation or extraction, since the question of ownership was debatable, even if it in practice amounted to the same. Disentanglement can perhaps be likened to the cutting of the umbilical cord. The birthing mother does not "own" her child, resembling the way contributors of samples do not "own" their samples either.

In UK legislation it is quite clear that a person cannot own his/her body. S/he has sole disposition rights over her/his body while alive, but only as against others' possible claims. Bodily gifts are irreversible, and the giver relinquishes all rights after the transferral, although even this unquestioned doctrine has recently been disputed. In the Moore-case, the US Supreme Court judges' ruling established a fundamental distinction between undeveloped human biological materials, which normally would have been treated as "waste", and the biological entities resulting from *inventions* based on such material. In the judge's view, Dr. Golde's error consisted in a breach of fiduciary duty and a failure to inform his patient about the intentions of his research. But from Mr. Moore's perspective, the illicit extraction of his lymphokines amounted to appropriation and confiscation.

To briefly return to the question of power, the ways of appropriating, extracting, confiscating or surreptitiously stealing biologicals described earlier up, can all be seen as instances of Bourdieu's "symbolic violence".

Bourdieu coined the expression as an extension of his term "symbolic power". He urged social scientists to always be on the outlook for and identify power, particularly where it is least obvious. When power asymmetry is accepted and referred to as "natural" by the dominated, there is reason for others to reflect on the researcher's role and ulterior motives. As opposed to the overt, enforceable power embedded in legislation, Bourdieu defines symbolic violence as that invisible capacity:

"to impose the means for comprehending and adapting to the social world by representing economic and political power in disguised, taken-for-granted forms", and "only through the complicity of those who do not want to know that they are subject to it or even that they themselves exercise it" (Bourdieu 1991: 164).

In a very different cultural context, the Amazon basin in South America, bioscientists have since the late 1970s sought out previously isolated and close-knit tribes such as the Karitiana Indians, the Surui- and the Yanomami peoples, to collect blood samples for research. This form of "biopiracy" has, arguably, replaced colonizers'

<sup>&</sup>lt;sup>10</sup> In 2009, a man who had donated a kidney to his wife (2001) demanded to have his kidney physically returned to him, or be paid compensation money. He claimed that his estranged wife who had been involved in several extra-marital affairs after receiving her husband' kidney had refused him access to their children, and sought to use the economic value of his donated organ as a bargaining plea in the couple's divorce settlement.

and missionaries' practice of helping themselves to indigenous peoples' carved figures and decorated weapons in exchange for pieces of cloth or other objects which the buyers deemed as having little value. In 1996, another bioprospecting team arrived, promising medicine in exchange for more blood samples, which were of great interest to the community of genetic researchers studying disease transmission over generations.

Contact with representatives of the Western World also resulted in access to the Internet. To the Karitiana Indians' consternation, they discovered that their blood and information about their DNA code was being sold around the world for \$85 per sample. And still no medicines had arrived in their settlements. Just as some people are against having photos taken of them because it involves a loss of "soul", so the Karitiana regarded the distribution of their blood and DNA as a violation of their integrity. Representatives of the Coriell Cell Depositories, a non-profit company, insisted that the samples had been collected in accordance with informed consent principles. However, it is questionable whether the Amazonian blood donors had sufficient consent competence, or any insight into the aims of Western medicine or modern bio-capitalist economics. From the Karitiana's and other Indian tribes' perspectives, they have been the victims of biological piracy or theft, Elgin–ed.

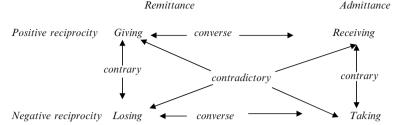
Disentanglement processes, through the strategic use of informed consent, like ways of redefining stolen art as compensation money, shows that the apparently neutral word "collection" sometimes masks over the highly questionable ways that these different kinds of depositories are put together.

# **Contributing Valuables: Seen from Different Positions**

Recruiting donors of biologicals and collecting art are basically concerned with the transfer of objects from private individuals to public institutions. The willingness of those who part with their "valuables" depends on how they view their "opposite number". Does one lose something when one gives a gift, or does one instead gain something, in a longer time perspective, as a promise of something in store for oneself or one's progeny?

Aristotle argued that the categories with the aid of which we think are informed by and are formed on the basis of likenesses and different kinds of opposites. Applied to the concept "gifts", giving is the contrary of losing, the converse of receiving and the contradictory of taking.

This, apparently abstract, model is relevant for understanding and nuancing people's apprehensions when and if they are asked to participate in a research project by donating samples. Do people whose tissue samples are collected during medical consultations experience that they have freely given, or rather, surrendered parts of their biogenetic material? Judging from the tribe-spokesmen's reactions in the Amazon area, the sampling of blood was seen as an illegitimate appropriation of something of great value to them by culturally ignorant biocommercial representatives. Part of their identity had in their view been stolen and was forever



Reprinted with permission from table C.A. Gregory's chapter 33. 'Exchange and Reciprocity', ref. Companion Encyclopedia of Anthropology, edited by Tim Ingold. Published by Taylor & Francis UK (1996) on page 923, table 2.

un-returnable. Their blood had already been globally distributed as specimens to research biobanks.

#### Conclusion

Seeing collections of biologicals as sharing important properties with art galleries, goes to show that analogies are polysemic and depend on being interpreted in line with some, but not with other connotations, if they are to add to our understanding.

Analogies have a didactic potential which at the same time carry normative implications. <sup>11</sup> If we put aside the unethical ways in which some art collections have been established, it would seem that the custodians of biologicals as well as bioethicists and health politicians could profitably reflect on the way art donors and public art museum directors conduct, and have conducted, themselves.

The fate of the Elgin Marbles continues to raise heated discussion. When the Museum of Modern Art in New York returned Picasso's "Guernica", this was the result of the painter's instructions in his will. In cases when works of art *are* returned to their proper owners, as happened with the Gustav Klimt paintings in Vienna's Belvedere gallery in 2006, this has been because they were stolen goods, not gifts. In the case of the Amazonian Indians, the premises for informed consent, namely that the donor understands what s/he is doing, were not present. Considering their lack of informed consent competence, their sense of loss and the damage done to their dignity, the extraction of their blood must in hindsight be recognized as a form of theft.

Another issue has to do with the destruction vs. protection of the valuables contained in biological depositories and national art collections. In such collections it would be regarded as unethical to destroy objects, even if e.g. the artist who has donated one or several of his or her paintings later wishes to destroy them because he/she regards them as badly executed and/or unrepresentative of his/her present

<sup>&</sup>lt;sup>11</sup> For this, see also chapter "Mapping the Language of Research Biobanking: An Analogical Approach".

point of view. In such, admittedly rather theoretical situations, the curators' evaluation would certainly overrule the artist's autonomy. Even if the artist has only *deposited* a painting in the Gallery, his/her work has already been judged as being of "national" value and hence his or her rights as depositor are perhaps not unlimited. The curators would in all likelihood claim that returning deposited works of art – when the artist's intention is to destroy them – would go against the public interest.

Although it is reasonable to protect contributors' biologicals for reasons of privacy, they also deserve to be protected for future research, and hence merit being stored as a national resource. The importance of salvaging these materials from destruction can be seen in the many documented examples of the way previously understood "waste" has later been transformed into "gold". Materials in biological depositories are subtly encoded, and it is up to future researchers to unlock the asyet-unknowable information embedded in them. If we disregard those collections, which according to legislation *must* be stored, it is in my opinion very unfortunate that the collections of systematically gathered and catalogued biologicals are not always saved for posterity and potential research.

Present legislation, which enables biological contributors to recall and destroy their material, can be seen as representing a somewhat overzealous respect for autonomy. It presupposes donors who believe that their biologicals have some kind of inherent power – resembling the way sympathetic magic is thought to function; whereas it is primarily the power of potential mis-users, which ought to be at issue. Such safeguarding, however, is, according to current Norwegian legislation, the responsibility of the national bioethics committees. The increasing emphasis on accountability and public support necessitates winning the general public's trust on a long-term basis. This is contingent on strengthening the independence of regional, and national bioethics committees, and on raising public awareness about the sine qua non of altruistic gifting for research for the research community.

It remains to be seen whether future contributors to biobanks are able and willing to see similarities between, on the one hand, donating blood for life-saving transfusions in the operating theatre, and on the other, the potential of donating blood for research purposes aimed at preventing and curing various diseases. Whether Titmuss' model – in which people's altruism and their negative stance towards economic compensation were key ingredients – will prevail over the model exemplified by Mr. Moore, in which expectations of dividends from research results were a central theme, cannot be predicted.

Using art galleries as a heuristic tool for probing into the nature and aims of biobanks enables us to distinguish and see similarities between gifts, deposits, extractions, confiscations and thefts which together form the sometimes dubious mixture of many countries' national art galleries. This list of noble and ignoble ways of procuring art constitutes a timely warning for the pioneers within biobanking. As a corollary, it highlights the important position of bioethics committees and their dual role as gatekeepers and bioethically reflective gate openers.

### References

Barth F (1993) Balinese Worlds. The University of Chicago Press, Chicago

Bourdieu P (1977) Outline of a Theory of Practice. Cambridge University Press, Cambridge, MA Bourdieu P (1991) Language and Symbolic Power. Polity Press, Cambridge

Callon M (1998) Introduction: the embeddedness of economic markets in economics. In: Callon M (Ed.) The Laws of the Markets. Blackwell, Oxford, pp 1–57

Hambro Alnæs A (2001) Minding Matter. Organ Donation and Medical Modernity's Difficult Decisions (Doctoral thesis). Oslo University Press, Oslo

Hofmann B et al. (2006) Teaching old dog new tricks: the role of analogies in bioethical analysis and argumentation concerning new technologies. Theoretical Medicine and Bioethics 26:397–413

Holm S (2007) Head to head. Should genetic information be disclosed to insurers? Yes. British Medical Journal 334:1196

Jakobson R (1956) Two aspects of language and two types of aphasic disturbances. In: Jakobson R, Halle M (Eds.) Fundamentals of Language. Mouton, The Hague, pp 55–87

Kopytoff I (1986) The cultural biography of things. Commoditization as process. In: Appadurai A (Ed.) The Social Life of Things: Commodities in Cultural Perspective. Cambridge University Press, Cambridge, pp 64–91

Lakoff G, Johnson M (1980). Metaphors We Live By. University of Chicago Press, Chicago

Landecker H (1999) Between beneficence and chattel: the human biological in law and science. Science in Context 12:203–225

López JJ (2006) Mapping metaphors and analogies. American Journal of Bioethics 6:49-57

Mauss M (1990) The Gift: The Form and Reason for Exchange in Archaic Societies. Translated by WD Halls. Routledge, London

Nelkin D, Andrews L (1998) Homo Economicus. Commercialization of Body Tissue in the Age of Biotechnology. Hastings Center Report 28:30–40

Norway (2003) Act on Biobanks, LOV 2003-02-21 nr 12: Lov om biobanker (biobankloven)

Ortner S (1973) On key symbols. American Anthropologist, New Series 75: 1338–1346

Sankar P (2004) Communication and Miscommunication In Informed Consent to Researcyh. In Medical Anthropology Quartlerly. Washington. 18, 4:429–447

Titmuss RM (1970) The Gift Relationship: From Human Blood to Social Policy. Allen & Unwin, London