

EXPLORING THE ARTICULATION OF AGENCY: POPULATION GENOME PROJECT IN LATVIA

Aivita Putnina, putnina@policy.hu

Introduction

Latvia is a small country of a population of 2,5 million stretching along the south coast of the Baltic sea. It has a long history of 700 years of colonization by Germans, Swedes, Poles and Russians. Latvia established its rather short independence in 1918 which was resumed in 1991 after 50 years of Soviet rule. All these events have left Latvia with a minority of Russian speaking Soviet population that actually makes a majority in the capital of Latvia Riga and on Latvian-Russian border. These geographical and historical facts are quite important to understand Latvian Genome Project.

The first activities concerning the Genome Project started in 2000, being carried out by a leading Latvian biomedical scientist. A working group consisting of politicians and scientists was established to promote the project and all the procedures linked to it. It amounted in accepting a Law on The Research of Human Genome on June 13, 2002 and a still circulating draft project of creating united database of Latvian population being pushed through the government now.

From the practical point of view, gene research in Latvia has a stable tradition, concentrating mostly on genetic research of such monogenetic diseases as cystic fibrosis, haemophilia B and fragile X syndrome and multifactoral diseases as breast cancer, collateral cancer, familial melanoma, coronary heart disease, obesity, diabetes mellitus (Pirags, 2002). Those research directions correspond to the statistically most problematic diseases in local population.

Latvia is also a polygon for different international research companies, mainly funded by corporate businesses. This research was typically what one could call the extension of colonialism – collecting the tissue material at a lesser cost. Due to the rather loose guidance for research in Latvia, it was rather easy to receive approval for research. The only official permit for such research had to be obtained from the Scientific Ethics Committee without specifying the specific committee. As a result multiple committees were established at each hospital or medical school, leading to small-scale corruption activities. Needless adding that no informed consent of the donors was ever required and asked. Critique was raised unofficially among the local research community concerning research on children and a group of people who received severe doses of radiation working in Chernobyl after the accident. The benefit of international research mainly reached the pockets of collaborating research institutions receiving some equipment in exchange for collaboration.

In this paper I will look at the three main aspects underlying genetic research topic in Latvia. The first one relates to the particular socio-historic context of Latvia. Political concerns about independence, positioning Latvia on the global map and nationalism are much reflected in the incentives of genome project. The second aspect is linked to the

place of biomedicine in relation to the public and political fields. Firstly, it is designed to uphold the borders between the biotechnology and the public. Genome project is articulated in exclusively biotechnological and biomedical terms which allows excluding the public. The third dimension of the genetic research concerns defining agency within the genome project and settling the respective rights, obligations and expectations of the participants.

I argue that framing it as a question of the development of science and nation curtails the opportunity for public debate and leaves the public without any 'proper' language to argue. Instead of ideas one should discuss "the question of ways and means", as Latour (1988:47) frames it. It allows transforming the closed borders of the biotechnological field and offers a common language for negotiations.

Discourse direction 1: Creating 'scientifically proved' Latvians

Here the historical background comes into the play. As Valdis Pirags, a member of the Latvian Genome Project Team, opened his presentation in an international seminar on legal aspects of genetic research, the project was important showing the 'civilised' face of Latvian nation. Thus, the project was much linked to eliminating the colonial experience of Latvians and establishing their own control over their genetic legacy. Moreover, as it is argued by anthropologists (e.g. Lock, 2002), the genetic research constructs cultural social group identities. Biological context is clearly used to support the national ideology in Latvia. The eventual political aim of the research into ethnogenesis was showing pedigree of Latvians, proving their honorable emergence amongst the other nations or using Latvian own idiom: "Proving that Latvian have not been fallen out of the back part of carriage". If Human Diversity Genome Project aimed at singling out 'indigenous' populations (Lock, 2001), then the target of Latvian Genome Project was exactly the opposite – to prove that Latvians do not belong to 'indigenous populations' and are part of the civilized world (Pirags, 2002).

The links long forgotten by Danish, Swedes, Germans were thought to be reassured via genetic research. Interestingly enough, the link with Russians proves to be quite different – here the drawing the boarder is required for political reasons. The research hoped to establish the true place of Latvians, putting their genesis within the context of rise of European nations. For these causes linguistic explanations formerly were used. They established the old and honorable origin of Latvian language putting it along other Indo-European languages and pointed at the authenticity of Latvian language through it perceived closed relation to "proto-Indo-European language" Sanskrit.

Genetic research would analyze "DNA polymorphisms of Latvia basic population", thus producing "deep and maximally objective data on ethnic composition, migration and regional differences in Baltics and Northern Europe" (Project Draft of United Population Genome Database, pp. 20 and 33). As it was argued above, these scientific efforts exclude the area of Russia and are based on socially evoked category of 'basic population'. It also clearly indicates the political agenda of Latvian external politics –

positioning Latvia within the area of Northern. Recently the group announced their first finding of Baltic gene despite the small sample taken. It was most expressed in Latvians. Although it appeared to be just a small fragment without much significance and its 'dense concentration' was not statistically significant, the finding was warmly embraced by media.

The issue is potentially quite sensitive in respect to the large Russian minority which interest is eventually excluded from the state funded program of Latvian ethnogenesis. Latvian stories of its historically grounded pedigree and long suffering so far have been taken rather ironically by Russian speaking media (Kruks, Sulmane, 2001). However, keeping the politicized context of the genetic research in mind, strained ethnic relations might emerge as one of the side effects as the Genome Project results are published.

Discourse direction 2: Advancing medical science

No wonder, when MP and medical doctor R. Razuks first introduced the Genetic Research Law to Latvian Parliament in Fall 2001, public interest was completely absent from his speech. MP stated two important causes for creating the Law. Firstly, that was one of the latest developments in medicine and biomedical sciences. Secondly, it was the direction our northern neighbors Estonians moved. I must add that Estonians are considered to be one of the most successful East-Europeans countries and chasing them had become sort of national sport in Latvia. Therefore, the MP added: "They [Estonians] are not moving that fast and successfully as they expected because their project also requires financial support".

Central Population Genome Database Project Draft strongly allies genetic research with progress and development; therefore it evokes a strong motive of the progress of science as a progress of the whole nation:

In case we were to refuse carrying out the formation of genetic database or were to delay its creation, medicine and health care system in Latvia would inevitably lag behind the standards and the level of developed countries. (p. 7)

The colonization motive based on former historical experience is also present when speaking of development in biomedicine. Genetic research is pictured as the instrument for colonization, therefore gaining a control over it is crucial.

On a smaller scale the colonization motive can clearly be applied to the relationship of the politicians and scientists to the public. The public experience of illness and health has been colonized through 'objectification' of its tissue material via specific processing of the information much the same way as state's experience can be colonized via development of genetic research outside Latvia.

The benefits of the genetic research for a broader population are seen in ability to predict and control the population health behavior. On the one hand, the research might lead to the more individualized treatment, decreased number of tests and more effective therapies

and drug treatment. On the other hand, the research results, on the contrary, might indicate higher risks and point at appropriate behavior to minimize these risks. In both cases, however, biomedical control over people's lives would increase and the options for choice decrease.

Another motive of biomedical discourse concerning genetic research is reestablishing medical authority which has become loose at the end of 20th century. As Comaroff (1982: 63) writes, medicine assumes a privileged role in the constitution of experience in any society. Medical knowledge serves as a basis to produce other kinds of knowledge. Medical knowledge is power, and medical discourse allocates it to the doctor creating asymmetrical power relations between the doctor and the patient.

Armstrong (1982: 109-122) argues that the focus on the subject in medical and human sciences discourses is recent. Subjectivity has rather been 'liberated', given its own moral rights, than 'created'. 'The patient' emerged as 'the product of a series of smaller discourses (on compliance, communication, etc.) which, though intertwined with one another, have contributed separate elements to the final perception of the patient: a 'subject' imbued with personal meanings, constructs, feeling, subjectivity, etc.' (ibid.: 119). As it was 'invented', it was provided with a history of oppression and a universal status.

This liberation has entered public health discourse giving rise to concepts of providing equal health care opportunities, patient's choice and informed decision-making. This process has been delayed in Latvia due to the Soviet regime which used biomedicine as means for political control. The most popular example of it was schizophrenia diagnosis for political dissidents based on scientifically justified beliefs on their inadequate perception of reality.

The new approach of medicine based on genetic research reveals 'truths' not only at the individual level, it determines relationships within and between populations. At the same time, this motive sets an agenda for respective rights and ownership of the information. The debate on property rights over genetic research data and products is closely linked to these imagined relationships. In Latvian case, property right issue is state and politically driven.

Discourse direction 3: Establishing agency¹ and rules for the game

Both ethnogenetic and medical advancement discourse topics are typical modernist discourses asserting two still powerful meta-narratives: nation and biomedicine. Therefore only two active agents – politicians and scientists emerged as the key figures in Latvian Genome Project. The tension between the two is clearly seen in the current Law. All genetic research in Latvia has been monitored, regulated and coordinated by a commission established by the Government and consisting of 3 members of Parliament, 3 Government appointees and a member respectively from Latvian Science Council,

¹ I use the term agency, following P. Bourdieu, stressing the capacity for social action embedded in particular entities participating in the game of genome project.

Latvian Board of Lawyers, Latvian Association of Medical Doctors and Central Committee for Biomedical Ethics. Only the last organization mentioned has a reputation of not being politicized.

The Committee has rather broad right regulating the research process itself. It decides on any research containing genetic component and obliges all researchers submit their data to the Genome Database. As it was recognized by the scientists involved in genetic research, it cut the freedom of scientists and seriously limited the scope for international cooperation. For example, scientist X expressed his worries concerning participation in international academic project on a common multi-factoral disease. First, it made the preparation for research much longer, making the road for the necessary permits much longer and bureaucratic. Second, the Law required the submission of data and research information to the database which contradicted to the aims of the project and eventually violated the interests of donors willing to participate specifically in this project. Thirdly, it prolonged the procedure of research since permits were required each time tissue material was to be exported to the research center abroad.

Scientists participating in the work group did not object since they their first objective was creating a legal framework for further political and financial advancement of the project. They believed any discussions concerning the Law would slow down the project itself. Scientists criticized the project and expected amending it soon after it is passed. Their passivity in Law therefore was a clever move in the whole game and asserted their capacity for agency.

Latvian population on the whole was absent. The MP mentioned above put the population in the project in a quite loose manner:

*“The main aim of the research is to ensure the voluntary participation of **donors, that is people** [my emphasis] offering the data, to guarantee safety and **computer anonymity** [translation precise, my emphasis], because data would be stored in computers, to protect the donor from the unlawful use of the genetic information; that is to guarantee human rights and to regulate the collection, processing and use of genetic information, ensuring the state control in this area”*

The text sounds the same strange in Latvian as it is translated in English. It creates an image of a Latvian inhabitant as a synonym for ‘donor’, whose ‘human rights’, according to EC Convention on Protection of Human Rights and Dignity in Biology and Medicine (1996), should be guaranteed. However, anonymity is seen not as something inherent in donors but rather in technical means. Therefore the main debate concentrated on safe storage of data rather than on private feelings of prospective donors.

The first draft of the Law on Genetic Research completely ignored the informed consent norms. The only means of control over the donated material and processed information allocated to prospective donors was claiming it back when data proved to be misused. This raised some objections in Latvian media articulated by an anthropologist and the Ethics Committee.

The Law was significantly improved, adding a chapter on informed consent and enlarging donors' rights. Informed consent had to be obtained only after handling a written information form concerning donor's rights, obligations and potential medical risks donating tissues. Rights of legally incapable were established. Donors also gained rights to withdraw their donated material and information related to it at any time. They also could demand a limited applicability of their donated material. However, these rights still remain contradictory since the Law elsewhere still demands submitting all research data to the central database.

Space for the public debate

Donor's rights, however, would not ensure the exercise of donor's choice since the overall context of choice is not present. Firstly, patients still have a rather low authority in medical decision-making. Secondly, consequences and social risks for the donation are not considered from the donor's perspective.

Current directions of discourse eliminate the voice of population. Even the Project Draft on Genome Database, created by scientists was more sympathetic to the public and its ultimate aim was the improvement of public health and quality of life, the image of the public was ambivalent:

The project of this scale should be based on the support of the major part of population. Therefore a careful educational campaign and free access to information is needed at any stage of the project. At the same time project should be protected against the rapid changes in public opinion or political situation.

General public thus is seen as potentially endangering the fate of the project.

Another reason for the absence of the public in the genome project is closely related the closed field of authority of medical science. As in early 20th century biomedicine, patient loses his or her competence to make informed decisions:

Public simply is not prepared to accept the [genetic] information as it is. Probabilities are hard to digest. Even many correctly interpreted facts can lead to discrimination. For example, if we learn that homosexuality has genetic correlations. Of course, scientists know what does it mean; public can misunderstand it. (Prof. Pal Veneianer, Biological Research Center of the Hungarian Academy of Sciences, 2002)

This belief particularly seems having contributed to the quick and silent launch of the Genome Project. Seeing it as a purely scientific project helps solving dilemmas concerning public participation and relationship between the science and public in specific.

This also seems to be true in relation to media. Looking at two cases – Latvian and Estonian genome projects – all of them have been launched rather quietly. It has been the

official policy to keep the project initiation low profile. Latvia accepted the project without much debate, the main body of information was provided by scientists and politicians initiating the project.

The media took its interest in project at its beginning and final reading. However, as it was marked by the journalists, the subject appeared to be of rather high complexity and it was difficult to expose it analytically. Journalists were most interested in topics covering such issues as protection of privacy and possible malicious use of the data collected.

There has been no information on the Law or project itself available officially on the genome project neither in the Government nor Parliament. However, most debate in the Parliament (which was the only official and open source of information) was dedicated to regulating functions of gene research.

Strategies for public participation

Looking at the Genome Project from the power relations perspective, several major strategies for the public involvement can be detected. Those are based not on ideological notions of medicine or nation but on practical (power) relationships of the main agents

A strong advantage of the Latvian genome project lies in its current specifically applied medical approach. Research directly contributes to the diagnostic and prospective treatment interests of the donors. Participation in each of the separate genetic research projects is based on close treatment relationship between the doctor and patient in the hospital.

However, this might change when the focus of research becomes general. Estonian Genome Project found the solution in information campaign which created a free of charge help-line, production of various booklets, TV, radio and Internet materials. General practitioners were trained specifically as the main collectors of genetic material. At the beginning of the campaign, only 1/3 of the Estonian population supports the project and is willing to offer their tissue material (Kruuv, 2002). No such opinion pool has been conducted in Latvia.

Transparency is a crucial aspect of the project. Even Latvian work group resisted the temptation to trust the collection of the genetic material to a foreign private company, as it was done in Iceland, the state control over the project alone does not ensure the public interest. Moreover, use of the state budgetary means and conceptualizing genetic material as public property adds more responsibility and restrictions on the Project group.

Transparency and accountability in relation to the good governance of the public genetic property therefore becomes the utmost task of the regulation of the genetic research. It loses any legitimacy when regulation becomes closed and secret.

It is quite clear that collection of the material itself would not cause that much concern that ownership and further use of that material. Claims to ownership are established

through the informed consent procedures and donor's further rights to control his or her material. Therefore it is essential that the use of the material is debated prior to transferring genetic material and data to different kind of property.

The Project Draft clearly indicates that the pharmacogenetic research can serve as an important source for further financing of the project. Offering the database to pharmaceutical research companies would lead to transforming the property rights over genetic material unless those are not underlined in specific contract.

The discourse should be extended towards political risks of interpreting the data. The current ethnogenesis project already evokes social differences amongst ethnic groups in Latvia. The same might appear true for other forms of discrimination based on individual's genome.

Conclusion

The paper discussed the current traits of Latvian genome project. Firstly, it looked how the Latvian Genome Project kept the borders between the biotechnology and the public. Genome project is articulated in exclusively biotechnological and biomedical terms which allows excluding the public.

Secondly, it is strongly advocated as a matter of advancement for the whole state. A whole range of images was produced to show Latvia without a genome project as a backward country.

Thirdly, the project imposes certain division of agency upon participants. The role of the general public is that of passive donors. Scientists and politicians take an active role of demiurges: data-keepers and analysts.

Playing a passive role, the public simultaneously becomes an ally of the project. However, greater public involvement can be achieved only forming efficient partnerships between all the participants and shifting the discussion contents from the biotechnological field to politics based on notions of participatory democracy. The problem of genome project lies not as much in the genome as such but in application of its data. This on its turn can be achieved only finally opening the project for the public debate and reformulating it in a different discourse line.

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