

INTRODUCING GENE TECHNOLOGY TO THE SOCIETY: SOCIAL IMPLICATIONS OF THE ESTONIAN GENOME PROJECT

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Abstract. The article discusses recent survey results of the public attitudes towards genetic research and Estonian Genome Project (EGP), placing these into the general debate about the impact of gene technology on modern society, with special attention on the possible social implications accompanying the creation of human genome banks. The applicability of the propositions of Ulrich Beck how to balance the latently growing importance of genetic thinking in society is reviewed in the context of the Estonian society with quite different history of the development of “risk society”. In comparison with Western European experience, Estonia is characterised by a lack of previous controversial experience with gene technology (i.e. debates over GMO, cloning, etc.), and the continuing very high appreciation of scientists, coupled with the lack of tradition of public critical engagement in science and technology related issues. This has resulted in overwhelmingly positive public perception of the gene project. Taking into account the crucial aspect by which the EGP differs from all other planned gene banks, namely by granting every donor the right for feedback, it is argued that in such social context, the fears of those concerned over the possible negative social impact of the rather unbalanced introduction of gene technology in different spheres of society are even more tangible.

Keywords: gene research, gene banks, public attitudes, risk society

1. Introduction

In the framework of the theory of risk society, introducing the idea of a population-based gene bank into the Estonian society is significant from several aspects. First, in most general terms, the latest developments in gene research, especially its pairing with medicine are posing a challenge to the theory of risk society developed by Ulrich Beck. Operating with the promise for better health, the primary value and necessity in modern societies, much of the public critical awareness of the potentially risky consequences of technological developments, manifested in other circumstances, is in this case seen to wither away to quite a

remarkable extent. The hitherto self-transforming power of the society is no more self-evident. Secondly, the creation of gene banks constitutes the next significant landmark on the road of introducing genetic knowledge into society, affecting directly and personally large parts or, in some cases, all the members of the target society. Thirdly, the Estonian case gives an opportunity to discuss the propositions by Ulrich Beck how to balance the latently growing importance of genetic thinking in the context of a society that has considerably different experiences compared to the societies upon which the theory of risk society has been modelled.

In the following article, these theoretical considerations will be discussed in the light of the empirical findings on the public perception of the Estonian Genome Project (EGP). It will be argued that the overwhelmingly positive public acceptance of the project is the result of peculiar social context into which the idea was introduced. However, such unreflected optimism gives ground to take seriously many of the ominous visions generated by the critics concerned over the quick advance of gene technology into the society.

2. Risk society and genetic research

The theory of risk society considers the technological developments of the last century to have shaken the very foundations of modern or industrial society, and produced a new type of risk environment, characterised by an ever-present possibility for a global catastrophe. As the political-institutional answer to the growing volume of risk is weak, the actual burden of risk management lies mainly on the shoulders of individuals (Beck 1994), forcing a new type of contingency into individual life courses (Beck 1994:168; Beck and Beck-Gernsheim 2002: 2–3). However, the obvious lack of power of the modern institutions to effectively provide any guarantees against these technology-induced risks is counterbalanced by the increasing capacity of the society to react. The escalating growth of knowledge and the parallel growth of individual cultural resources (via mass education) have created emancipated, self-confident agents, ready and willing to participate in interpreting and contesting meaning. Science, the organising principle of industrial modernity is gradually losing its autonomous position and has become open to contention. As science can no longer produce clear and absolute answers, also the definition of what constitutes a risk has been removed from the closed circle of experts and been opened up to more active citizen participation and wider public debate (Beck 1994:20; Delanty 2000:159).

Such reflexive space, created in this fashion is considered a sign of the eventual humanising of technology, or the “introduction of moral issues into the now largely “instrumental” relation between human being and the created environment” (Giddens 1990:170). It is interpreted as a sign of a new or alternative modernity, defined as “risk society” or “reflexive society” (Beck 1992, Giddens 1990), where the human society has admitted responsibility towards nature in order to prevent ecological disaster. In more abstract terms, this is a vision shared by Toulmin (1990)

who is arguing for the need to reconnect the two roots of modernity, science and humanistic thought. Successful campaigns by anti-nuclear and other environmental movements for a stronger societal scrutiny over different spheres of scientific and technological advances are the living proof of such developments, as well as different attempts for gaining greater moral control over science via ethics committees, or including the wider public into decision-making in scientific issues by creating so-called public forums or panels, e.g. in UK or Denmark (see e.g. Jallinoja 2002).

However, recent developments in gene technology, foremost the introduction of its latest discoveries in medicine, seems to be undermining these developments. Until recently, risks created by gene technology were treated as one among many technologically induced hazards (see e.g. Giddens: 56). Similarly to other technological developments, advances in genetic research have triggered public debate since the 1950s, with different loci of contestation (Dijk: 30). The latest include e.g. large-scale campaigns against genetically modified crops or heated debates around animal cloning.

The introduction of genetic technology into medicine has blurred the basis of this contention to a great extent. The concept of risk society is to large extent based on the idea that people have become concerned and start to react to the consequences of technological development. One has to admit, however, that the prime trigger behind much of the action by the anti-technological camp has been people's concern about their health. In this respect, gene technology, once applied in medical research, makes many of the arguments of the subjects of the risk society less justifiable. Fighting against nuclear power, big pollution industries, or against GM food has always meant also fighting against known or unknown risks for people's health. In this context, struggle against gene research in the service of improving diagnostics and treatment of sickness holds considerably less moral legitimacy. Already the unpredicted popularity of (scientifically yet poorly researched) gene tests intended for life-style change have demonstrated that geneticists have found an efficient "bridgehead" to gain wider public support for their science, namely people's heightened concern over their health. It has proven not too difficult to accommodate the alluring promise of the new genetics for improved knowledge and better treatment in the social context where health has the status of one of the primary social values (Beck and Beck-Gernsheim 2002: 142). Different considerations underlying public stance towards different spheres of application of genetic research is evident also from empirical research, which shows much stronger support towards medical application of genetics than for any other applications, e.g. in agriculture which has been met with much greater suspicion (Böhm et al 2000).

Hanging on to the promises of better health, much of the public critical awareness of the potential risky consequences of technological developments detected in other circumstances seems to wither away to quite a remarkable extent. Modern societies have been characterised by growing "obsession" with health since the mid-20th century. Already before the first gene tests, a shift in focus had been

detected from treatment to enhancement in the health rhetoric, i.e. from treating sicknesses to increasing individual responsibility for staying healthy or keeping oneself fit (Katz-Rothmann, 17; Beck-Gernsheim 2000). The introduction of gene technology into medicine has thus not caused a crucial shift in thinking about one's own responsibility for his or her health, though it has managed to open it up to a rather frightful horizon. However, the "gene turn" has brought about quite a considerable redefinition of the nature of medical practices themselves. With the increasingly elaborate diagnosing, a shift from diagnosis upon symptoms to genetic diagnosis is taking place, with the accompanying shift in language from causality to that of risk, resulting in more uncertainty. This has changed the meaning of illness or "health" and created so-called "presymptomatic patients" – people who have no symptoms, but according to a genetic test, may develop disease in the future (Webster 2002:447). Furthermore, while the ability to diagnose existing and potential illnesses has grown at an enormous pace, at the same time the ability to really use this information effectively to either prevent or heal the probable illnesses lags considerably behind (Beck 1992:205). This, according to Beck, once more leaves much of the risk produced by these new inventions to be carried by individuals. For people made conscious about their health, such a situation can generate but uncertainty and fear. Here, Beck is forced to dismiss his belief in the self-transformative and reflexive power of society to set limits to technological advancement in society:

If the developments of human biology and genetics continue to be implemented solely as called for by market, the constitution, freedom of research and the belief in medical progress, then the cumulative effect will be, in the truest sense of the word, a profound 'genetic' change of society, and not by parliamentary or governmental decision. Instead, this will occur through the unpolitical private sphere, the decision of millions of individuals, parents and mothers, with the advice of doctors and such bureaucratic test-tube creatures as genetic counsellors (Beck 1994:47).

This is a prediction shared by many theorists, concerned with the introduction of human genetic knowledge into society. Though it is commonly accepted that genes determine only a small part of human variety, it has been argued that the public discourse is characterised by increasing "geneticisation," i.e. explaining more and more social phenomena through genetic predispositions (Conrad 1999; Rose 2000; Katz-Rothman 1995), illustrated e.g. by the search for the "gay" or "criminality" gene, thus tacitly creating certain genetic normativism (Habermas 2003:23, Rose 2000:68). Even if no actual limitations are set on people's choice of life-style or reproductive behaviour, precaution or "biological responsibility" (Katz-Rothman: 18) is becoming a social norm (Beck 2002:148, Habermas 2003: 23). Consequently, any resistance to make use of such measures may conclude in social exclusion, e.g. difficulties in participating in the labour or insurance market (Bertillon: 12; Rose 2001:19, Beck 2002:144).

Beck sees a solution in decisive inclusion of different interest groups (patients' organisations, ethical committees, politicians, etc.) into the monitoring and decision-

making of the medical research process, i.e. introduction of the “reflexive mode” also in the medical sphere, which until now has managed to escape it (Beck 1994). Giving up the belief in self-induced social transformation, underlining the “classical” theory of risk society that would balance such creeping “genetic change,” he seems to be calling for an artificial creation of the society’s “risk consciousness” in this sphere, a demanding task in the generally very positive aura surrounding gene technological applications in medicine.

3. Social implications of the Estonian Genome Bank

At the moment, when the use of genetic technology is still rather marginal and, in principle, a question of individual choice (however independent and well-informed), the murky visions cited above may seem to be overstretched or at least belong to somewhat more distant future. Nevertheless, with the launching of population-based gene banks, especially in the cases where the whole population will be involved, the fears of the spilling over of such routines from individual choice to a social necessity seem to suddenly become very close. As already referred to before, the growing ability of medical technologies to diagnose – one of the main goals also of the gene banks, has not been met with equal rise in the ability of prognosis or therapy, thus leaving the whole burden of tackling the distributed knowledge of health risks to the individuals with no means of providing the actual cure.

The conscious choice by the majority of the initiators of gene banks, e.g. in UK and Iceland, to rule out the possibility of feedback, saves these societies for the time being from an enormous range of complexities related to the sudden wide availability of personal genetic information that yet does not simultaneously provide better treatment. One cannot deny that there are ethical challenges related also to anonymous gene data banks, concerning e.g. possible misuses of data in research and the questions of the just sharing of benefits (common to all large-scale scientific ventures). One can also suppose that the mere existence of “gene projects” of such scale can indirectly lead to further geneticisation in public thinking. In this respect, however, Estonian Genome Bank stands out from other similar projects by one significant aspect – namely the decision by its founders to keep the possibility of decoding the data and the right of every donor to ask for feedback.¹ This takes the ethical challenges related to the possible side effects of the project on society to a qualitatively different level, bringing the much-feared vision of a genetic-normative society into tangible future.

Such a daring decision by the founders of the project is emblematic of the rather peculiar context of the Estonian society, into which the idea was introduced. In his theory, Beck sees a solution to the market-ridden development in gene technology in a more conscious intervention by the state and concerned interest

¹ Actually, similar rights to the participants has been granted only in the planned Latvian Genome Bank, fashioned to a large extent on the Estonian model.

groups. This, however, presumes the existence of a developed “reflexive society”, formed patterns of creating “reflexive mode” in different spheres of life. In Estonia, the social context substantially differs from the countries upon which Beck’s theory has been created. The application of a patient’s consent form in medical practice is quite a new practice; also until recently, the medical researchers had largely preserved their considerable unscrutinised freedom concerning patients’ health data.² This has resulted in a situation where the “reflexive” capacity of society has been realised to a much lesser extent, tradition of public critical engagement in scientific or medical issues in forms of public panels or even lobbying by different patient groups, common in many countries, is almost non-existent. Though there is gradual change, the legacy of the Soviet society, an extreme version of the industrial modernity, in the context of which Estonia developed for half a century, is still apparent. The Soviet ideology was characterised by a strong emphasis on the ideal of the progressive emancipation of the individual through the rationalisation of the world on the basis of reason, science and technology. This has resulted in the continuing high esteem of science and scientists, as well as great enthusiasm about new technologies, e.g. IT. The technological advancement as a key to the success of the country is fostered also in the national identity discourse. The Eurobarometer studies have revealed that in this respect, the Estonian population is similar to other East European nations, who compared to e.g. EU citizens are less risk-conscious in respect to the latest scientific accomplishments.³ Besides, Estonian society is characterised also by lack of previous experience in “gene issues”, in the latest large debates that have raised heated discussions in many European countries, e.g. genetically modified organisms or animal cloning, Estonian public remained a passive observer.

These aspects seem to have had an impact both on the actual developing of the project, as well as its acceptance by society at large. For the execution of the project, special legal framework was adopted – the Human Gene Research Act. The law rules out any kind of discrimination on the basis of genetic information, as well as establishes societal monitoring over the scientific process via the Ethical Committee of the Genome Project. In the context of the theory of reflexive society, formally, the launching of the project could be presented as an example case of introducing “reflexive mode” into science-making. However, the preparation and passing of the law caused no wider public debate, thus it is based on expert knowledge rather than wider range of interest groups. Also some provisions set up to ascertain public monitoring of the project lack real influence, e.g.

² Differences in the traditions of medical research are reflected also in the fact that only very recently, a national daily *Postimees* published an article reporting on the indignation of the cancer researchers over the new law on the defence of personal data that requires the researchers to ask for the consent of the patients for using their health data in medical research. (See Alo Lõhmus. Seadus peatas meditsiiniregistrite põhjal tehtavad teadustööd [Law Stopped Research Based on Medical Registries]. In *Postimees*, 15.10.2003).

³ Candidate Countries Eurobarometer on Science & Technology. Cc-Eb 2002.3. http://europa.eu.int/comm/public_opinion/

according to the law, the members of the Ethical Committee, invited to inspect the activities of the Genome Project, can be called back from the Committee by the council of the project. Furthermore, as the participation is voluntary, the recruitment of donors is done by family doctors who are paid per “head” for the costs involved in taking the blood sample and gathering the health data. With such a regulation, it will be difficult to assess the impartiality of the information given to the potential donor over the pros and cons of the project. It can be argued that in the specific social context, the provisions in the law provide only formal compliance with true “reflexive mode”. Though such involvement by the state grants high level of legitimacy to the private initiative, no real societal monitoring is actually guaranteed.

4. Public attitudes towards the Estonian Genome Project

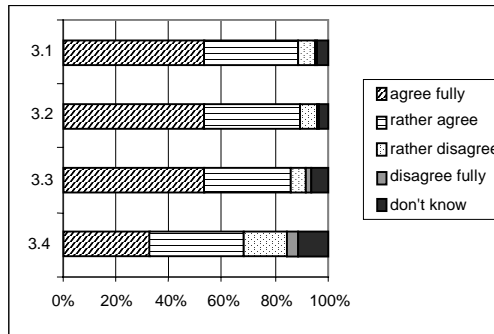
The results of the survey studying public attitudes towards technology in general and genetic research in particular indeed show that compared to the Western counterparts, the Estonian population seems to have to a large extent preserved the high modernist ethos of science and scientists, as well as a rather unchallenged acceptance of all new technology.⁴ By majority, the benefits provided by the new knowledge are valued higher than the accompanying risks. The Estonian population is characterised by exceptionally high expectations of genetic research. The survey indicated strong public support for using genetic tests for getting information on possible illnesses (89% agree fully or rather agree). However, the support is high also for “applying” this information, e.g. for deciding whether to give birth to a child with genetic disorder (86%) (see Figure 1).

Although these responses do not reflect one’s own potential behaviour in such a situation, they reflect the dominant attitudes in society. In the literature on the social impact of genetic technology, fears have been expressed that the introduction of prenatal genetic testing will increase the pressure for the use of available preventive measures, e.g. people unwilling to make prenatal genetic tests can be considered irresponsible (Clarke 1999, cf Jallinoja et al 1998). These results show that such fears have even greater relevance in the Estonian case that only recently abandoned the Soviet pattern of dealing with disability of any sort, which was mainly handled via exclusion into special institutions. Generally, parents were encouraged to give up a child with disability into “state care” rather than given support and counselling to cope with the situation. In such a context, the support for preventive measures by prenatal testing or “selective abortion” might be more

⁴ A nationally representative survey with 914 respondents was carried out in December 2002. The goal of the survey was to map the attitudes of the Estonian public towards science and technology, the hopes and fears related to new technologies generally and to the Estonian Genome Project in particular, on both personal and societal level.

⁵ Candidate Countries Eurobarometer on Science & Technology. Cc-Eb 2002.3. http://europa.eu.int/comm/public_opinion/

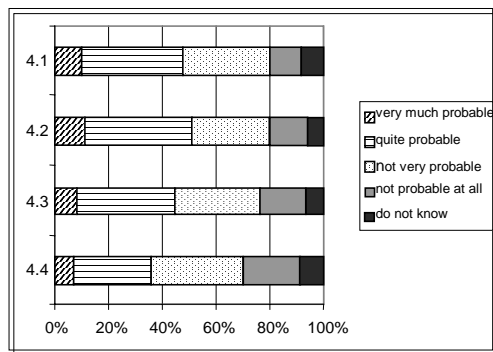
accentuated than in societies which have taught their members to accept variety more effectively.



- 3.1 People should be encouraged to be tested in young adulthood for disorders that develop in middle age or later in life.
- 3.2 Parents have a right to ask for their child to be tested for genetic disorders that develop in adulthood.
- 3.3 Genetic information may be used by parents to decide if children with certain disabling conditions are born.
- 3.4 Couples who are at risk of having a child with a serious genetic disorder should be discouraged from having children of their own.

Fig. 1. Attitudes towards application of Genetic Testing.

In general, in the public eye, the possible societal benefits created by genetic knowledge seem to triumph over the ethical dilemmas in respect to the autonomy of an individual. This is also reflected in the willingness of three fourths of the respondents to allow the police access to the genome bank during criminal investigations, putting public safety above privacy.



- 4.1 Insurance companies will start to demand the gene test results for determining the level of insurance premiums.
- 4.2 The employers will start to demand gene test results from candidates to certain jobs.
- 4.3 Gene information will start to influence interpersonal relationships, e.g. choice of partner.
- 4.4 The spreading use of gene information will clear road to a new type of society where the population is divided into "better" and "worse" depending on genetic makeup.

Fig. 2. Attitudes towards possible implications of genetic knowledge on society.

The majority of the respondents exposed similar lack of concern when they were presented with the possible "gloomy" scenarios of the further dissemination of genetic knowledge in society. Up to now, though, the majority of the respondents

⁶ From all those who are definitely planning to participate in the Genome Project or have not yet decided. Among the respondents, who definitely plan to participate (24% of the population), altogether 96% plan to ask for their gene card.

consider the introduction of genetic information in the employment or insurance relations improbable, and even more decisively refute the idea of a possible effect on personal or social relations. This is perhaps the greatest difference with other societies in the process of launching a gene bank. The Estonian population does not stand out for its general optimism, but rather for its very low level of scepticism. Recent Eurobarometer surveys have detected considerably high expectations for genetic research in all European societies, due to the alluring promise in medicine.⁷ However, the majority show also much bigger concern over possible misuses of data, as well as demonstrate different levels of support for different applications. In Estonia, this other side of the coin seems to be much more weakly present.

Similar overwhelming optimism characterises the public acceptance of the Estonian Genome Project. According to the survey, for the majority the benefits of the project, both personal and those of the whole society, outweigh the probable risky consequences, e.g. leakage of data or possible psychological stress. The major advantages of the EGP are considered to be medical, however, also its contribution to economic development and international recognition of Estonia are considered important. According to Tammpuu (2003), in the national printed media the Estonian Genome Project has been presented in a relatively technocratic framework, viewing the project as a national venture, promising international fame as well as progress in science and medicine. The dominating optimistic attitude towards EGP and genetic research in general reflects to a large degree the patterns of public presentation of the project.

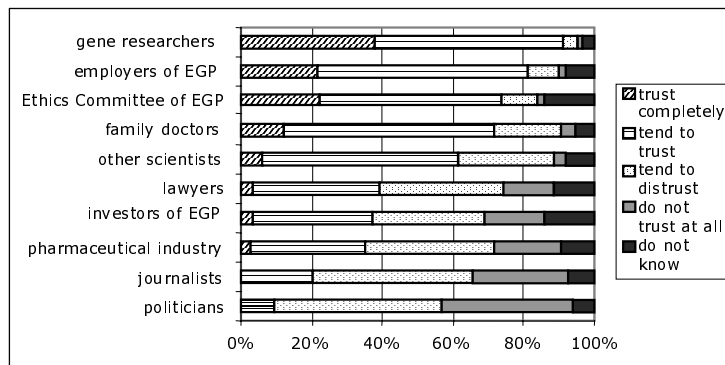


Fig. 3. Trust in statements about the EGP by the following persons and institutions.

The weak risk-consciousness is revealed also by the popularity of the idea of personal gene cards. This is perceived as one of the major benefits of the project.

⁷ Europeans, Science and Technology. Eurobarometer 55.2, 2001. http://europa.eu.int/comm/public_opinion/

According to the survey, from the potential donors 83% plan to definitely apply for one, while only 2% reject it decisively.⁸

Noteworthy are the results of the study related to the question of trust of different persons and institutions as the most reliable sources of information on the project. Genetic scientists and the employees of the Estonian Genome Project are trusted by more than 80% of the population, trust in the persons connected to the project outweighs that in e.g. family doctors (70%) – the actual contact persons of the potential gene donors – and other scientists (little over 60%). The public attitude shows especially low trust in journalists (20%), although for the majority, printed media and television constitute the principal sources of information on the project, leaving other sources far behind (e.g. family doctor, friends, relatives).

However, all these results have to be considered in the light of a few other significant findings. Despite the quite large-scale publicity the EGP has enjoyed during the past 3 years, by the end of year 2002, only two thirds of the population claimed to have heard of the project, and only 7% considered themselves well informed. Furthermore, although the general attitude towards the project as a national venture is positive and optimistic, it is given high appreciation as a national venture bringing benefit and international fame. At the same time, only 24% of the population knowledgeable about the project have decided to take more have decided negatively (40%), while many have not made up their mind (36%). Hardly reflecting the final outcome of the project in terms of actual participation rates,⁹ these figures reveal rather low actual interest in such issues from the part of the majority of the population. Moreover, the people who intend to participate and who are “opting out” do not show significant differences in their attitudes towards the project or to genetic research in general. The lack of coherence of views in this respect gives reason to assume that the final decision by the potential donor is susceptible to haphazard influences and will be quite easily refutable under “favourable” circumstances. This means that the role of the family doctors and their “efficiency” in recruitment may become a crucial factor determining the actual participation rates. The validity of this assumption, however, will require further qualitative research after the project has been launched in full scope.

5. Conclusion

The **introduction** of gene technology into medicine has been enjoying wide public support in many societies. If in Beck's theory, the application of gene technology in medical sphere is providing a challenge to the “mature” reflexive

⁸ From all those who are definitely planning to participate in the Genome Project or have not decided yet. Among the respondents who definitely plan to participate (24% of the population), altogether 96% plan to ask for their gene card.

⁹ At the end of the year 2003, when the pilot study (in three counties) had been going on for more than one year and the nationwide project for a few months, the participation rate was below 10 000, considerably below the initial expectations.

society, the effect on the society with weakly developed public “risk consciousness” seem to be even more profound. First, it has proven easier to introduce ideas that would most probably meet strong resistance in more “reflexive” societies. Such smooth and quick acceptance and support for the project of such a scale with no real discussion on the possible social and ethical consequences is most probably possible only in a society which has “escaped” all the earlier genetic issues that gained critical public attention elsewhere, e.g. concerning GMO food or animal cloning and entered the “gene debate” as a blank sheet only lately.

Beck saw as a solution to the creeping geneticisation in the society a more decisive regulation by the state. The launching of population based databases, by the mere scale of such enterprise and heightened public interest, provides a good chance for evoking ethically challenging aspects related to such research as putting down legislation framework for firmer public scrutiny. However, the Estonian case proves that also with best intentions, the lack of previous experience in the area as well as lack of engagement of wider public can leave considerable loopholes in the legislation, as well as allow debatable provisions that seem to serve the commercial interests rather than the target population at large. The decision by the founders of the EGP to allow full information of one’s genetic makeup to all the donors contradicts the practices in competing projects. This has been accepted by the majority of the population as one of the major advantages of the project, without too much reflection on what could be the results of the introduction of such knowledge into the society without correspondingly effective means of treatment.

At the moment of the survey, the project enjoyed a significantly positive image in the eyes of the population. The popularity of the project is based on its skilful promotion as a impressive national scientific venture. However, taking into account several characteristics of this acceptance – that the general knowledge of the project is rather low, that most of the information is received from public sources, rather than personal contact; and that people have considerably higher trust in the persons directly involved in the project rather than possible critics, then support is gained on rather abstract level and might not reflect the actual eagerness of the people to personally become a donor. Moreover, the survey revealed only a weak correlation between personal stance towards the EGP and the intention to participate or not. This seems to make the final decision susceptible to the haphazard context of decision-making. The validity of this assumption, however, can be estimated only after further research into how the growing experience of personal involvement in the project, i.e. the actual process of data collecting “on the ground,” will be affecting the public perception of the project.

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