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Geneticization and Biobanking

Abstract: While biobanks constitute an indispensable source of scientific data, they also generate many concerns related to the ethical, legal and social aspects of acquiring and storing of human biological material, particularly when it comes to the matters of privacy and confidentiality of data and commercialization of research results. It is important as social perception of biobanking may have a bigger impact on the donors than real scientific achievements, while negative images of biobanks may negatively influence the readiness to donate. This, in turn, may impede the functioning of biobanks. Thus, the aim of this paper is to describe the main social anxieties related to gathering and usage of human biological material. Beginning with the concept of geneticization, the paper will tackle the most important social concerns regarding biobanking: creation of a unique genohype, geneticization of diagnostics and identity, the risk of genetic discrimination and commercialization of genetics and gene patenting.

Keywords: biobanks, biobanking, ELSI, geneticization, genohype

Introduction

The announcement of the first draft of the human genome in the year 2001 resulted in emergence of a new paradigm: genetic determinism (Rose 1995; Strohman 2003; Łuków and Żekanowski 2005), and by opening new areas for medical interventions, especially in the field of diagnostics, it has created a vision of science that promises to solve most of the world's health problems. This trend is further intensified by the rapid progress in genetics, genomics and epigenetics which contribute to an increase in significance of collecting and storing of samples of human biological material. This, in turn, has resulted in the rapid development of biobanking institutions (De Souza and Greenspan 2013; Pawlikowski 2013) which exemplify social expectations that scientific research will help to identify the genes responsible for many diseases and bringing hope for personalized preventive and therapeutic programs (Hewitt 2011). Such expectations stem from the conviction that a combination of genetic and medical data from a wide spectrum of population will enable establishment of correlations between genes, environment and diseases. Such an approach, will generate new knowledge about the pathogenesis of many diseases, contribute to the development of novel therapies and improvement of medical care.

Nevertheless, although biobanks are the key source of data necessary for scientific research, there are also many anxieties surrounding ethical, legal and social (ELSI) issues

related to acquiring and storing of biosamples, especially in terms of privacy and confidentiality of data and commercialization of research results (Budin-Ljøsne, Harris, Kaye et al. 2012; Bledsoe 2017; Caulfield and Murdoch 2017). The reason for these concerns is that the social implications of a new genetics and biobanking exceed their original purposes, i.e. development of modern diagnostics and therapies, as basic categories of genetics transform the way we understand health and disease, human relations and social institutions. It is important as social images of biobanks may have a much bigger impact on the public perception of biobanking than real scientific achievements (Ogbogu, Toews, Ollenberger et al. 2014).

At the same time, while biobanking for clinical purposes has a long tradition in Poland, gathering human biological material for non-clinical purposes, i.e. scientific research, and population biobanking in particular, has just started (Pawlikowski, Sak and Marczewski K. 2010; Pawlikowski 2013: 51–63; Kozera, Strapagiel, Gleńska-Olender et al. 2018). Consequently, it is not surprising that a large part of Polish society do not possess adequate knowledge on the purpose and range of the activity of biobanks. Moreover, many people do not event know that such institutions already function in the country (Krajewska-Kułak, Kułak, Van Damme-Ostapowicz et al. 2011; Pawlikowski 2013: 108–111). Thus, while many people express positive opinions on the idea of establishing (national) biobanks and declare readiness to donate their biological samples for research purposes, lack of knowledge about and negative images of biorepositories correlate with respondents' reluctance to participate in biobanking (Krajewska-Kułak, Kułak, Van Damme-Ostapowicz et al. 2011: 103).

Functioning of Polish biorepositories is also hindered by the fact that many biobanking institutions do not meet basic ethical and organizational standards in terms of informing the donors, coding their samples and informed consent. Although the majority of Polish biobanks obtain written consent (92%), only one half (54%) of donors have a chance to talk to the biobanks experts, and only 29% distribute easily accessible information leaflets to donors (Pawlikowski, Sak and Marczewski 2009: 508; Pawlikowski, Sak and Marczewski 2011: 898). Moreover, as Poland still lacks legal regulations in this matter, each biobank has to establish its own code of conduct and organizational principles; the reason being that current Polish legal regulations apply mainly to tissue banks and those that gather biological material for transplantation purposes, blood banks and blood donation centers, and not to biobanks established for scientific purposes[1] (Pawlikowski 2013: 58). Another problem results from the fact that while there are around forty large biorepositories in Poland, including three population-based biobanks working locally (in Wrocław, Łódź and Białystok) and many other specialist biorepositories (Kozera, Strapagiel, Gleńska-Olender et al. 2018: 14), they do not cooperate with one another. Consequently, just until recently, Poland

[1] In Poland biobanking, especially for clinical purposes, is regulated by the so called transplantation act, i.e. the act from July the 1st 2005 on the gathering, storing and transplantation of cells, tissues and organs, which was promulgated by the National Center for Tissue and Cell Banking that coordinates and controls the development and functioning of biorepositories. Nevertheless, in reality it does not supervise biobanks that gather biological material for research purposes. On the other hand, the Polish National Blood Centre supervises and coordinates only blood banks and blood donation centers (Pawlikowski 2013: 51–63). For that reason, a few years ago, a discussion began on standardization of ethical and legal aspects of biobanking in Poland.

lacked both a national network of biobanks and unified organizational and legal standards for working on human biological material[2].

Therefore, because establishing any new biobank is not possible without a contribution from a large number of donors who offer samples of their biological material for scientific research, it is also crucial to know the attitudes of the public toward biobanks which influence the level of trust and support for the idea of biobanking of human biological material. Thus, as there are plans of establishing a Polish national genomic biobank for research purposes (Sak, Pawlikowski, Goniewicz and Witt 2012; Witoń, Strapagiel, Gleńska-Olender et al. 2017; Kozera, Strapagiel, Gleńska-Olender et al. 2018) this paper aims to describe the most important social anxieties related to geneticization in the context of biobanking: emergence of discourse of exaggerated claims over genetics, application of the genetic model to interpretation of most diseases, the risk of genetic discrimination and commercialization of genetics, including gene patenting.

The Geneticization Thesis

Social anxieties related to genetics and biotechnologies are best exemplified by the concept of geneticization formulated in the 1990's, by a Canadian researcher Abby Lippman. The term itself refers to a process by which: 'the differences between individuals are reduced to their DNA codes, with most disorders, behaviors and psychological variations defined, at least in part, as genetic in origin' and 'interventions employing genetic technologies are adopted to manage problems of health' (Lippman 1991: 19). Geneticization defined as such has two dimensions: conceptual and practical. The former manifests itself in the increasing tendency to define health and disease in terms of modern genetics, and the latter is characterized by promulgation of genetic technologies to diagnose and treat states which earlier have been defined in other way (Lippman 1999).

Indeed, increasing molecularization of medicine leads to constant stressing of genetic factors at the expense of the entire organism. Consequently, many researches on the etiology of disease are conducted at the molecular level, as more and more diseases are defined on the genetic level or statistically evaluated presymptomatic genetic risk rather than the entire organism, particular organs or cells (Hedgecoe 2001, 2002; Novas and Rose 2000). At the same time, apart from its technological dimension, geneticization manifests itself on the social and cultural level, as many social institutions engage in promotion and application of genetic technologies. This in turn transforms functioning of these institutions. Among these the leading role is ascribed to biobanks which are being established in many countries (De Souza and Greenspan 2013).

Thus, one of the effects of geneticization is that entire human biology is being equated with genetics and most somatic diseases, psychiatric disorders, physical features, personality traits and human behaviors are interpreted in genetic terms, while genetic technolo-

[2] Since 2013, Poland has formally participated in the activities of the European research infrastructure for biobanking—BBMRI-ERIC, and is currently establishing its own Polish Network of Biobanks which meets the standards for biobanks and cooperation to guarantee development of biomedical sciences and international collaboration between Poland and other countries (Witoń, Strapagiel, Gleńska-Olender, Chróścicka et al. 2017; Kozera, Strapagiel, Gleńska-Olender, Chrościcka et al. 2018).

gies are prioritized as the best solutions for many human health problems (Lippman 1991; Hedgecoe 1999; ten Have 2001). While it is hard to deny that geneticization of medicine rests on a solid, rational basis, and frequently takes a moderate form, when it also stresses the role of the environmental factor in the etiology of disease, its critics argue that geneticization results in a unique colonization and expansion of genetic thinking into dimensions that should be explained in a different manner. Therefore, it is not propagation of biotechnologies in medical practice itself that has been criticized, but rather excessive generalization of genetic way of thinking, which rests on the following premises (Domaradzki 2017a: 15–16):

- genetic reductionism, which stresses that all features and functions of living organisms can be explained by the description of molecular processes and mechanisms occurring in particular genes (Strohman 2003; Łuków and Żekanowski 2005),
- genetic determinism, which argues that all biological processes in the human body are of genetic character, and external factors, including the environment, play a minor role, as all the information about any disease is written in the genes (Rose 1995; Strohman 2003),
- genetic essentialism, according to which entire instruction on the structure and functioning of the human being is written in the genes, and DNA itself constitutes the essence of being, an ontological basis of self and uniqueness of a person (Phelan 2005; Dar-Nimrod and Heine 2011; Domaradzki 2017b),
- genetic fatalism, which stresses that due to unique and stable nature of DNA, human character and all other features are already predetermined and unchangeable (Alper and Beckwith 1993).

At the same time, it has been argued that a unique 'molecular optics' (Novas and Rose 2000) which rests on these premises is further bolstered by progressing technologization of biomedicine. Again, it can best exemplified by constant computerization, digitalization and data banking (Clarke, Shim, Mamo et al. 2003: 173).

Biobanking and Genohype

One of the most significant implications of biotechnological revolution is that it generates a unique genohype which Neil Holtzman defined as a discourse of exaggerated claims, overstatements and hyperboles attached to DNA and the effort to map the human genome (Holtzman 1999: 409). Indeed, there is an exaggerated optimism spread to society about the latest genetic discoveries and applications of biotechnologies, which is accompanied by overemphasis of expected benefits and overpassing of possible threats related to various biotechnologies (Caulfield 2004; Caulfield and Bubela 2004; Domaradzki 2018: 113–119). Although the term genohype was coined in reference to genetic tests, it can be also observed in relation to biobanking. Research on media discourse shows that the expected benefits resulting from collecting and storing of human biological material are reported much more often than the possible risks. Both the media and the experts are especially eager to report on the expected progress in the knowledge on etiology of many diseases and the development of new therapies. On the other hand, possible risks of bioresearch are frequently omitted.

Even when the media do mention threats posed by biobanks to privacy, confidentiality and autonomy, they are still framed positively or neutrally (Ogbogu, Toews, Ollenberger et al. 2014).

Another revolution steaming from the advances in biotechnologies is the discovery of a new technology CRISPR (Clustered Regularly-Interspaced Short Palindromic Repeats)/Cas9 that enables gene editing[3] (Musunuru 2017; Thurtle-Schmidt and Lo 2018; Soniewicka 2018: 21–27, 267–269). It allows removing mutated excerpts of DNA and replacing them with new ones (for example synthetic DNA), adding or altering particular locations in the genome. Its biggest advantage is that, in contrast to the other existing genome editing methods and the traditional gene therapy which is characterized by inaccuracy of genetic interferences, difficulty in controlling introduced genetic changes and the risk of uncontrolled side effects, CRISPR/Cas9 is much faster, cheaper, more accurate and more efficient. Moreover, it enables introduction of modifications in many genes simultaneously. Consequently, it may also be used in polygenetic diseases. Finally, as it may be employed both in somatic and reproductive cells, it allows removal of genetic mutation from a reproductive cell before fertilization. Apart from all the hype around CRISPR/Cas9, it also poses many threats. As gene editing may be used not only for clinical purposes, many argue that it may also serve to enhance human potential or, as some call it, production of "Genetically Modified Humans," the so called "CRISPR babies." It is worth noting that such attempts have already been undertaken both in China and Japan as well as in the UK and the US (Cyranoski 2018; Soniewicka 2018: 25–26).

It is important, as creation of an atmosphere of excessive euphoria and hope may result in many negative consequences, including creation of unrealistic expectations toward scientific research and medical biotechnologies. This in turn, may result in premature implementation of some biotechnologies, as exemplified by lethal cases of gene therapy (Sibbald 2001; Frank, Hogarth, Miller et al. 2009). After being highlighted in the media, information about such failures may create a feeling of disappointment and mistrust toward science which may further lead to reduction of funding. Moreover, a decrease in trust toward scientific institutions may also result in discouragement of potential donors and reduce the amount of samples donated for research purposes. One must bear in mind the fact that most respondents object to research with presumed eugenic or commercial potential (Gaskell, Gottweis, Starkbaum et al. 2013; Simon, L'Heureux, Murray et al. 2011; Lemke, Wolf, Hebert-Beirne et al. 2010).

Health and Disease in the (Biomedical) Risk Society

Rapid growth of knowledge on the genetic basis of many diseases has changed substantially the way we understand health and disease, which more and more often are being defined at the molecular level (Braun 2007). Thus, one of the main expressions of geneticization is the

[3] CRISPR-Cas9 uses a natural immunological mechanism present in bacteria which captures and cuts snippets of DNA from the invading viruses and then uses them to create the so called CRISPR arrays. Thanks to these new segments of DNA, bacteria "remember" the viruses and during another attack they use CRISPR arrays to produce RNA segments to target the invading viruses' DNA. Finally, the bacteria use some enzymes, including Cas9, to disable the virus by cutting its DNA.

tendency to interpret an increasing number of diseases and disorders in accordance with the genetic paradigm described above, and establishing explicit links between a disease and a particular stretch of DNA (Stempsey 2006). Indeed, there can be observed a tendency of application of a model of interpretation typical of such rare monogenetic diseases as: Huntington disease, sickle cell anemia or cystic fibrosis, also to the conditions with a more complex etiology, including cancer, diabetes, depression or schizophrenia (Goodman 1999; Hedgecoe 2001, 2002). Although many biomedical researchers take into account the role of extragenetic factors, genetic interpretations are prioritized, while social, economic and environmental factors are often omitted or even ignored. Thus, by underplaying these factors, geneticization may shift our attention from the need for social and environmental reforms that might give better results than concentration on human genetics (Lippman 1991, 1999; Holtzman 1999).

At the same time, geneticization of diagnostics radically changes our perception of risk. As biomedicine concentrates on genetic predispositions to various diseases; it stresses rather the internal than external character of the risk, and the responsibility for its management is assigned to individuals who belong to a 'risk group,' rather that the State (Lemke 2004). At this level geneticization manifests itself in a wide usage of biotechnologies in medical practice (Lippman 1991, 1999; Holtzman 1999). After all, it is believed that many human health problems can be solved due to advances in genetics and genomics, exemplified by the hopes reposed in pharmacogenomics or gene therapy. Such hopes are manifested by the wide application of genetic diagnostic tests (clinical, pharmacogenetic and nutrigenetic), which allow to asses one's health risks. What is problematic, is that although in many cases genetic risk is only probabilistic, it is frequently perceived with certainty, and genetic predispositions are equated with disease itself. It can be exemplified by the American actress Angelina Jolie, who, after being diagnosed with BRCA1 mutation, underwent prophylactic double mastectomy, and later also ovariectomy (Kamenova, Reshef, and Caulfield 2014).

Some authors also argue that prognostic capability, accuracy and reliability of genetic test is often overrated. Consequently, negative test results may generate a false sense of security and negligence of preventive actions. On the other hand, detection of genetic predispositions may make some individuals overly preoccupied with their health and generate a 'genetic hypochondriasis,' as geneticization of prevention leads to premature medicalization (Melzer and Zimmern 2002). Nevertheless, unduly stressing of genetic predispositions and biotechnological solutions to many health problems ignores the fact that each human being is a carrier of many genetic mutations which may, or may not, result in the development of a genetic condition, as it is the environment and individual lifestyle that affect gene expression. Consequently, geneticization may lead to concentration of health funding on individual interventions at the expense of those realized at the social level (Holtzman 1999; Strohman 2003; Holtz, Holmes, Stonington et al. 2006). Nevertheless, relocation of intellectual and economic resources on genetic research seems to ignore the fact that health promotion and social reform could be much more effective than focusing on individual's genetic makeup. For example, although a very low percentage of cancer cases has a strictly genetic basis, molecular research on carcinogenesis absorbs a significant part of the funds spent on the war against cancer (Master, Claudio, Rachul et al. 2013).

Geneticization of Identity

The information about the genetic risk provided via genetic tests may also influence the way an individual defines and experiences one's self. Because genetic information about a person is perceived as sound and unchangeable, some individuals may define themselves in terms of modern genetics. Such geneticization of identity (Dar-Nimrod and Heine 2011; Domaradzki 2017b) can be observed mainly among persons with a family history of genetic disease or who belong to a group of genetic risk. Because deterministic and fatalistic vision of one's destiny stemming from genetics has a strong self-stigmatizing potential, being aware that one belongs to a group of genetic risk affects an individual's entire life, significantly influences one's concept of self and may become a source of social and self-stigma (Klitzman 2009; Williams, Ayers, Specht et al. 2009). Consequently, one of the reasons that discourage the potential donors from participating in a biobank is the fear of discovering of a disease, and genetic predispositions in particular (Porteri, Pasqualetti, Togni et al. 2014: 4).

Thus, the modern concept of disease, stemming from genetic determinism and fatalism, and concentration on genetic risk give rise to a belief that health is a state of 'presymptomatic morbidity,' which allows to define almost all individuals as 'asymptomatic patients' (Lemke 2004; Stempsey 2006). Consequently, geneticization of identity may cause healthy individuals, who are aware of their genetic risk, to anticipate the disease or even death, although they may never develop the disease. Nevertheless, an awareness of the risk may significantly influence one's perception of self and redefine his or her social roles. It is especially problematic in the case of incurable rare diseases, when the information about genetic risk may lead to self-stigmatization and discrimination.

At the same time, it should be noted that, apart from these concerns, for many individuals constant progress in genetic knowledge is a source of hope and optimism. Indeed, genetics may contribute to substitution of seemingly deterministic vision of disease, which makes some persons passive and compliant, with the imperative of (genetic) activism (Hallowell 1999). For many persons who belong to a group of genetic risk such knowledge is a source of empowerment and becomes an important element of reflexive self-identity. In fact, genetic knowledge molds personal experience of self in terms of modern genetics, and accessible biotechnologies provide new tools for management of the body and allow expression of one's self as genetic self (Novas and Rose 2000; Rose 2007). Moreover, constant development of new genetic technologies, including CRISPR/Cas9 mentioned above, gives people hope that the risk can be anticipated, adequately assessed and controlled. Consequently, human destiny, again, seems to be open and undetermined. For that reason Nikolas Rose and Carlos Novas (Rose and Novas 2004; Novas 2006) write about "a political economy of hope": while knowledge about genetic risk may hinder leading normal life and planning future decisions regarding family planning, reproduction or professional career, it may also become a source of empowerment and a basis for a new social identity. It may mobilize individuals to change their unhealthy behaviors and stimulate preventive actions. It also offers a new hope that further scientific progress will increase our knowledge about many diseases and generate effective treatments. What is more, while information about the genetic risk may be a source of one's spoiled identity, it may also give rise to new forms

of biosocialities, i.e. self-help groups and organizations which integrate, educate and support their members and stimulate further research (Rabinow 1996; Rose 2007; Rose and Novas 2000).

Genetic Discrimination

A possibility to dissect (genetic) information about a person from one's tissue, cell or genetic material, just as its digitalization and storing, is the reason why many donors feel anxious over privacy and confidentiality of their data (Lemke, Wolf, Hebert-Beirne et al. 2010: 371–372; Lewis, Clotworthy, Hilton et al. 2013: 4, 8; Gaskell, Gottweis, Starkbaum et al. 2013: 17; Caulfield and Murdoch 2017). The majority of people are concerned over the possibility of linking their biological samples with his or her personal data, and that it may result in their stigmatization and genetic discrimination (McGuire, Hamilton, Lunstroth et al. 2008: 51; Simon, L'Heureux, Murray et al. 2011: 825; Feldman and Darnell 2013; Spruill, Gibbs, Laken et al. 2014: 101; Porteri, Pasqualetti, Togni et al. 2014: 4, 7; Shabani, Bezuidenhout, and Borry 2014: 1059–1060). For that reason, the donors less frequently declare donation for the research on genetic diseases, incurable somatic diseases and such stigmatizing mental disorders and personality traits as schizophrenia, alcoholism, homosexuality, intelligence, susceptibility to addictions or aggressive behaviors (Schwartz, Rothenberg, Joseph et al. 2001: 339, 341; Goodson and Vernon 2004: 136; Lemke, Wolf, Hebert-Beirne et al. 2010: 371). It is due to the fact that a large part of society perceive genetic information as much more sensitive and susceptible for misuse (Wauters and Van Hoyweghen 2016). Moreover, attribution of a feature to a person's genetic makeup strengthens the essentialist view on human nature and the belief that one's feature is innate and unchangeable. This in turn, makes the stigma even more severe and lasting. Especially so that due to its presumed genetic character, it may be also attributed to other family members.

Some also fear that 'naturalization' of the existing social categories may enforce stereotypes and biases toward some social groups, as can be observed in the case of individuals with a family history of genetic disease (Klitzman 2010) and some ethnic minorities, including: African-Americans, Mexican-Americans, native Americans, Hawaii and Alaskan Natives (Fong, Braun, and Chang 2006; Heredia, Krasny, Strong et al. 2017). For that reason, members of these communities express concerns over misuse of their biological samples. Such fears result from their negative experiences with colonization, eugenic movement and medical experiments, including the Tuskegee Syphilis Study.

Because biosamples donated for biobank research may be linked to one's personal data, many fear that the third parties, and the government, insurance companies and employers in particular, may have access to such information, and that it may result in discrimination of the donors and their families. While such fears were mainly articulated when the first draft of human genome was announced (Tambor, Bernhardt, Rodgers et al 2002; Geller, Bernhardt, and Holtzman 2002), they are also present in the context of biobanking (Spruill, Gibbs, Laken et al. 2014; Shabani, Bezuidenhout, and Borry 2014; Caulfield and Murdoch 2017). It is important as some studies show that social images of biobanking and scientific research in general, influence public perception of biobanking investigations, willingness

to donate and donors' preference for broad consent (Beskow and Smolek 2009). It may also influence participants' preference of a type of donated tissues and a type of research they are eager to participate in. As many studies on public attitudes toward biobanking have shown, it is the lack of trust toward scientific and biobanking institutions that affects the public willingness to participate in biobank research. Trust in turn is mainly shaped by the donors' perception of risks associated with the privacy and confidentiality of their samples and their fears over stigmatization and discrimination (Porteri, Pasqualetti, Togni et al. 2014: 4, 7; Simon, L'Heureux, Murray et al. 2011: 825; Spruill, Gibbs, Laken et al. 2014: 101; McGuire, Hamilton, Lunstroth et al. 2008: 51; Shabani, Bezuidenhout, and Borry 2014: 1059–1060).

For that reason, it is argued that special antidiscrimination acts should be promulgated which would protect individuals from government institutions or insurance companies that might discriminate some social groups on the basis of their alleged vulnerability to various diseases and mental disorders or from the employers interested in learning about a person's susceptibility to some known risky behaviors or toxic substances present at the workplace (Caulfield and Murdoch 2017). A notable example of such regulations is the The Genetic Information Nondiscrimination Act (GINA) promulgated in the United States of America in 2009 which forbids any type of discrimination based on one's genetic makeup and restricts insurance companies' and employers' access to personal genetic research results (Feldman 2012). It also forbids insurers requesting such information and employers to employ, terminate or promote a person on the basis of genetic information.

Commercialization of Biotechnology and Gene Patenting

As genetic information constitutes an important value not only for science and medicine but also for modern economy, genes are often perceived as a unique type of a 'resource,' 'commodity' and 'stock,' i.e. trade objects that can be patented, sold and bought. Thus, although there is a widespread agreement on the benefits that the developments in genomic science bring to the biotechnological industry, many also fear that it can lead to commercialization of genetics (Everett 2003; Dickenson 2009) and gene patenting in particular (Caulfield, Gold, and Cho 2000; Caulfield, Bubela, and Murdoch 2007).

Social anxieties over excessive marketization of biotechnologies has already been expressed during the rivalry between two research teams working on the sequencing of the human genome, when a team led by Craig Venter, head of Celera Genomics, was commonly criticized for leaving a governmental project to a private company and his attempts to patent the research results. These concerns were then manifested when the Human Genome Diversity Project was launched. As it intended to collect genetic samples from various populations from different regions of the world, representatives of many indigenous tribes and communities accused the researchers of neo-colonial practices and biopiracy. As a result, the entire project was closed down (Marks 2006). Distinctively, all these fears are now exemplified by the court battles, the so called 'gene wars,' including such famous cases as: Diamond v Chakrabarty, Moore v. Regents of the University of California (Dickenson 2009: 21–28; Kawłatow 2012: 80, 87; Stanek 2016), HeLa cell line or attempts at patent-

ing genes BRCA1 and BRCA2 by Myriad Genetics corporation (Caulfield, Bubela, and Murdoch 2007).

At the same time, both the researchers and the public agree that the results obtained from the studies using human biological material may be treated in terms of (intellectual) property and that gene patenting enables progress in the research, which otherwise would be unprofitable or impossible to conduct. For that reason, in the context of biobanks, most donors are not so much interested in profit sharing but rather want to be in control over the use of their samples and research results. Many studies show that the respondents are concerned that they can be used in research contrary to the donors' values (Goddard, Smith, Chen et al. 2009: 120; Gaskell, Gottweis, Starkbaum et al. 2013: 16; Porteri, Pasqualetti, Togni et al. 2014: 4). Consequently, they often oppose research involving human embryos, human cloning, combination of human samples with animals, stem cells research, genetic engineering and the so called 'designer babies' (Goodson and Vernon 2004: 136; Lewis, Clotworthy, Hilton et al. 2013: 7; Heredia, Krasny, Strong et al. 2017: 52).

Apart from the issues related to informed consent, some controversies also surround the issue of property and distribution of profits. At the same time, social opposition against gene patenting is based more on the assumption that natural objects, such as genes, cannot be considered as inventions and thus be patented. Therefore, the public is anxious that patenting of a given discovery will limit the access of researchers to scientific information, which in turn will strangle development of the research and may endanger patients' health and life. Nevertheless, controversies surrounding commercialization of genetic research are not so much focused on gene patenting itself, as on who has the right to the profits: researchers form the private sector who made the 'discovery' of DNA sequence or gene mutation, individuals who donated their biological material or society at large (Caulfield, Gold, and Cho 2000; Everett 2003; Kawłatow 2012; Stanek 2016). All these controversies are also present in the context of commercial biobank for which donated biosamples constitute a property ownership and without which they cannot conduct their research (Evers, Forsberg, and Hansson 2012). Although some studies show that respondents believe that it is the biobank that owns both the samples and the research results, others suggest that the donors want to have their share in the profits (Master, Claudio, Rachul et al. 2013: 5; Porteri, Pasqualetti, Togni et al. 2014: 5, 8). It has been confirmed by studies that the majority of the public trust scientific institutions, including university hospitals and distrust commercial institutions, and pharmaceutical-companies, and private biobanks in particular (Lemke, Wolf, Hebert-Beirne et al. 2010: 373; Lewis, Clotworthy, Hilton et al. 2013: 8; Shabani, Bezuidenhout, and Borry 2014: 1059; Master, Claudio, Rachul et al. 2013: 5–6).

While discussing commercialization of biobanks, it is also important to consider the issue of biobank sustainability and the risk of a biobank's bankruptcy (Cadigan, Lassiter, Haldeman et al. 2013). Such concerns result from two famous examples of such bankruptcy: the Icelandic population biobank deCODE Genetics, which closed down in the year 2009, while being in possession of 140,000 samples from the Icelandic population, and a Québec Genizon biobank which at the moment of its bankruptcy in 2011 had at its disposal samples from 50,000 the French Québec population (Caulfield, Burningham, Joly et al. 2014: 106–107; Saulnier 2016). The validity of these concerns is confirmed by a study conducted among biobankers, who confess that apart from limited financial resources, most biobanks

lack any plan for what will happen to the collected biosamples if the biobank closes down (Cadigan, Lassiter, Haldeman et al. 2013).

Conclusions

Because genetics and genomics rank among the most dynamically developing fields of bioscience, biotechnological progress generates great promises related to the new discoveries on the molecular basis of many diseases and developments of new therapies. Nevertheless, organization and supervision of biobanks needs to acknowledge a broader social, cultural and historical context in which they operate (Hoeyer 2010: 349–350). While the biotechnological revolution generates an atmosphere of expectations toward biobanks, its public perception is also influenced by a number of social forces and cultural trends, which may generate excessive euphoria or, on the contrary, exaggerated fears related to the misuse of donated samples and interrelated data, and thus influence people's willingness to donate. This in turn, may endanger future functioning and development of biobanking institutions.

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