

FINAL REPORT
**Representation of genomics research among Latin American laymen and
bioethics: a inquiry into the migration of knowledge and its impact on
underdeveloped communities**

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Description of Project:

The main aim proposed we can point out that in searching knowledge about Human Genome Project social representations we have identified some variables determinant in the social construction.

Level of knowledge, academic background, gender, age and occupation have been selected as ordinal and nominal variables to characterize the person interviewed and the social and cultural conditions that would determine the Human Genome Project social representation.

We believe that the migration of scientific knowledge from the laboratory to civilians is influenced by the level of exposure to media which strengthens expectations related to the imagery and the collective fantasy. This phenomenon has been proved using the hostility and anxiety scales of the verbal content analysis applied to those interviewed in reference to the Human Genome Project (we presented a symposium for the public on this technique).

With respect to the specific aims proposed we can point out that up to date we have built two instruments; one qualitative, which is the semi-structured interview, whose questions came about from applied tests of semi directed conversations. In these we look for accessing both specialists and laymen imagery. The six questions have been designed to be applied to biomedical researches, lawyers or legislators and civilians of different socioeconomic level and academic specialty, where only one question of the six has to be with the specialty of the interviewed.

The second instrument is a questionnaire with a likert scale which measures how much they know the interviewed about the Human Genome Project. The main characteristic of this instrument is its self-administration. It is oriented to gather standardized data and has four sections with closed-ended questions: knowledge on

Genomic Research; Meanings associated to Scientific Research (Semantic Differential); Interest on Science; and Personal Information.

Statistical analysis will be applied to the data gathered through the questionnaires

It is important to point out that the quantification of data obtained through the questionnaires responds to the Classification and Regression Tree (CART) method of Breiman.

Finally, it is important to point out that the statistical analysis just described will be accompanied by the content analysis of verbal conduct gathered through interviews and whose aim is to evaluate the degree of hostility and anxiety that subjects have in relation to the Human Genome Project, according to the variables previously described: gender, age, occupation, level of studies, socioeconomical level.

The content analysis evaluates quantitatively psychological attributes in the spoken and written language; it is based on spontaneous speech, without imposing limitations or favoring the projection of a distorted image.

Purpose of Project:

Aim Purpose

To produce general knowledge on social representations regarding the human genome in relation to expectations derived from cultural imprint and organization of social systems in Latin America

Specifically objectives

1. Uncover and examine the normative impact of human genome research results in groups and societies in which forefront research is absent
2. Bring into focus the relationship between this impact and the methodical and argumentative practices current in Latin American bioethics
3. Assess the expertise and knowledge of professionals regarding the normative and practical implications of human genome research results
4. Evaluate the importance and depth of knowledge in civil society
5. Gather information on potential applications in the medical, legal, and social areas as they are imagined or constructed by laymen and professionals
6. Deliver a model of statistical relations between degree of knowledge, access to information, and social constructions in relation to the human genome

Results obtained through Interviews and questionnaires

Although it was proposed to sample 324 individuals only 311 have been interviewed to date. We have studied an equal number of males and females. Median age of those surveyed is 38 years.

The results shows that a significant percentage of the surveyed population possesses an incomplete university education. Among those who are more highly educated it is worth highlighting the group of physicians. Lay citizens reported high school education more often.

In term of subgroups, physicians considered themselves to have the highest level of knowledge about HGP, while Lay citizens informed having the least.

Mexicans claim to know the most. With regard to the variables, people said they know most about applications in health, such as cloning and genetically modified organisms. Trend could be attributed to the impact of mass media, particularly television. This is across all subgroups with physicians expressing highest level of knowledge. The lay citizens demonstrated the least knowledge regarding HGP legislations, and 58% don't know anything about it. The situation is similarly in other selected topics.

One of the more important of the methodology, it was the Semantic Difference, in order to analysis the social discourses.

Score for each semantic factor: *Evaluation, Potency and Activity*, was computed for different topics. The sum of all scores for each factor, for those interviewed a score of one through seven, provided the final score.

The distribution of the new variables "the added score" of each factor from classification of six evaluated concepts is not a normal curve.

The semantic differential was based on the score (1-7) given to Evaluation, Potency and Activity on topics pertaining to the HGP, with a higher score indicating a higher level of agreement.

Analysis consisted in adding the total score, understanding that the minimum score that a concept could receive is 3 and the maximum 21. Thus, a score of 12 represents a neutral opinion.

Collected data showed that Potency receives higher scores than Evaluation and Activity. Over all, in terms of Evaluation, Science received the highest score, being viewed most favorably, while Genetic diseases and HIV received the lowest score. 29.4% of those interviewed are informed about science. Of these, 62.2% are physicians. One third of lay citizens inform themselves eventually about science, like the students. Within the Lay citizens, students seem to seek information about science more often.

The main way to obtain information about HGP is Internet. Physicians seem to be technically informed and use specialized books and journals more than the Internet.

Data indicate that physicians involve science more often in their daily life, while the lay citizens so to a lesser degree.

A comparison of countries shows that science impacts legislators in Argentina. Physicians most influenced by science are from Mexico. The most interested lay citizens can be found in Chile.

Out of 308 persons who were interviewed, 70.45% were Catholics. A slightly greater percentage of students and lay citizens professed to be Catholic than did physicians and legislators. Peru had the greatest percentage of Catholic informants while Chile had the smallest.

Results obtained through newspaper analysis and its impact in the social representations about HGP

The newspapers revised were from Mexico, Argentina, Peru and Chile were evaluated. The newspapers selected were from 1997 to 2003. Moreover, two newspapers from each country were chosen based on their higher social impact.

The principal objective of this analysis was to show the relationship between Science and Bioethics in Latin America.

Bioethics as social discourse that tries to integrate ethical values through a multidisciplinary perspective generally is incorporated to social discourse through oral and written news.

We have examined the presence and the semantic association of the word "bioethics" in the written news of four Latin American countries: Mexico, Peru, Argentine and Chile.

The search was undertaken using the internet news met searcher www.cibercentro.com

After identifying the quantity of newspapers, the word "bioethics" was searched in the last six months publications up to august 2004.

This search is limited to the written news media registered by the met searcher and the availability of their web sites.

The amount of publications related to "bioethics" by country is: Chile 21, Argentine 62, Mexico 16 and Peru 74.

These numbers have the biased that not all news sites were available. It is interesting to rescue that the maximum amount of publications related to "bioethics" takes place in Peru where there are less quantity of newspapers. Nevertheless, the case of Peru is special since news obtained from Lima Post which is hyperlinked to a world news media in English.

The semantic relation established more often with bioethics is: Cloning, with more than 27 specific references in the texts selected. There are also 22 references to the word bioethics itself. Other topics frequently associated are contraception and abortions, as well as genes and genetics

With respect to press releases in Chile, the category drugs and genetic vaccines 76 articles addressed this topic. The general emphasis was informative but, we must indicate that the *Revista Punto Final* and *Revista Qué pasa?* Have as focus alarming the public. Human Genome was addressed in 28 articles. The general perspective of these articles is to alarm the public with respect of this phenomenon. Artificial fertilization was addressed by 11 articles. The emphasis was specifically informative.

In the case of socio cultural impact, there were 71 articles, focusing both in informing and alarming about biotechnology development in the social and political life. Cloning

concept was addressed by 74 publications with a focus in alarming the public about human cloning. Transgenic were addressed by 35 articles, focusing in alarming towards biotechnological changes.

What is written in legal and biomedical articles is similar to the data gathered through interviews with lawyers and researchers. Lay civilians, on the other hand, seems not to be influenced much by the scientific literature, they rather tend to rely on what they hear and see in the media.

Results of the revision of news papers from Chile

It was revised 312 articles of news papers and magazines from Chile during 2002-2004. The newspaper were; El Mercurio, La Tercera, La hora, La Nación, Las Ultimas Noticias, Estrategia, El Diario, La Cuarta, La Segunda, Revista and the magazines were; Qué Pasa, Revista Elle, Revista Ercilla and Revista Punto Final

The categories of analysis were medicament and genetics vaccines, Human Genome, artificial fertilization, socio-cultural impact, cloning and transgenic.

In relation with the category medicament and genetics vaccines, were published 76 articles. 25 were edited by news paper El Mercurio and 25 by La Tercera.

The general emphasis was informative but, we must indicate that the Revista Punto Final and Revista Qué pasa? has a focus related to alarm respect this topic.

Human Genome has had 28 articles, which 15 were published by El Mercurio. The general perspective of these articles is to alarm respect of this phenomenon

The Artificial fertilization has 11 articles which was 6 by El Mercurio. The emphasis was specifically informative. In the case of social cultural impact, there were 71 articles, which was 27 by El Mercurio. In relation to this category, the focus was equal between to inform and to alarm about the biotechnology development in the social and political life.

The Cloning concept has 74 publications, has been La Tercera whom published 24. The general focus was to alarm about the human cloning

Finally the product genetics modified has 35 articles, has been 10 by news paper El Mercurio. Again in front the biotechnological changes, the general emphasis was of to alarm.

Results about social representation HGP

Biomedical researchers appreciate more the benefits of the HGP, but they see or experience the lack of governmental support for research. University students worry

about the lack of equity in access to genomic medicine in the population and the instrumentation of human beings.

Lawyers and legislators are worried about the regulation of genetic information because of its possible manipulation by power interests, of possible eugenic selection of embryos and of possible genetic discrimination by health insurers and employers. Commercialization of genetic products for agriculture, for example, is seen as negative by all groups since it will benefit mostly the international biotechnological companies and not local farmers.

Lay civilians fear that genetic manipulation may take away God's role in human creation since new babies would be designed according to human will not by natural means.

In general, human reproductive cloning is negatively valued by all groups, being associated with loss of singularity for clones, since they will be genetically identical to their parental nucleus; a form of manipulation or using human beings as means to an end (role in society defined before the clone is born); as a source of power by using clones for example for war or as servants; or as altering human behaviors making clones more aggressive or having psychological problems; some lawyers and legislators see it as an instrument of power which should be prohibited since certain genotypes would be chosen by those who take decisions using clones for purposes such as war or as means for an end, while others consider that it needs to be regulated.

Among lay civilians, influenced by media portray, it is spread the uncritical belief that a human clone does not have a soul because it would be a replication of a being already in existence and that a clone is an exact copy of a person including his/her personality and conscience.

Biomedical researches see benefits in the generation of transgenic for increasing productivity and enhancement of properties for cattle and agriculture, such as vigor, duration, nutrition and plague resistance.

Lay civilians and university students tend to consider genetically modified organisms as dangerous for health, especially of inducing cancer and as artificial which is equated to lack of trustworthiness for consuming them.

Physicians and Latin American researches in Latin America worry about the commercial mentality associated with genetic research and its applications which may lead to increase the excessive gap that exists between developed and underdeveloped countries.

There are also objections to the commercialization of genetically modified organisms, since the tendency is to use the genetic richness of Latin American natural products for patenting new organisms in developed countries. Additionally there are worries about the possible effect of a decrease in biodiversity because of the use of genetically modified organisms in agriculture.

Human reproductive cloning was in general negatively valued. It was associated with loss of singularity, manipulation or using human beings as means, as a source of power or as altering human relations. On the contrary, human therapeutic cloning received a better judgment, although their critics point this technique as manipulating human beings by using them just as source of organs.

There are also worries regarding the managing of genetic data recover for population studies. Particularly, indigenous populations are often studied genetically without proper informed consent since for them is difficulty to understand the purpose of genetic research and because they place a great value to their blood, which is taken as sample.

Among the possible risks researches and lawyers identified genetic discrimination, particularly at work because of avoiding hiring someone due to his/her genetic constitution (i), and by insurance companies, which may establish their fees according to the risk of having diseases with information derived from genetic tests (ii).

There are also worries of using the genetic information for eugenic purposes with racist motivation or choosing or modifying embryos with selected characteristics. Particularly, abortion of fetuses or embryos because of their genetic constitution is seen as a form of eugenics (iii). Genetic determinism is considered false by scientists since it ignores the influence of social, cultural and physical environment in human behavior.

We also found that there were worries about the access to genetic information and the necessity of legal regulation, the possible political manipulation of the issue when governments tend to be authoritative and the important influence of the Catholic Church in Latin American countries which places moral demands on genetic research

Results from Content Analysis:

With respect to the technique of content analysis of verbal behavior, there is an inverse relationship between the level of anxiety and the level of knowledge.

The group which produces the greatest level of total anxiety is which retire lay civilians whom have very little knowledge on genomics, followed by lay civilians, university students, lawyers and legislators.

Biomedical researchers are the group with less anxiety. Fisher's homogeneity test gives a significant variance among the groups in total anxiety (>95%) so that there are significant differences among the groups in the anxiety generated by genomic issues.

Mutilation, guilt and shame anxieties present the greatest levels. Mutilation is associated mainly with the fear of being subjected to genetic manipulations which will affect health. Guilt is associated mainly to moral disagreement towards certain forms of genetic manipulation such as cloning or eugenics. Shame refers mainly to lack of knowledge about genetic research and to personal private information which should not be shared by others, but is not explicitly disapproved.

In relation to levels of hostility using the Gottschalk and Gleser method, the outer covered hostility is most present in lawyers and legislators associated with aggressive behavior occurring in solving litigations and in their worries for genetic discrimination.

Lay retired civilians present the greatest level of inner hostility towards themselves because of feeling not worthy and ambivalent hostility of others to them because of feeling being discriminated or disrespected by others, probably associated to their situation of lack of social support in general in Latin America for which they feel discriminated and they lack self esteem. There is significant difference in variance among the groups (>95%) using the Fisher's homogeneity test so that there are

significant differences among the groups in the level of hostility felt being generated by genomic issues.

Results from regression trees analysis

Applying regression trees allowed classifying individuals in each country base on rules for variables related to the cultural context of each country.

In Chile the most important variables for describing level of knowledge about genomics and the human genome project were: level of education, profession, evaluation of the concept: hereditary diseases, age and degree of agreement about value given to science.

In Peru, the most important variables were the evaluation given to cloning and science, degree of interest about scientific topics, way of obtaining information on genomics and degree of agreement about value given to science.

With respect to the relative importance of independent values, greater importance is given to the influence of media in Peru.

In Argentine, the most important variables were the evaluation given to cloning and AIDS patients, and the way individuals are informed about scientific issues.

In Mexico the most important variable was the degree of interest about scientific topics.

Scientific Knowledge migration:

The migration of scientific knowledge from the laboratory to civilians is influenced by the level of exposure to media which strengthens expectations related to the imagery and the collective fantasy.

This phenomenon has been proved using the hostility and anxiety scales of the verbal content analysis applied to those interviewed in reference to the Human Genome Project.

The variability of the level of knowledge explained by the Trees of Regression in the case of Chile, Peru, Argentina and Mexico is, respectively, 77%, 70% 64% and 73%. Differences arise as for the variables which form the diagrams and their relative importance; this allows determining distinguishable subgroups in each country.

In term of subgroups, physicians considered themselves to have the highest level of knowledge about HGP, while Lay citizens informed having the least. Mexicans claim to know the most. With regard to the variables, people said they know most about applications in health, such as cloning and genetically modified organisms. Trend could be attributed to the impact of mass media, particularly television. This is across all subgroups with physicians expressing highest level of knowledge.

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One third of lay citizens inform themselves eventually about science, like the students. Within the Lay citizens, students seem to seek information about science more often. People use the Internet with the highest frequency to inform themselves about science. Physicians seem to be technically informed and use specialized books and journals more than the Internet. Lay citizens access information about science the least. Data indicate that physicians involve science more often in their daily life, while the lay citizens so to a lesser degree. A comparison of countries shows that science impacts legislators more in Argentina. Physicians most influenced by science are from Mexico.

Finally, most interested lay citizens can be found in Chile. Medians indicate that people agree that doing science has benefits and is not useless in general. In general, people disagree with the idea that science is opposed to God.

Products obtained:

Publications

1. Rodríguez, E., Valdebenito, C., Lolas, F., "El Proyecto del Genoma Humano en la Literatura Biomédica en cuatro países Latinoamericanos , *Acta Bioethica* (2004) X: 167-180.
2. Rodríguez, E., Valdebenito, C. Kanner, E., Lolas, F., "El Proyecto del Genoma Humano y las Regulaciones jurídicas en cuatro países latinoamericanos", *Jurisprudencia Argentina* (2004) IV (5): 42-50.
3. Rodríguez E., Valdebenito C., Misseroni A., Fernández L., Outomuro D., Schiattino I., Lolas F. "Percepciones Sociales sobre Genómica en Cuatro Países Latinoamericanos. Implicaciones Ético Legales", *Derecho y Genoma* (2004) 21: 141-164.
4. Rodríguez E, Valdebenito C, Misseroni A, at.el "Attitudes towards genomic research in four Latin American countries" (EJBiotech/RES/237) de los autores, ha sido aceptado para su publicacion en Electronic Journal of Biotechnology. Vol. 8 No. 3, Issue of December 15, 2005
5. Schiattino L., C.- Silva Z., F. Lolas S. C. Valdebenito H., E. Rodríguez Y. Descripción de las percepciones sobre el proyecto genoma humano en Chile, Perú, Argentina y México. Saldrá publicado en Revista Quirón de Medicina y Bioética. Vol 36 N° 1/3 . 2005.
6. Schiattino L., C.- Silva Z., F. Lolas S. C. Valdebenito H., E. Rodríguez Y. Descripción de las percepciones y estados emocionales sobre el proyecto genoma humano en la Región Metropolitana .Aceptado para publicación en la "Revista Chilena de Salud Pública" Dic 2005

7. Lolas F, Daar A, Valdebenito C, Rodríguez E, Schiattino I, Feinholz D. Representation of genomics research among Latin American laymen and bioethicists: an inquiry into the migration of knowledge and its impact on underdeveloped communities (in preparation)

Seminar and Congress presentations

1. Rodríguez, E., Valdebenito, C., Lolas F., "El Problema del Manejo de la Información Genética en Latino América", III Congreso Mundial de Bioética SIBI, Cuenca (2004).
2. Australia 9-11 noviembre 2004, Sydney Congreso mundial de bioética, presentación: Representation of genomics research among Latin American laymen and bioethicists. A inquiry into the migration of knowledge and its impact on underdeveloped communities (panelista)
3. Santiago de Chile, 13, 14, 15 de Julio 2005. Videoconferencia: Biotechnology, genomic, bioethics and its implications in public health
4. Descripción de las percepciones sobre el proyecto genoma humano en Chile y Perú. Schiattino L. C. Silva Z. F. Lolas S., C. Valdebenito, E. Rodríguez A. Misseroni CLATSE VI. Universidad de Concepción. 3 al 5 de Noviembre 2004
5. Descripción de las percepciones y estados emociales sobre el proyecto genoma humano en la Región Metropolitana. I. Schiattino L. C. Silva Z. F. Lolas S., C. Valdebenito, E. Rodríguez . Jornadas Nacionales de Estadística (JNE), Valparaíso, 26-28 de Octubre de 2005
6. Valdebenito C, Rodriguez E, Lolas F, Schiattino I. Ottawa, Canada 18 de febrero 2006. National Conference *Creating and Maintaining Trust: Ethical Issues in Research with Humans* February 18 & 19, 2006. Lecture: Representation of genomics research among Latin American laymen and bioethics: a inquiry into the migration of knowledge and its impact on underdeveloped communities

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