

PSYCHOLOGY AND BIOETHICS

Biobanking — a new environment for psychological research and applications

Elena V. Bryzgalina^a, Andrey L. Ryzhov^{b*}, Olga A. Tikhomandritskaya^b,
Alexander S. Tkhostov^b, Yuri P. Zinchenko^b

^a *Faculty of Philosophy, Lomonosov Moscow State University, Moscow, Russia*

^b *Faculty of Psychology, Lomonosov Moscow State University, Moscow, Russia*

Corresponding author. E-mail: andrey.ryzhov@gmail.com

Biobanking is an emerging medical, research, and social institution that has many implications for psychological science and practice. The bibliographic study of abstracts and full text articles retrieved from major databases (PsycInfo, PubMed, EBSCO, SAGE) indicates that the role of psychology in the establishment and functioning of biobanks is not well articulated. Two promising directions of biobank-based studies are concerned with studies of risk factors for various disorders and with genetic and epigenetic mechanisms of psychological and behavioral trait development, and are closely tied to a developing model of a new “personalized” medicine. It is important to carefully select the psychological variables and measurements, with consideration of their suitability for genetic studies, possibilities for networking and sharing of results, economic limitations, and biobank purposes. Of special importance is a systemic foundation of mental functions that requires not only the assessment of efficacy, but also the search for simple, natural, and objectively observable components. Applied tasks of professional psychologists in the field of biobanking can be defined, such as donor selection and management of ethical issues. As a new technology, biobanking poses several challenges to society and the individual that need to be studied in order to prevent misuse and to earn the public trust. The hidden dangers of eugenics-like ideas, of consumer practices with genetic products, and of over-emphasis on human enhancement are particularly stressed. We conclude that while biobanks represent a promising and fertile ground for psychological research and applications, there is a need for a comprehensive psychology of biobanking to make them fruitful.

Keywords: biobank, depositories of human biological samples, personalized medicine, molecular genetics of human behavior, phenotype description

Introduction

This article is a result of bibliographic research and analysis in course of preparing to establish a national biobank depository of living systems in the Russian Federation. Biobanks are believed to be an important advance in molecular genetic research and to offer the possibility of a new type of personalized medicine (Gottweis, 2008; Elger & Biller-Andorno, 2010; Liu & Pollard, 2014; Karimi-Busheri & Rasiuli-Nia, 2015). Nevertheless, their emergence seems to have been largely ignored by the psychological community. The PsycInfo search conducted in April 2015 with keywords “biobank OR bio-bank AND biobanking” yielded 277 results, but there is a marked prevalence of non-psychologists (molecular geneticists, psychiatrists and other physicians, sociologists, ethicists) as authors¹. Thematic analysis of abstracts and some full texts roughly divided those papers into the following groups: (a) bioethical problems, (b) informed consent and other protocol documents, (c) public attitudes towards biobanking, (d) motivation in biobank participation studies, (e) reports on studies conducted using biobanks, (f) discussions of the scientific potential of biobanking, (g) other, and (h) non-relevant.

Many of these papers take up highly psychologically relevant problems, so it would be wrong to conclude that this research area is alien to psychology; but there is an undoubted lack of articulation of the role of psychologists in biobanking, as well as uncertainty about how biobank-based studies can contribute to the progress of psychological science. Our conviction is that biobanks promise to be a fertile ground for psychological research, particularly in clinical and health-related psychology, and that biobanks not only can profit from psychological assistance, but also need it if they intent to make sense of human behavior.

What is a biobank? What types of biobanks are there?

Biobanks were only recently conceived as a singular social, technological, and scientific invention and still have no commonly accepted definition. Broadly, the term is used descriptively and comprises any collection of biological samples with research purposes, so it can equally refer to accumulated residues from private medical practice or from national institutions with a highly elaborated infrastructure and many thousands of participants. More narrowly, databanks are specialized institutions that can be characterized by (a) simultaneous storage of two sets of data — biological (ordinarily including DNA sequencing results and cryo-conserved tissue samples), and personal information (clinical, demographic data as well as some test results), (b) a defined scientific, medical, or other purpose, (c) an emphasis on a non-individualized approach, favoring processing of archived anonymous data, and (d) an important role for bioinformatics that allows interchange and collaboration with other biobanks or research institutions (Bryzgalina et al., 2016).

¹ This initial search strategy was too narrow and led to omission of some relevant articles. Next, a more flexible strategy was used, looking for possible synonyms (“depositories of biological material”, “genetic databases”), spreading to related subjects (genetic testing, tissue and cell donation), and using other databases for full-text availability (ScienceDirect, EBSCO, SAGE, and PubMed). A total of 536 abstracts and 88 articles were reviewed for a preliminary outline of major directions of research in the subject. The analysis of monographs on biobanking, behavioral genetics, and genomics leaves a similar impression.

The last two tendencies play crucial roles in making biobanks a unique research institution: separate specialized depositories ready for use by different research projects. Of particular importance is the possible availability of biobank materials for commercial organizations (pharmaceutical companies, for example).

Biobanks are quite varied. They can be classified on the basis of their source of financial support (private or state), their access regime (international, national, university or closed biobanks that demand special access), type of biological data stored (cell, tissue, organ or even cadaver, or a virtual biobank that holds DNA-sequencing results without conservation of biological material).

For the purposes of this paper, it is important to differentiate between the following types of biobanks:

1. Clinical biobanks that store biomaterial and clinical data of patients affected by specific diseases and are the basis for biomedical studies;
2. Population biobanks that cover the general population or some particular group (such as an age or ethnic cohort) and have broad aims; they tend not to be involved in a research process;
3. Biobanks that are part of a particular research project and have defined purposes and a specifically designed set of archived data;
4. Specific types of biobanks, such as forensic ones, aimed at personal identification.

Uses of biobanks in psychological research

The primary interest underlying biobank creation is the possibility of conducting studies in genetics, molecular biology, biochemistry, etc. So far this type of research (for example, Alfimova, Chertkova, Egorova, Parshikova, & Pyankova, 2013) is not so common in human behavioral genetics, with twin, adoption, and genealogical research-designs still dominating the field¹. Difficulties of the molecular genetic approach to understanding of human behavior should be acknowledged. These include interactive multi-gene mechanisms of inheritance, the importance of epigenetic mechanisms and environmental influences, the rarity of some genetic variants, and difficulties in defining relevant phenotypic traits and their quantitative nature (O'Neill, 2010; Dodge & Rutter, 2011; Plomin, deFries, Knopic, & Neiderhiser, 2012).

Biobanking could provide a timely answer to some of these challenges. A new generation of population-based, genome-wide association studies, focused on the analysis of variance of genome sequences, requires processing of huge sets of data, requiring accumulation, storage, interchange, and sharing of the results. Arguably this could lead to major advances in understanding of the genetic basis of individual differences and common psychiatric diseases (Cook-Deegan, 2011; Davies et al., 2011).

¹ Some authors counterpose human behavior genetics as mainly psychological, to human molecular genetics as mainly psychiatric (Panofsky, 2014). While the main purpose of behavior genetics is to estimate trait heritability, molecular genetics is more concerned with gene-trait associations. Moreover, the two approaches usually provide contradictory results, with overestimation of heritability deriving from behavioral genetics studies and underestimation of genetically explained variance of traits from molecular genetics studies.

This is a new area of study, so the main important findings are to be expected in the future. Still it is possible to trace some major research trends from published articles. Most striking are clinical biobanks based studies devoted to investigation of etiological factors and pathogenic mechanisms of specific diseases, such as schizophrenia, autism, affective spectrum disorder, and degenerative dementias. A common drawback of those studies is that they were accomplished in a purely biomedical paradigm, thus presenting only indirect interest for psychology. Most of them also employ only formal definitions of a disorder (e.g., DSM diagnosis), largely ignoring important clinical data and psychological assessment results that otherwise could shed light on the nature of gene-environment interactions in producing the pathological result.

There are also genetic studies based on normal population biobanks. Of special interest are the twin registers' biobanks, which make it possible to combine molecular genetics analysis with traditional twin study design (Boosma et al., 2002; Nilsen et al. 2012; Brescianini et al., 2012).

However, we should note the preponderance of practically oriented works that are concerned with the study of risk and protective factors in the development of psychological or somatic disorders and general health¹. Most population-based biobanks postulate health-promoting and protective goals as central for their functioning, such as the joint China-UK project Guangzhou Cohort Study (Jiang et al., 2006). The advantage of biobanks for studies of this type is the size of the sample that can be obtained, varying from thousands to hundreds of thousands of participants. In some countries, nearly complete generation cohorts are documented, such as the Danish newborn screening biobank (Norgaard-Pedersen & Hougaard, 2007). Related studies may have a common cross-sectional design and use no DNA or other conserved biological material at all, reducing the role of the biobank to a platform for gathering anthropometric data.

Biobanking presents the possibility of prospective large cohort studies. A perfect example is the Dutch longitudinal project TRAILS (TRacking Adolescents Individual Lives Survey), the one with the most sophisticated psychological assessment batteries (Oldehinkel et al., 2015). The importance of a longitudinal design depends on the understanding of the role of epigenetic mechanisms, of early environmental exposure shaping the later phenotype and diathesis, including lifetime changes at the biological level.

Interest in the study of aging and longevity has to be regarded as a separate area in biobanking research. There are biobanks specially devoted to the study of genetic causes of involution, health problems and diseases associated with aging, and the well-being of elderly people (Avlund et al., 2014).

Clinical biobanks provide similar study designs, focusing on comorbidity problems and identification of biomarkers. It should also be noted that some clinical biobanks focus on tissue or organ collection (brains or brain structures taken postmortem) for further biomedical research, rather than on DNA sequencing (see Rivid, 2014).

¹ This could be because the main sources of financial support are national health services or private foundations.

The choice of relevant psychological variables for biobank creation and subsequent studies

The success of molecular genetic research rests not only with the advances of technology for obtaining biological data and information processing, but also with “interpretative expertise” (Foley et al., 2014). A crucial problem is the selection of relevant phenotypic (psychological) variables. This problem could be seen as a simple one by researchers from the natural sciences who are managing biobank creation — just a matter of defining the main psychological abilities of interest, e.g., intelligence, important personality traits, and signs of disorders. Psychologists are aware, however, how many competing constructs and measures exist for describing every single aspect of human behavior and experience. So there is a need for a research psychologist to participate actively in biobank planning in order to secure its scientific potential. Dodge and Rutter (2011) have called for “theory-guided” data analysis. This has to be done in collaboration with other stakeholders, once the project goals and purposes are defined.

There are several questions that should be taken into consideration.

The first is the type of biobank and the purpose of the repository. A biobank can be created in connection with some particular research project or can be planned as a multi-purpose platform for subsequent studies. The ultimate goal of biobank can also be different: from identification of specified traits and biomarkers to preservation of species diversity. The approach to choosing variables to be included can be more or less narrow. Typically, clinical biobanks with concrete goals and areas of interest represent a narrower approach.

A common purpose of biobank creation is the evaluation of valuable traits (either from an individual or an evolutionary prospective) and overall health. Complex measures such as IQ, EQ, quality of life, health behaviors, social adaptation, and symptom checklists are likely to be included. The danger of adopting too narrow an approach should be stressed — focusing on only one area could easily overlook disadvantages of the selected traits. Minimal requirements for a sufficient appreciation of health, well-being, and adaptation should be elaborated. If the task includes preserving and studying individual variability, an even more differentiated approach is needed, and measurements of efficacy will not be enough and will have to be supported by measurements of style or modes of adaptation (e.g., cognitive styles, temperament, personal values and attitudes).

The second problem is that biobanks deal with biology; therefore, the parameters for inclusion should be biologically based. High heritability is a cue, but is not enough for molecular genetic research. Usually in psychology we deal with complex characteristics that are a result of a long course of development of the functioning of the entire brain, characteristics which are socially and culturally shaped. Most of them should be seen as constructs derived from psychologists’ conceptual analysis. For genetic study, it is important to identify traits that can be regarded as natural entities that are simple, heritable, and related to basic brain functions. Plomin et al. (2012) point to the importance of tracing the developmental pathways of gene-brain-behaviors to overcome difficulties of attempting genetic linkage for most behavioral traits. The concept of endophenotypes, proposed by Shields and Gottesman for etiological study of schizophrenia, is usually cited

(Gottesman, Gould, 2003; O’Neill, 2010; Plomin et al, 2012). Such “internal phenotypes” are observable only on the microscopic level of analysis¹, are objectively detected by psychophysiological methods, are highly heritable, and contribute to the development of a behavioral disorder or complex trait formation. It should be noted that neither endophenotypes nor their accumulation constitute a trait or a disorder, so, in conducting the genetic research, all endophenotypes and behaviors (traits) have to be measured separately. The principle of the systemic foundation of higher mental functions endorsed by the Russian psychological school (works of Vygotsky, Leontiev, Luria, etc.) can serve as a frame of reference.

The third question concerns the possibilities of sharing results and data exchange. Standardization, unification, and optimization of procedures are prominent and inevitable trends for large population biobanks. Some representatives in the field of biobanking insist that biobanks should refrain from direct involvement in research activity (Karimi-Busheri & Rasiuli-Nia, 2015). Hence, the data they store should satisfy broad research interests, although this is hardly possible, since the bigger the biobank, the more effort is required to collect substantial psychological data. However, even for smaller clinical or research-oriented biobanks, there are many gains when applying assessment methods that are used widely. There are a number of diagnostic measures commonly used in biobanking, such as SCL-90-R, BDI, CBCL for children, NEO-PI, but no standard battery exists,² nor are popular tests employed equally for all major areas of psychological functioning (for example, health behaviors are usually assessed by specially developed scales). Quantitative methods with good psychometric properties are preferable; their availability and the suitability of national adaptations must be established. In most cases, one would look for non-culturally-biased measures. Compatible age-adjusted assessment measures must be found for longitudinal projects.

We should mention the importance of tracing the context. As Dodge and Rutter (2011) point out, most behavioral genetic studies ignore specific environmental variables, focusing only on genes and phenotype traits. Most biobanks obtain vaguely defined “lifestyles” data (e.g., smoking, alcohol consumption), based on simple questionnaires. A more detailed account of life events and stresses could bring a new current into behavioral genetic research. There is an even more difficult problem of early environmental influence and epigenetic development (O’Neill, 2010)³. Reliance only on self-report data can be disputed. The inclusion of per-

¹ For schizophrenia, some candidate endophenotypes are delayed eye-tracking, working memory and attention deficit.

² Project PhenX, led by National Human Genome Research Institute (U.S.) represents such an attempt to devise a set of consensus-based quality measures for 21 different phenotype domains, including psychiatric and psychosocial ones (Hamilton et al., 2011).

³ An illustration of the importance of epigenetic factors in the development of a disorder is phenylketonuria. This is a Mendelian-type heritable condition resulting from enzyme deficiency, which damages normal phenylalanine metabolism. But whether this deficiency will result in dangerous symptoms, including mental retardation, depends on diet, most importantly in early stages of development. Biochemical analysis of affected probands was sufficient to discover the central mechanism, a screening tool, and a remedy for PKU. For more complex diseases, it is necessary to document DNA, protein changes, environmental factors, and phenotypic results.

formance-based measures as well as observational data (from specialists, such as evaluations by a psychiatrist or teacher) can help to obtain more accurate information. This is very demanding though, and can be recommended only for smaller projects where the quality of psychological assessment is crucial (as in some clinical biobanks or longitudinal prospective cohort studies).

Finally, financial considerations pose another important question for determining which variables and measures to include. It is not only matter of time and money: Requirements for the professional level of psychologists, difficulties in obtaining consent in case of repeated assessments, risk of drop-outs, and software limitations need to be examined. The choice of variables becomes a compromise between demands for the quality and integrity of psychological evaluation and the financial limitations of the project (Zinchenko, Ryzhov, Tkhostov, & Bryzgalina, in press).

Biobank donor assessment

Unlike what has been discussed above, donor assessment is not scientific, but a practical task in biobank creation. Usually a practicing psychologist, for example a staff member of mental hospital, performs this task. There are some reasons why donor assessment is required.

First, verifying a psychopathological condition could be required, either for selection or exclusion of donors. A clinical biobank might need reassurance that a disorder is present or to exclude cases with concurrent disorders or comorbidity. Population biobanks might want to rule out subjects with psychopathological problems.

Second, for biobanks with special research purposes, a selection of subjects based on psychological assessment is needed (as in a study of giftedness, for example).

Third, donor assessment is necessary for avoiding cohort-shift and controlling the representativeness of the sample¹, or making matched groups (e.g., a clinical and a control group). This work should be done after a preliminary analysis of possible trait associations and shift expectancies is accomplished. Alternatively, the presence of rare variants of trait distribution can pose a research interest for some biobank projects. Specific problems for donor assessment also include malingering and the ability to give informed consent for evaluation.

It is difficult to know now whether donor assessment is equally necessary for clinical and other types of biobanks. The inclusion of a simplified screening form even for large population biobanks, which can be integrated with measurements required for research purposes, is likely an optimal solution. For clinical biobanks, a detailed assessment is needed in most cases. This is one of the expert duties of a professional psychologist that goes beyond the biobanking activity, but the creation of a special protocol and recommendations is desired. At the moment there are no universal guidelines for biobank donor assessment. To develop such guidelines, a

¹ See an interesting article by Lipworth, Forsyth, and Kerridge (2011) on motivation of potential biobank participants, mentioned below.

more common practice of donor assessment — such as in organ transplantation, sperm/egg donation, and genetic screening — could be examined. Those areas also raise different kinds of ethical problems.

Ethical problems in biobanking

Among different aspects of biobanking, the ethical ones are the most studied by scholars in the human sciences, leading to the publication of some volumes dedicated to the subject (Elger, Biller-Andorno, Mauron, & Capron, 2008, Solbakk, Holm, & Hofmann, 2009; Mascialzoni, 2015). The “hot topics” are: informed consent and its limitations, property rights (for biological samples, results, or profits), privacy and security, relation of the individual and the common (national, humanitarian) welfare, equal availability of genetic technologies for different social groups. The impact of commercialization and encouraged sharing of samples and results between researchers is of special relevance. The famous case of the Icelandic private company deCODE genetics, Inc., which attempted to compile a virtually complete genealogical database of the country’s residents, before being banned by a national court, is a referential example (Winickoff, 2015). There is a consensus that special ethical governance of biobanks is needed, and attempts to elaborate universal regulatory principles and harmonize them with national legislative systems are in process (Bryzgalina et al., 2016).

Ethical problems in biobanking should be tackled from the broader point of view of medical bioethics (Bryzgalina, 2012). Psychologists need to participate actively in the elaboration of principles of ethical conflict resolution from their professional perspective. Still, the real advantage of psychology in the field of medical ethics comes from the psychologist’s clinical work in difficult situations and the possibilities of empirical research about ethical decision-making.

In some cases, psychological expertise is needed to evaluate the ability to give informed consent, especially when dealing with mentally disabled or elderly people. There are many issues that could require psychological counseling or guidance. The most obvious are when donors are children. For example, knowing about a genetic risk after DNA screening can have a stigmatizing effect on child development. The way the results are communicated to parents, as well as support to the child and family, are domains of psychological professional work. Psychological qualification is needed to estimate maladaptive coping strategies, erroneous cognitions, family and personality dynamics, as possible sources of negative effects of otherwise appropriate and useful medical events.

Psychological management of ethical conflicts should be conducted by working psychologists from mental hospitals or other organizations affiliated with the biobank, much as in the case of donor assessment. The biobanks should provide special education for professionals, based on knowledge of specific problems connected with biobanking. Following Patenaude (2010b), it is possible to distinguish four areas of further professional training: education (e.g., knowledge of genetic concepts, language, research findings, and possible treatments), collaboration (work with patients, professionals, and families), ethics (privacy, consent, proxy consent, right not to know, etc.), referral (knowing when, how, and where to

make a referral for further professional services) (see also Kaut, 2006; Patenaude, 2010a).

What was said above best describes clinical biobanks. The role of psychological guidance in the case of population-based biobanks is less obvious. There the role of conflict mediator and organizational manager could become more important.

Challenges posed by biobanking to the individual and society

In 2009 biobanking was mentioned by *Time* magazine among 10 ideas “changing the world right now” (Karimi-Busheri & Rasiuli-Nia, 2015). The apparent or declared profits of new biotechnology are enormous: determination of the genetic causes of common diseases and their prevention and remediation, possibilities of life prolongation, family planning, preservation and reproduction of especially talented individuals, personal identification on the molecular level, etc. But what is the other side of the coin?

First of all, the ghost of eugenics emerges. The idea was never completely abandoned and tended to resurrect regularly in medical and scientific circles during the 20th century, with surprising ignorance of the history of previous debates (Lippman, 1991; Joseph, 2004; Cook-Deegan, 2011; Panofsky, 2014). It is easy to imagine its reinforcement by the development of biorepositories. The spreading of parental and prenatal genetic testing, apart from undeniable benefits, has some dubious aspects, as the results could be grounds for serious decisions (like family planning or abortion), or, in milder form, for stigmatization in various ways, yet the knowledge of genetic risk of health problems is very incomplete and probabilistic. Theoretically, the exact or potential value of a gene for a species or a specimen is hard to determine.

Other caveats are raised by questions of security and privacy. Biological databases that cover large populations are regarded by some as potential means of excessive government control of individuals (personal identification, determination of cognation, discrimination based on genetic predisposition to some forms of undesired behavior, etc.). If many of those alleged threats are likely to be illusory or delusory, neither supported by technological possibilities nor legislative permission, there are concrete risks of abuse related to commercialization and open access to such databases, with possible failures and limitations of anonymization and data protection (Varhotov et al., 2016). Surveys show that vulnerability due to possible personal genetic data leaks is one of the major concerns of potential participants in biobanking (Haddow, Cunningham-Burley, Bruce, & Parry, 2008; Lipworth, Forsyth, & Kerridge, 2011; Toccaceli et al., 2014).

There are also less obvious dangers from biobanking technologies because of some tendencies of contemporary social policies, particularly those ascribed to consumerist society and a culture of narcissism. Authors express divergent opinions on whether knowledge of personal genetic information should be regarded as empowering and liberating, allowing responsible decision making, or the opposite, leading to deindividuation, forced choices, and social control by consumption practices (Fishman & McCowan, 2014). The issues of identity and altered self-representation related to genetic technologies play a pivotal role. Quitterer (2014) argues that the personal genome is to be regarded as a successor idea to that of the soul, an es-

sential (substantive) basis for individuality. The actual tendency to include genetic information in one's representation of the self was termed "geneticization" by Lippman (1991)¹. At the same time the "belonging" of genes is not so easily identified — whether they are personal, parental, lineal, or just a variation of an ethnic group's genome. Therefore, genes can easily be thought of either as a core part of the self or as an external condition of existence. The instability of self-representation can be easily exploited by advertisements, as in the case of direct-to-consumer genetic services that are closely tied to biobanking. There are online companies offering remote DNA sequencing, with decoding various kinds of medical, anthropological, ancestry, and other information. Notably, one of the best-known sites of this type — 23andMe.com — promoted their services by offering visitors the chance to "*find out which traits make you stand out from the crowd*"². One can hypothesize that in the future there will be genetic body-modification technologies, in addition to the currently prevalent piercing, tattoos, dieting, and heavier forms of self-mutilation (with inherent search for identity and self-destructive tendencies). If such an idea is rather extreme (but many body-modification practices are extreme too), self-construing by fine-tuning narratives, autobiographies, and behaviors, is more likely (Zwart, 2009). Proactivity and responsibility for one's health can be seen as a socially compelled form of perfectionist behavior, with substitution of personal goals and values by a "false self", by illusory and conformist means of gaining social acceptance.

Genetic data can also be regarded as revealing the inner nature of a human being, a person's virtues or sins, defining personal qualities, revealing affinity. It can be used for justification and explanation of personal differences, types of conduct and actions³, mating choice and family planning. We can trace those ideas in a particular field of biobank applications — that of haplogroup and ancestry studies, remotely resembling Freudian "family romance" fantasies. Benjamin (2015) refers to two examples: an attempt of transcription of a Mexican genome as a response to their apparent exclusion from North American genomic studies, and genomic arguments in political discourse about justification of the caste system in India.

Another idea underlying biobanking is that of human enhancement. According to this approach, entering the era of personalized medicine means that traditional clinical medicine will fade, with the practitioner's expertise being replaced by precise laboratory testing, and treatment by experimentation and trial being abandoned. If we know exactly what inside the organism is broken we can repair it, preferably on the molecular level. People will no longer suffer from genetic diseases; moreover, they will not deteriorate if the genetic mechanisms of ageing are found

¹ An autobiographical account on how the DNA sequencing influenced personal life was written by Craig Venter, the owner (or carrier?) of the first-ever DNA sequence to be published, in his book *A Life Decoded*. Also, an important media event was Angelina Jolie's mastectomy after a DNA scan test for breast cancer risk.

² As quoted by Quitterer (2014), accessed by him on January 2013. No such text was found on the website at the time of preparation of the current article.

³ Controversially, the Italian court reduced by one year the prison sentence of a murderer because he was found to be a carrier of genes supposedly linked to antisocial behavior (Forzano et al, 2010).

(or at least they will become decrepit at a much older age and more smoothly). This fits well with narcissistic values of overcoming natural limitations, longevity, and the capacity for eternal enjoyment, health and activity, open possibilities, and self-definition (see Lasch, 1979). At the extreme, the idea of conservation and reproduction of the biological being conveys the fantasy of omnipotence — of humans beating nature, of immortality, of avoidance of grief and feelings of dependence. Of course, there is nothing wrong with enhancing human health in itself, but one could question whether such research projects are reality-oriented. For example, personalized medicine for most psychiatric disorders (excluding some neurodegenerative conditions) at the moment is a rather utopian idea.

Speaking generally, there is a need for investigation (both theoretical-speculative and empirical) of possible consequences of biobanks as a new social institution and biotechnology. Not only could this throw light on the unique features and limits of human existence in contemporary society (Emelin & Tkhostov, 2010), but also to outline potential “psychosocial syndromes” linked with biobanking and other genomic technologies¹. The evidence from empirical studies so far indicates that perceived threats of biobanking and genetic testing are to some extent exaggerated, as is their empowering potential. No global changes in identity formation and behavior occur, and the prevailing critical attitude of users of genetic technologies was even contrasted to far less balanced opinions expressed by scientists and practitioners (Fishman & McCowan, 2014). However, such findings may reflect the fact that these technologies are not yet popular and are accessed by well-educated and informed people, so further research is needed (Zwart, 2009).

It is possible to distinguish two possible and equally important directions of empirical research: one that focuses on public attitudes toward biobanking, and a second that focuses on professionals’ aspirations and understanding of the situation in this field. The former direction is less represented in literature, while there are several reported studies of public opinion. The main object of this work is to articulate and overcome conflicting attitudes, to find better ways of dealing with ethically ambiguous situations, to detect and explain fears, misgivings, and prejudices, and, finally, to integrate genetic information and technologies in medical and social practice. The importance of studying lay theories and misconceptions about genetics is further related to the mediating effect of “genetic literacy” (Patenaude, 2010a; Fishman & McCowan, 2014) on decision making. An applied aim is to motivate potential donors by developing public trust and interest in biobanks.

Studying participants’ motivation to donate to biobanks is important for a correct appraisal of the results and making improvements in the donor recruitment and assessment process. Thus, Lipworth et al. (2011) came to an interesting conclusion after reviewing a number of qualitative sociological studies of donors’ reasoning for participation in biobanks. While a general proneness to participate and altruistic motivations are reported, a lack of concern about the consequences is notable. The authors argue that this could point to recklessness and a low level

¹ Di Chiara defined psychosocial syndromes as collective behaviors that cause immediate or foreseeable future distress but are not abandoned, despite the absence of objective reasons to continue them (di Chiara, 1999).

of intentionality that can be seen either as an individual or situation-induced trait. This can either result in a population-shift (with people with particular personality traits or disorders more likely to participate) or in more drop-outs. Regretfully, so far most studies (most of them sociological or marketing-oriented) employ only a survey method, with no known attempts to link the attitudes and values to psychological variables or even to compare different groups.

Conclusion

Both genetics and psychology call for a more personalized and individualized understanding of human nature. This is particularly important in medical settings. Personalization is conceived in different ways. For geneticists, personalization means knowing one's risks and vulnerabilities. For psychologists, personalization is the appraisal of the influence of personality, cognitions, significant relations, etc. on manifestations and maintenance of psychological symptoms and behaviors. Whether the future will be a genetic or psychological one is difficult to predict. The right answer is, "hopefully, both". Psychology needs to keep up with the advances of the biological sciences. It is equally important for molecular genetics to be supported by psychological expertise. Otherwise the highly technologized and costly studies can turn into "exercises in futility" (Joseph, 2004). Biobanking is a new technology that intends to help extend our knowledge of human beings and to make a qualitative impact on the world of medicine. It is not only about genetics. Biobanking is a social and cultural phenomenon, and social and psychological pitfalls should not be ignored. Lipworth et al. (2011) call for a "sociology of biobanking". A comprehensive psychology of biobanking is also needed.

Acknowledgments

This research was supported by Russian Science Foundation grant, project No. 14-50-00029.

References

- Alfimova, M.V., Chertkova, Yu.D., Egorova, M.S., Parshikova, O.V., & Pyankova, S.D. (2013). Psychological adaptation: Molecular genetic analysis. *Behavior Genetics*, 43(6), 505–506. doi:10.1007/s10519-013-9623-9
- Avlund, K., Osler, M., Mortensen, E.L., Christensen, U., Bruunsgaard, H., Holm-Pedersen, P., ... Lund, R. (2014). Copenhagen Aging and Midlife Biobank (CAMB): an introduction. *Journal of Aging and Health*, 26(1), 5–20. doi:10.1177/0898264313509277
- Benjamin, R. (2015). Racial destiny or dexterity?: The global circulation of genomics as an empowerment idiom. In S.E. Bell & A.E. Figert (Eds.), *Reimagining (bio)medicalization, pharmaceuticals and genetics: Old critiques and new engagements* (pp. 197–215). New York, US: Routledge.
- Boomsma, D., Vink, J., van Beijsterveldt, T., de Geus, E., Leo Beem, A., Mulder, E., ... van Baal, C. (2002). Netherlands Twin Register: A focus on longitudinal research. *Twin Research*, 5(5), 401–406. doi:10.1375/twin.5.5.401
- Brescianini, S., Fagnani, C., Toccaceli, V., Medda, E., Nistico, L., d'Ippolito, C., ... Stazi, M. (2013). An update on the Italian Twin Register: Advances in cohort recruitment, project

- building and network development. *Twin Research and Human Genetics*, 16(1), 190–196. doi:10.1017/thg.2012.85
- Bryzgalina, E. (2012). Bioethics in the space of philosophy and rights. In T. Zamudio (Ed.), *Bioética: Herramienta de políticas públicas y derechos fundamentales en el Siglo XXI* (pp. 45–57). Retrieved from <http://agusvinnus.prodiversitas.org/libros/bioetica/LIBRO.pdf>
- Bryzgalina, E. V., Alasania, K. Yu., Sadovnichy, V. A., Mironov, V. V., Gavrilenko, S. M., Varkhotov, T. A., ... Nabiulina, E. A. (2016). Sozialno-gumanitarnaya ekspertiza funkzionirovaniya natsionalnykh depositariy biomaterialov [Social and humanitarian expertise in the functioning of the national depositaries of biomaterials]. *Voprosy Filosofii [Issues in Philosophy]*, 2, 8–21.
- Cook-Deegan, R. (2011). Gene-environment studies in the era of full-genome sequencing: Some lessons from eugenics and the race-IQ debates. In K. Dodge & M. Rutter (Eds.), *Gene-environment interactions in developmental psychopathology* (pp. 235–257). New York, US: The Guilford Press.
- Davies, G., Tenesa, A., Payton, A., Yang, J., Harris, S., Liewald, D., ... Deary, I. (2012). Genome-wide association studies establish that human intelligence is highly heritable and polygenic. *Molecular Psychiatry*, 16(10), 996–1005. doi:10.1038/mp.2011.85
- di Chiara, G. (1999). *Sindromi psicosociali: La psicoanalisi e le patologie sociali [Psychosocial syndromes: Psychoanalysis and social pathologies]*. Milano, IT: Raffaele Cortina.
- Dodge, K., & Rutter M. (2011). Genes, environments, and public policy. In K. Dodge & M. Rutter (Eds.), *Gene-environment interactions in developmental psychopathology* (pp. 258–276). New York, US: The Guilford Press.
- Elger, B., Biller -Andorno, N., Mauron, A., & Capron, A. (Eds.) (2008). *Ethical issues in governing biobanks: Global perspectives*. Aldershot, UK: Ashgate Publishing Limited.
- Elger, B. S., & Biller-Andorno, N. (2010). Biobanks and research: Scientific potential and regulatory challenge. In Ch. Lenk, J. Sandor, & B. Gordijn (Eds.) *Biobanks and tissue research: The public, the patient and the regulation* (The International Library of Ethics, Law and Technology, Vol. 8, pp. 37–52). Dordrecht, Netherlands: Springer Science + Business Media B.V. doi: 10.1007/978-94-007-1673-5
- Emelin, V. A., & Tkhostov, A. S. (2010). Tekhnologicheskije soblazny informatsionnogo obshchestva: predel vneshnih rasshireniy cheloveka [Technological temptations of the information society: the limit of external expansions of mankind]. *Voprosy Filosofii [Issues in Philosophy]*, 5, 84–90.
- Fishman, J. & McCowan, M. (2014). Will personal genomic information transform one's Self? In B. Prainsack, S. Schicktanz & G. Werner-Felmayer (Eds.), *Genetics as social practice: Transdisciplinary views on science and culture* (pp. 29–42). Farnham, UK: Ashgate
- Foley, A., Pitceathly, R., He, J., Kim, J., Pearson, N., Muntonu, F., & Hanna, M. (2014). Whole-genome sequencing and the clinician: a tale of two cities. *Journal of Neurology, Neurosurgery, and Psychiatry*, 85, 1012–1015. doi:10.1136/jnnp-2013-306264
- Forzano, F., Borry, P., Cambon-Thomsen, A., Hodgson, S. V., Tibben, A., de Vries, P., ... Cornel, M. (2010). Italian appeal court: A genetic predisposition to commit murder? *European Journal of Human Genetics*, 18(5), 519–521. doi:10.1038/ejhg.2010.31
- Gottesman, I., & Gould, T. (2003). The endophenotype concept in psychiatry: Etymology and strategic intentions. *American Journal of Psychiatry*, 160(4), 636–645. doi:10.1176/appi.ajp.160.4.636
- Gottweis, H. (2008). Biobanks in action: New strategies in the governance of life. In H. Gottweis & A. Petersen (Eds.). *Biobanks: Governance in comparative perspective* (pp. 22–38). London, UK: Routledge.

- Haddow, G., Cunningham-Burley, S., Bruce, A., & Parry, S. (2008). Generation Scotland: Consulting publics and specialists at an early stage in a genetic database's development. *Critical Public Health*, 18(2), 139–149. doi: 10.1080/09581590701824086
- Hamilton, C.M., Strader, L.C., Pratt, J.G., Meise, D., Hendershot, T., Kwok, R.K., ... Haines, J. (2011). The PhenX toolkit: Get the most from your measures. *American Journal of Epidemiology*, 174(3), 253–260. doi:10.1093/aje/kwr193.
- Jiang, C., Thomas, G.N., Lam, T.H., Schooling, M., Zhang, W., ... Cheng, K.K. (2006). Cohort profile: The Guangzhou biobank cohort study. *International Journal of Epidemiology*, 35, 844–852. doi:10.1093/ije/dyl131
- Joseph, J. (2004). *The gene illusion: Genetic research in psychiatry and psychology under the microscope*. New York, US: Algora Publishing.
- Karimi-Busheri, F., & Rasiuli-Nia, A. (2015). Integration, networking, and global biobanking in the age of new biology. In F. Karimi-Busheri (Ed.), *Biobanking in the 21st Century: Advances in experimental medicine and biology* (pp. 1–9). Cham, Switzerland: Springer International Publishing AG Switzerland. doi: 10.1007/978-3-319-20579-3
- Kaut, K.P. (2006). Counseling psychology in the era of genetic testing. *The Counseling Psychologist*, 34(4), 461–488. doi: 10.1177/0011000006286349
- Lasch, Ch. (1979) *The culture of narcissism: American life in the age of diminishing expectations*. New York, US: WW Norton & Company (1991 Edition).
- Lipmann, A. (1991). Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law and Medicine*, 18, 15–50.
- Lipworth W., Forsyth R., & Kerridge I. (2011). Tissue donation to biobanks: A review of sociological studies. *Sociology of Health & Illness*, 33(5), 792–811. doi: 10.1111/j.1467-9566.2011.01342.x
- Liu, A., & Pollard K. (2015). Biobanking for personalized medicine in the age of new biology. In F. Karimi-Busheri (Ed.), *Biobanking in the 21st Century. Advances in Experimental Medicine and Biology* (pp. 55–68). Cham, Switzerland: Springer International Publishing AG Switzerland. doi: 10.1007/978-3-319-20579-3
- Mascalzoni, D. (Ed.) (2015). Ethics, law and governance of biobanking: National, European and international approaches (The International Library of Ethics, Law and Technology Series, 14). Dordrecht, Netherlands: Springer Science + Business Media. doi: 10.1007/978-94-017-9573-9
- Nilsen, T., Knudsen, G., Gervin, K., Brandt, I., Roysamb, E., Tambs, K., ... Harris, J. (2013). The Norwegian twin registry from a public health perspective: A research update. *Twin Research and Human Genetics*, 16(1), 285–295. doi:10.1017/thg.2012.117
- Norgaard-Pedersen, B., Hougaard, D.B. (2007). Storage policies and use of the Danish Newborn Screening Biobank [abstract]. *Journal of Inherited Metabolic Disease*, 30(4), 530–536. doi: 10.1007/s10545-007-0631-x
- O'Neill, S. (2010). Public health genomics. In K. P. Tercyak (Ed.), *Handbook of genomics and the family: Psychosocial context for children and adolescents* (pp. 577–593). New York, US: Springer. doi:10.1007/978-1-4419-5800-6_23
- Oldehinkel, A., Rosmalen, J., Buitelaar, J., Hoek, H., Ormel, J., Raven, D., ... Hartman, C. (2015) Cohort Profile Update: The TRacking Adolescents' Individual Lives Survey (TRAILS). *International Journal of Epidemiology*, 44(1), 76–76n. doi:10.1093/ije/dyu225
- Panofsky, A. (2014). *Misbehaving science: Controversy and the development of behavior genetics*. University of Chicago Press. doi:10.7208/chicago/9780226058597.001.0001
- Patenaude, A. F. (2010a). Training, practice, and collaboration: New opportunities for pediatric psychology and genomic medicine. In K.P. Tercyak (Ed.), *Handbook of genomics and*

- the family: Psychosocial context for children and adolescents* (pp. 559–576). New York, US: Springer. doi:10.1007/978-1-4419-5800-6_22
- Patenaude, A.F. (2010b). Genetic testing and psychology. In G. Patrinos & W. Ansorge (Eds.) *Molecular diagnostics: Past, present, and future* (2d Edition, pp. 549–562). London, UK: Academic Press. doi: 10.1016/B978-0-12-374537-8.00038-9
- Plomin, R., DeFries, J., Knopik, V., & Neiderhiser, J. (2012). *Behavioral genetics* (Sixth edition). New York, US: Worth Publishers.
- Quitterer, J. (2014). The changing self: philosophical concepts of self and personal identity in a post-clinical age of genetics. In B. Prainsack, S. Schicktanz & G. Werner-Felmayer (Eds.), *Genetics as social practice: Transdisciplinary views on science and culture* (pp. 43–58). Farnham, UK: Ashgate.
- Ravid, R. (2014). The uniqueness of biobanks for neurological and psychiatric diseases: Potentials and pitfalls. *Pathobiology*, 81(5–6), 237–244. doi: 10.1159/000369886.
- Solbakk, J. H., Holm, S., & Hofmann, B. (Eds.) (2009). *The ethics of research biobanking*. Dordrecht, Netherlands: Springer Science + Business Media. doi:10.1007/978-0-387-93872-1
- Tocaceli, V., Fagnani, C., Gigantesco, A., Brescianini, S., d’Ippolito, C., & Stazi, M.A. (2014). Attitudes and willingness to donate biological samples for research among potential donors in the Italian Twin Register [Abstract]. *Journal of Empirical Research on Human Research Ethics*, 9(3), 39–47. doi: 10.1177/1556264614540601
- Varkhotov, T.A., Gavrilenko, S.M., Stambolsky, D.V., Ogorodova, L.M., Bryzgalina, E.V., & Alasania, K.Yu. (2016). Zadachi sozialno-gumanitarnogo soprovozhdeniya sozdaniya natsionalnogo banka-depositariya biomaterialov cheloveka [Objectives of social and humanitarian support for the establishment of the national depository bank of biomaterials in Russia]. *Voprosy Filosofii [Issues in Philosophy]*, 3, 124–138.
- Winickoff, D. (2015). A bold experiment: Iceland’s genomic venture. In D. Mascalonzi (Ed.), *Ethics, law and governance of biobanking* (The International Library of Ethics, Law and Technology, 14, pp. 187–210). Dordrecht, Netherlands: Springer Science+Business Media. doi: 10.1007/978-94-017-9573-9
- Zinchenko, Yu.P., Ryzhov, A.L., Tkhostov, A.Sh., & Bryzgalina, E.V. (in press) Problemy ochenivaniya psikhologicheskikh kharakteristik donorov biobanka: nauchnye i prakticheskie aspekty [Challenges in psychological assessment of biobank donors: scientific and applied aspects]. *Russian Psychological Journal*.
- Zwart, H. (2009). Genomics and identity: The bioinformatization of human life. *Medical Health Care and Philosophy*, 12, 125–136. doi: 10.1007/s11019-009-9187-x

Original manuscript received May 10, 2016

Revised manuscript accepted September 12, 2016

First published online March 30, 2017