

## **Parallel Session 4: Cultural Identity Implications in Genomics Research and Communication**

### **TALKING WITH YOUNG PEOPLE ABOUT GENOMICS: NEW STRATEGIES FOR DEVELOPING A SCIENCE EXHIBITION**

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#### **Abstract**

Mexican people deal with media information about genes, cloning, stem cells, etc. But how accurate is the information they get? And how can people integrate this information to their everyday knowledge?

I analyzed the previous conceptual framework that young students (16-20 years old) have about genomics in order to promote significant relationships between a museum exhibition and the previous knowledge that they have about this topic.

The methodology involved a meeting with students at school. They were submitted to a survey to find out their conceptual frameworks concerning genomics. Data will serve as a guide for developing a science exhibition.

**Key words:** science exhibition, conceptual frameworks.

#### **Context.**

For the last decade scientific terms as “cloning”, “gene therapy” and “transgenic” are available to people through the mass media. But how do people understand these words? How do social constructions of genetics relate to media information? And how can the Science Museums use these conceptual frameworks to enhance communication with the public? During the elaboration of a guide for a genomics exhibit I was surrounded with this questions. Young students between 16 to 20 years old are the expected public for the exhibit. Therefore, I decided to ask them their opinions, conceptions and misconceptions about genetics.

#### **Objective**

This study will help to identify the previous ideas that Mexican students have about genomics in order to develop a guide for developing a science exhibition at Universum Museum.

## Methods

100 male and female students between 16 and 20 years old were submitted to a 5 questions survey concerning genetic terms. After the application of the survey, students were exposed to a one-hour lecture and workshop with an expert. The answers are being analyzed and constitute the preliminary considerations for developing a science exhibit at Universum Science Museum.

## Results

Some questions brought to light interesting and surprising misconceptions that show the confusion that stands after mass media exposure (radio, press, TV and movies) to genetics terminology without enough scientific backgrounds. It is important to point out that the survey took place at a school. The answers came from students who had at least basic understandings of chemistry and biology. Nevertheless, the study shows that students do not integrate mass media information from their everyday activities with the science lessons they learn at school.

For every question, the highest percentages are discussed below; only in particular but interesting cases we selected some answers to be presented.

The first question asked for a definition for “genome”. All answers (correct and incorrect ones) were short and simple. The most common answer involves 20% of the students, who wrote, “It is the genomic information”. A high percentage could not answer the question (18.5%). Some students (11%) considered that it concerns “a gene that science can manipulate” while others (7%) specified that it is a “substance that rules how the person will be in the future”.

About genes and their location, 22% answered that genes “are located inside the cells and they have a circular shape”, while another 22% wrote that genes are “inside DNA and have a cell shape”. A particular student said: “genes are located inside the brain, because they rule everything”.

It seems to me that the establishment of a relationship between DNA, genes and cells is not being understood. Students establish a conceptual network between genes being located inside the cells, and cells having a rounded shape (which, by the way, is not a necessary condition of all cells). Therefore, genes must have a circular shape.

A third question about genes manipulation brought these main answers: 30% of the students think that genes manipulation has to do with “cloning stuff”. 28% did not answer, and 15% consider that “it is a good method to cure illnesses”.

Students emphasized the importance of mass media communication: 28% of them agreed in getting their opinions through television. TV is followed by the internet (18%). School got only 11%. The highest percentage was reached by students who did not answer the question (39%).

The last question involved their opinion about cloning. It is interesting to notice that students gave an answer that include ethical or moral issues more than considering any scientific fact. The highest percentage was reached by students

who claimed to “agree with cloning” (without giving any argument to emphasize their opinion). On the other hand, 13% disagreed. 15% said “it is good but dangerous” and 7% believe “cloning is good because it will bring the dead ones back to life”. Only 15% thinks cloning is a difficult topic and they can’t give an opinion until having enough information.

### **Conclusions**

The survey helped the museum team to notice students’ questions and ideas that we should consider. Our science exhibit involving genomics must have several levels of communication. It is clear that students do not deal correctly with the molecular and the cellular level at the same time, and the exhibit can help in visualizing this information.

Although limited resources are “a museum’s everyday life”, after the survey we decided to include several themes about cellular biology. A new survey to find out what our visitors think about genomics and cells is taking place at Universum Museum.

Mass media coverage is responsible for some of the myths and misconceptions that Mexican students have; even if they go to school and have public libraries to attend, students seem to believe what they listen from the mass media without questioning the quality or the certainty of the information.

Metaphors and analogies can emphasize confusions in the public.

Some of the topics inside the exhibition should try legal, moral and ethical aspects because it is obvious that our public is interested in those themes.

**Parallel session 4: Cultural identity implications in genomics research and communication**

**SCIENCE COMMUNICATION THROUGH SOCIALLY  
CONSTRUCTED MONOLOGUE**

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**Abstract**

By applying ‘social constructivist’ and related ‘public understanding of science’ (PUS) perspective paper empirically examines the social construction and communication of the Latvian Genome project through media discourse analysis with emphasis of its underlying pattern of expert-lay relations. Major part of media coverage on this issue is occupied by technologically deterministic expert discourse leaving little room for lay people’s narrative. Public interests are somewhat externally constructed via medical, national, economic, political and other rhetoric with yet only limited attempts made by other relevant social groups to modify and oppose those.

**Key words:** genome project, science communication, media discourse analysis, expert-lay divide

**Context**

Following the lead of many countries in regard to national gene pool exploration Latvia has recently initiated the population genome project anticipating to create national gene database for medical research as well as development of preventive and treatment measures. However, despite voiced promises of gene technology it is increasingly being subjected to critical assessment as to its implications for social realm. With its potential positive and negative consequences extending to various aspects of human life there is a need for wider involvement of society in the discussion and appraisal of these issues.

**Objective**

Building on the ideas of social constructivist perspective (Bijker, 1995, 1999; Pinch, Bijker, 1999; Gergen, 2000) this study aims to perform a qualitative media discourse analysis regarding the ideological basis and attributed meanings of this gene technology in printed media. By utilising related concepts of the PUS research (Wynne, 1995; Gregory, Miller, 1998) this study also aims to detect the character of expert-lay relations within the framework of this science communication case.

**Methodology**

In line with constructivist perspective, through analysis of language used in a particular field of social practice, discourse analysis admits the existence of manifold realities and alternative perspectives with diverse underlying

assumptions and values (Fairlough, 1995; Van Dijk, 1997; Lehtonen, 2000; Wetherell *et al.*, 2001). Based on the notion that media are among prime agents involved in defining social reality and communicating science, media discourse analysis as one of general discourse categories and one form of public discourse was chosen as basis for studying social construction of this technology and interrelations of relevant social groups. Empirical data in the form of articles were obtained from a range of most widely distributed 11 national newspapers of Latvia covering period of time from January 1999 to February 2003.

## **Results**

The media discourse analysis of the project points to a rather persistent dominance of the so-called public deficit model, which basically implies a monologue instead of a democratic dialogue with major part of contribution constituted of ideas voiced by project initiators and lack of strong alternative discourse by other relevant social groups. Lay people present a very low involvement with no special resources to influence the forming discourse while it is rather high to the genome project group involving various potentialities. By suppressing dominating latent interests of researchers these are being transformed into manifest universal values - advancement of national science, national self-respect and self-determination independent of foreign interests, contribution to economic prosperity of the country, future promises for healthcare, diverse control options over 'national property', nature, future, etc., thus redefining the problem and the meaning of technology in order to please groups that might not comply with its initial formulation. Project promoters acknowledge a need for discussion on the subject in a wider public while understanding it as a unidirectional – informative and educational – communication. The main stress is laid on the refutation of existing negative information instead of discussing the problematic aspects since the former is seen as created by unsubstantiated fears, lack of trust in novel developments, etc. It is not the new technology but the attitude that is considered problematic and alterable. Public is seen as a passive mass with no actual choice options given before launching a project with only some *post factum* options of discussion.

## **Conclusions**

Media discourse analysis of the Latvian genome project let to categorize it as a complex discourse formed by a range of more specialised discourses – both dominating and subordinate ones. In this sense it is rather ample discussion of this technology with certain interpretative flexibility due to the range of meanings attributed to it beyond its strictly medical and biotechnological interpretation. Nevertheless, it is rather one-sided by the dominant relevant social groups represented by experts trying to highlight mainly the benefits but not that much the accompanying disadvantages, risks and threats. Since the latter is less likely to be done by those directly involved in the project widening of the discussion area is essential through the development of civil society, increased public participation and making ones own choices. Alternative argumentation and views are important especially under current conditions when the particular technology has not yet reached its closure.

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## **Parallel session 4: Cultural Identity Implications in Genomics Research and Communication**

### **“EGOS AND GENOMES”: AN ANALYSIS OF BRITISH MEDIA COVERAGE OF THE HUMAN GENOME PROJECT**

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#### **Abstract**

The announcement of the human genome project ‘first draft’ on the 26th June 2000, appeared to conform to traditional notions of a ‘scientific breakthrough’ news event involving elite sources and attracting worldwide media attention. This paper demonstrates how the ethical, legal and social implications of scientific research which are rarely reported were now given prominence. It draws on systematic content analysis of all British media coverage of human genetic research in the year 2000 and interviews with key players (e.g. scientists, journalists, source organisations) to reveal how this science story was heavily orchestrated for wider media and the lay public.

**Key words:** media, genetics

#### **Introduction**

On the 26 June 2000 the teams involved in mapping the human genome announced to the global media that they had completed the ‘first draft’. Widespread coverage of this ‘landmark’ in human genetic research was characterised by the discourses of hope and fear: on the one hand the media presented an optimistic future of post-genomic medicine and, on the other hand, they highlighted a pessimistic vision of post-genomic society.

The Human Genome Project [HGP] announcement was a heavily orchestrated event involving highly prestigious source activity. The dawning of the post-genomic era was heralded in simultaneous, satellite-linked press conferences in Washington and London, involving Prime Minister Tony Blair, President Bill Clinton and a host of leading public and private sector scientists.

The timing of the announcement was determined not by the trajectory of the scientific research however but by close liaison between the key players. This was partially in response to the efforts of American company, Celera Genomics, headed by Craig Venter to position themselves as ‘ahead’ in the ‘race’ with the UK based Sanger Institute, headed by Sir John Sulston. The research teams had become embroiled in an acrimonious public struggle and an announcement was designed to bring this to a close. Indeed this context clearly influenced the emphasis of information to be circulated to journalists. As one press officer explained “because of (Celera) one of our key messages was that the information was free and publicly accessible so scientists all over the world can use this for the greater good” (Wellcome press officer).

Science journalists were acutely aware that this was not a simple 'science' story. As one reporter commented: '(The HGP) wasn't finished. It was an arbitrary date for publication. I mean the whole thing was hype. But we were much more interested in what was leading up to that and the battle of the patenting and whether it was going to make money' (TV news reporter). Another science editor stated openly that 'The [June 26<sup>th</sup> announcement] was orchestrated for political and commercial reasons' (Broadsheet Science Editor).

### **British Media Coverage: Key Results**

Coverage of the Human Genome Project announcement represented a peak in British media reporting of human genetics for the year 2000 (see Graphs 1 and 2). The prominence of the 'first draft' in the UK media was demonstrated by its coverage in all national UK newspapers from Monday 19 June to Sunday 2 July 2000 (7 front page stories, 10 editorials; 8 special features) and as the headline news story for the television evening news. This reporting typically represented the 'first draft' as a 'watershed' in history. The human genome was presented through metaphors (a map, blueprint, key, recipe, code, book); the 'breakthrough' in mapping was compared to the greatest moments of social, artistic and scientific 'progress' (e.g. the invention of the wheel). The historical associations, the use of language and the range of metaphors all implied an optimistic view of scientific progress (Nerlich et al, 2002).

Cancer cures and longevity were foregrounded as the medical promises of the post-genomic era (e.g. 'The biggest medical breakthrough for a generation could cure dozens of diseases' (BBC 2100, 26 June 2000). Journalists emphasised that they were careful to avoid 'over hyping' the findings however there were tensions between this and news values which required that the science should be made relevant to people's everyday lives (Henderson and Kitzinger, 1999).

Media coverage also raised implicit concerns (e.g. 'Barcoded at birth. Would anyone have let Beethoven do music if they'd known he'd go deaf?' (Channel 5, 26<sup>th</sup> June 2000). Numerous newspaper articles (55%) focused on the ethical, legal and social implications of new human genetic research and this was pattern was mirrored within the television news sample (6 out of the 8 news bulletins focused on ELSIs).

Indeed it was striking that the Human Genome Project announcement served as a platform for journalists to address issues which are often absent in media reporting (e.g. genetic determinism). Twenty five percent of articles about the HGP announcement critically addressed the question of 'geneticisation' (compared to 10% of articles over the year as a whole). The issue became the main focus of several articles (e.g. 'We are bigger than our genes - thank God' (Sunday Times, 2 July 2000). This is particularly interesting in light of accusations against the media that they traditionally promote the 'geneticisation' of life and it would seem that the hyperbole surrounding the HGP announcement facilitated more critical or reflective reporting around the implications of genetic testing and the promise of expanded life spans. In contrast to previous findings (e.g. Nelkin & Lindee 1995; Conrad 1997, 1999a) some press reporting did question the social value of genetic science.

## **Egos and genomes: framing the story**

Framing the story as a 'battle' between Venter and Sulston was a common strategy which helped to dramatise some of the issues about information access; control and commercialisation. Typical headlines included: 'Locked in battle for key to life' (Mirror, 21 June 2000); 'Scientists at War :Two projects, two views of science' (The Times, 23 June 2000). Journalists utilised the personalities of Venter and Sulston to characterise and personalise the conflict. Nine articles profiled or interviewed these men; Venter's image appeared fifteen times, Sulston's appeared on fourteen occasions. Their beliefs were consistently portrayed as being diametrically opposed: 'John Sulston: altruist or moralist? Craig Venter: maverick or monopolist?' (Guardian 26 June 2000); 'war veteran fights ex-hippie over 'Book of Life'' (Daily Telegraph, 27 June 2000).

Journalists saw the opposition between these two key players as a significant opportunity in media and news value terms. As one TV science editor explained: "You had two fantastic characters. ... (John Sulston) is a natural and ... a brilliant scientist.... Craig Venter himself is very media savvy but comes across as a very different personality to an English audience. It was certainly very easy to set one against the other in cinema terms and word terms. I think in that case it was fair to do it because there were very different philosophies at work and Craig and John personified those two philosophies' (TV Science editor). Another journalist commented: 'Because of the characters and the race and Venter in particular, it meant that the coverage was more extensive than it would have been. People find science quite hard I think so if there are personalities to identify with it makes it easier for the readers definitely'"(Broadsheet Science Editor).

This reduction of the issues to personal antagonism was influenced by the operation of news values that rate conflict and 'real' people as more interesting than consensus and 'impersonal' organisations. On the one hand it opened up the discussion to questions of funding, ownership and commercialisation that placed the science into its economic and political context. On the other hand, it was presented very much within science's own terms. As disability activist, Professor Tom Shakespeare commented: 'The debate was presented as the 'good guys' versus the 'bad guys. The scientists say 'Yes there are ethical concerns but not with us - Celera, they are the people to be anxious about. The old distancing effect.'

The social, political and economic context of genetic research and its implications were highlighted in coverage of the HGP announcement to an extent, and in ways, which it had seldom been before (e.g. concerns about commercialisation of genetic science appeared in 41% of newspaper articles compared with 15% of press coverage for the year). Debates about access and control over genetic information appeared in 36% of newspaper articles about the announcement (compared with 15% of press coverage over the year).

## **Conclusions**

Despite the increased discussion of ethical, legal and social issues there were some specific areas which remained marginalized including civil liberties, surveillance and the complications that human genetics poses to the legal and

medical professions. The potential for genetic science to become the basis for weapons technology was entirely absent and there was little discussion of the 'therapeutic gap' between genetic diagnosis and medical interventions. Reporting emphasised medical benefits and few reports discussed medical risks. Elite sources continued to dominate coverage and the vast majority of sources were research scientists, funding bodies and policy makers. The human genome project announcement does provide a valuable case study for exploring the ways in which 'science reporting' is firmly embedded within broader socio-economic issues. It demonstrates how ethical, legal and social implications may under certain circumstances move to the foreground of media reporting. This reflects the high profile given to these issues by those working in the field and shows how the announcement offered an opportunity to address public anxiety. However the impetus behind the announcement was intrinsically tied in with concerns over access to such information and how this may operate in practice. This raises the possibility that scientific and political sources involved in the project might emphasise the aspects of social concern that suit their needs at the time and that can be addressed by legal and regulatory frameworks rather than raising more fundamental challenges.

### Notes

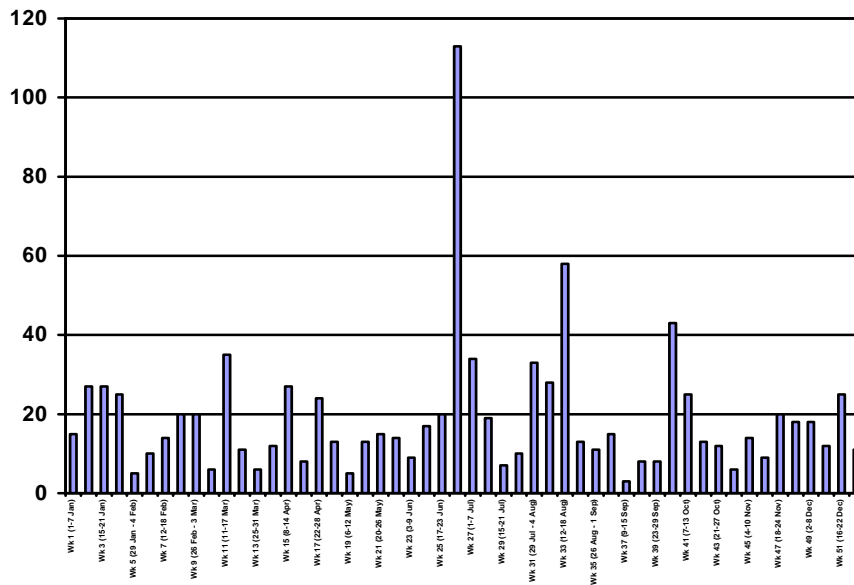
This paper is based on research conducted for the study *Media coverage of the ethical and social implications of human genetic research* The Wellcome Trust Award no: GR058105MA.

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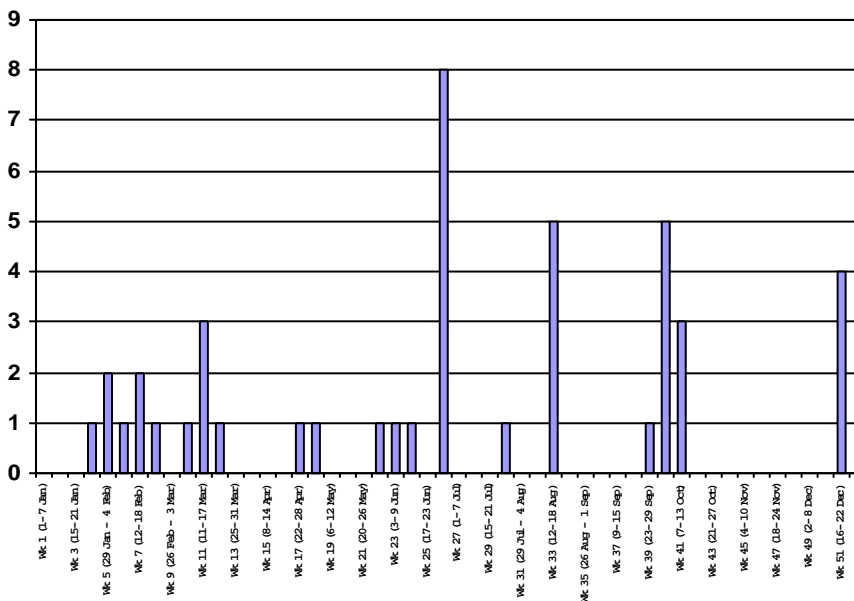
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## Figures and tables

**Figure 1.** Graph showing the number of British newspaper reports on Human Genetic Research for each week during 2000



**Figure 2.** Graph showing the number of British main television evening news bulletin reports on Human Genetic Research for each week during 2000.



## **Parallel session 4: Cultural Identity Implications in Genomics Research and Communication**

### **DECOLONIZING THE THRIFTY GENE THEORY**

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#### **Abstract**

This paper describes elements of a decolonizing textual science study of the ‘thrifty gene’ theory. Grounded in the notion that the construction of scientific knowledge is deeply imbricated in cultural and historical contexts, this research uses the production of ‘thrifty gene’ theory as a case study to explore, to decolonize, and to clarify the potential implications of the current production of medical-genetic knowledge about Aboriginal bodies, health and wellness. Here I problematize the recently burgeoning and uncritical linkages between evolutionary science, contemporary medical-genetic research and Aboriginal peoples’ health in Canada.

**Key Words:** Thrifty Gene Theory, Decolonization, Aboriginal Wellness

#### **Text**

The ‘thrifty gene’ theory is currently a simplistic and captivating explanation for the high prevalence of non-insulin dependent diabetes mellitus (NIDDM) among Indigenous peoples globally. Originally proposed in 1962 by population geneticist James V. Neel, the ‘thrifty gene’ theory was based upon the evolutionary notion that hunter/gatherer populations survived feast and famine living conditions because they possessed a *thrifty* genetic predisposition to accumulate and store fat. Neel (1962) suggested that under recent conditions of rapid “Westernization” and related lifestyle and dietary changes, this naturally selected genetic predisposition, which sustained populations during times of famine, has led to the onset of obesity and diabetes among contemporary populations.

In subsequent publications in 1982 and 1999, confronted with evidence showing significant flaws in the original hypothesis, Neel re-adjusts its specifics and continues to argue, very convincingly, for the existence of the ‘thrifty gene.’ Despite its non-existence, the ‘thrifty gene’ theory does indeed exist in the current Aboriginal health literature as powerful explanation for NIDDM. While it waits, almost impatiently, for scientific authorization, the tale of the ‘thrifty gene’ theory is a telling sign of things to come in the construction of medical-genetic knowledge.

This paper is based on a decolonizing textual science study of the primary literature which constructs the ‘thrifty gene’ theory, namely the texts published by

James V. Neel in 1962, 1982 and 1999, to which I refer as the 'thrifty gene' papers. This research is grounded in the traditional teachings of two Aboriginal people, Flora Fiddler and Albert Fiddler. It also draws upon the social studies of genetic science (Hedgecoe, 2002; Lippman, 1991; Rabinow, 1996) and has linkages with global decolonizing literatures (Smith, 1999; Whitt, 1998). Decolonizing the 'thrifty gene' involved three primary methods: centering indigenous epistemologies of holism; critically understanding and challenging the principles of Euro-western scientific research; and revitalizing indigenous knowledge systems geared toward the larger project of self-determination. Here I describe the analysis involved with the second principle, namely the critical assessment of the assumptions, conclusions and the implications of 'thrifty gene'.

The analysis of the 'thrifty gene' papers reveals several key findings. While it is never acknowledged in current literature, the 'thrifty gene' theory is produced and reiterated from eugenic, evolutionary and neo-colonial perspectives. Where Neel explicitly looks to eugenic solutions for population health, the principles of his theory are based on incorrect categorical groups and problematic primitive/civilized binaries. Moreover, it fails to account for complex Aboriginal genealogical histories and wrongly assumes genetic homogeneity within Aboriginal communities. As such, the 'thrifty gene' not only remains an unproven hypothesis, but it also embodies an approach to Aboriginal disease where social, economic, and historical conditions (namely colonization) become naturalized or fixed. Where social conditions are treated as fixed, the Aboriginal body becomes the site of curative transformation. This shift is responsible for the way in which racialized bodies and individual moralities are necessarily blamed for illness. Already marginalized peoples become further entrenched in a biological paradigm which not only re-affirms racial categories of difference, but also bears little resemblance to Aboriginal healing knowledges, histories, communities and peoples.

Future genetic research about Aboriginal disease may not be accurate in terms of the assumptions it makes about populations, and therefore, it may not be useful in a curative sense if applied clinically. In fact, it may be harmful, not only by categorizing, stigmatizing and surveilling the peoples it describes, but also by spear-heading a trajectory of racialized genetic explanation, research, surveillance and treatment (Poudrier, 2003).

There is an additional chapter in the slick story of the 'thrifty gene' that needs to be told. It could begin with the mythical Trickster – the Raven. Like Donna Haraway's (1999) call to converse with coyote who is the manifestation of continually problematized binary distinctions, the Raven tale might break down problematic and reductionist binaries like civilized/primitive, modern medicine/Aboriginal wellness and nature/culture. It would most certainly highlight the importance of valuing and revitalizing Aboriginal healing knowledges. Future efforts geared toward decolonizing medical/genetic knowledge remain a strong possibility for advancing the projects of self-determination and the ongoing development of appropriate and emancipatory healing knowledges in current contexts; even in the genetic future.

## Acknowledgements

I respectfully acknowledge the teachings of Flora Fiddler and Albert Fiddler of Waterhen Lake First Nation, Saskatchewan Canada which embody the substance of this research.

## Notes

<sup>1</sup> Following other Canadian scholars, here I use the term “Aboriginal” to refer to Indigenous peoples of Indian, Inuit, and Metis heritage.

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**Parallel session 4: Cultural identity implications in genomics research and communication.**

**MEDIA COVERAGE OF HUMAN GENETICS IN SPAIN: THE CASE OF  
*EL PAÍS* (1976-2002)**

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**Abstract**

Public representations of science are influenced not only by research itself, but also by the cultural context where they develop, and both science and its popularisation are laden with cultural and ideological values. In the Spanish public sphere of the late seventies and early eighties, when the country was defining most of its public policies after 40 years of dictatorship, most of the actors were very aware of the political values involved in human genetics (which they identified with right-wing positions) and preferred environmental and psychological explanations for most behaviours and diseases. But coinciding with the growth of Spanish participation in genetic research and the biomedical industry, the critics vanished. It was not just a shift among scientists. At the end of the century, journalists —closer to biological scientists than before, accepted with no questioning, the experts' discourses and presented this scientific field in very laudatory terms.

**Key words:** Scientific journalism, human genetics, history

**Context**

Historical and sociological studies on science popularisation show how this process cannot be interpreted just as a diffusion of expert knowledge to broad audiences. On the contrary, diverse interests of many different actors shape media images of science, competing with each other to gain public support. In the case of human genetics, actors are not only geneticists; other professional groups like politicians, psychologists, philosophers, business men, citizens and family doctors, conveyed their peculiar representation of human genetics, while journalists had an active role choosing which theories and which people they paid attention to.

On the other hand, recent studies about popular accounts of human genetics have not reached a common view: while some specialists argue that the public image of genetics is becoming less determining, others maintain that an overvaluation of genetic factors in medical, behavioural and biological events is taking place.

Only particular case studies can reveal both the cultural determinations of science popularisation, and the degree of “genetisation” –if such a thing exists- in a particular local context.

### **Objective**

The objective of this research is to reveal the Spanish peculiarities of the public account of human genetics in the last quarter of the twentieth century, as it appeared in the pages of the newspaper with greater circulation in the country.

### **Methods**

In resorting to *El País*' database, a comprehensive corpus of more than 1,200 documents containing the words 'genetics', 'genome' 'DNA', and 'gene' was made and analysed with particular attention to the following themes: genetics as pure science and the Human Genome Project, genetics and disease, genetics and behaviour, ethical and legal implications of human genetics, and genetics as metaphor beyond scientific contexts. For the analysis, both qualitative and quantitative tools were used.

### **Results**

What has been observed over the 27 years covered by this study, is an evolution from the image of human genetics as a secondary science, opposed to psychological and environmental explanations and full of ideological prejudices, to the idea of a fundamental field with positive medical and social consequences, which ought to be promoted and served to gain public respectability.

During the first years of the period studied, the use of ideological arguments was common among Spanish public actors, especially psychologists and psychoanalysts that perceived that geneticists were occupying their therapeutic fields. These professional groups responded linking genetics with eugenics and reductionism. During these years, everyone seemed to be aware of how any conception of disease and behaviour influenced the definition of public policies in education and health, a crucial problem for Spain in those days. At this stage, ethical and philosophical implications of human genetics were treated overtly, and in very critical terms.

This situation changed dramatically in the late eighties and nineties, when the country entered a more stable political phase. Spanish research in human genetics grew and became more visible. The first prenatal and diagnosis tests became available in Spain and new scientific journalists, very close to the scientific community and shared values and interests, arrived to *El País*. Coinciding with a more aggressive communication campaign from scientists and its institutions, texts full of technical details presented science as a neutral activity, in which only experts could have a relevant opinion, but whose consequences were at a different level from scientific research. The coverage began to forget the economical, political and ethical dimensions of human genetics, stressing the hopes for magic cures for almost all human diseases, while discussions about genetic determinism

or the concept of human nature derived from genetic knowledge were relegated to marginal spaces, like letters to the director. Spanish scientists discourse merged into American discourse. But on the other side of the Atlantic Ocean these discourses were part of a strategy to gain public funds for an extremely expensive research; in Spain the same arguments were used to present the local scientific community on a level with their American colleagues.

The editorial position of the newspaper itself shifted during the period studied here: it shifted from a conception of science and technology as an integral element of society, and thus, as a field in which everyone had the right to express its opinion, to an extreme defence of scientific research claiming for public support and for the isolated advance of science.

### **Conclusions**

Scientific popularisation is a historical event, and as such, it is influenced by its cultural, social and economical context. Although in the last quarter of the twentieth century a homogenisation of scientific popularisation took place, in every local process, numerous particularities can be observed.

## **Parallel session 4: Cultural identity implications in genomics research and communication**

### **SPANISH NEWSPAPER COVERAGE OF THE TOPIC “GENETICS”: A SEVEN-YEAR LONGITUDINAL STUDY**

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#### **Abstract**

This study is aimed at analysing the daily press coverage of one medical topic among health and medical news: Genetics, perhaps one of the most exciting issues of health and medical subjects that promotes debate and touches ethical and political aspects. With this objective, a seven-year longitudinal monitoring of the press content of genetics (1997 to 2003) in five Spanish newspapers with the largest circulation was carried out using the Quiral database. According to the data provided by the Oficina de Justificación de la Difusión (OJD), these five Spanish newspapers are El País, ABC, El Mundo, La Vanguardia and El Periódico de Catalunya.

#### **Methodology**

The Quiral database gathers all the information concerning medical and health issues. After analysing all the news quantitatively and qualitatively an annual report is written: the Quiral report. This study was possible thanks to the support of the non-profit-making organization Fundación Vila Casas, and forms part of a larger project called *Proyecto Quiral* set up in 1996 at the Scientific Communication Observatory at the Pompeu Fabra University (UPF) in Barcelona.

**Key Words:** genetic news, Spanish newspapers, follow-up.

Since 1997, 12705 newspapers (1815 each year) have been revised and all the information regarding medical and health issues has been gathered in the Quiral database which gives the opportunity to study daily press coverage in the 5 Spanish newspapers revealing topic news that have an acute pattern of information or the ones that are covered during the whole year (chronic pattern). The news with an acute pattern and the ones with a chronic pattern have different characteristics:

*Acute pattern:* this kind of news attracts a lot of interest but only during a short period of time. They disappear suddenly but sometimes they can get a chronic pattern, and their presence in the frontpage of the newspapers is higher than for other news. They produce more letters to the editor and opinion articles and they share very often the same title in different newspapers. These news

are prone to produce more sensationalism and are more dependent on news agencies.

*Chronic pattern:* the news with a chronic pattern have an interest during the whole year but can get an acute pattern sometimes. Examples of this kind of news are the ones concerning cancer, AIDS, tobacco... Their presence in the front page of the newspapers is not more frequent than for other news and they don't produce opinion articles above the median. In general, the journalists that write these news that belong to this pattern use more information sources.

Table1 shows the total number of health news, number of news about genetics and the distribution of news by newspapers.

The topic genetics covers different issues like cloning, human genome, stem cells, molecular biology, biotechnology, transgenics and genetic manipulation, gene therapy, embryology and bioethics.

As shown in the table, from 1999 to 2003 there is a median of 1000 news each month.

The newspaper ABC was found to be the most productive with a total of health news of 17556 with respect to La Vanguardia with 11733 news since 1997. This finding can be attributed to the design of the newspaper and the importance given to one information or another. The ABC newspaper publishes a lot of brief news and short news while La Vanguardia and El Periódico publish longer news. This fact is translated in a decrease in the number of news.

The news of the year were:

1997: Cloning ("Dolly" the sheep), "Medicamentazo", Meningitis

1998: Medical assistance, Viagra, "Medicamentazo", Cloning of human beings, Eutanasia.

1999: Dioxines and Coca-Cola (food contamination), Corporative issues about doctors.

2000: epidemy of *Legionella*, Human Genome (draft of the sequence), Mad Cows, Waiting lists.

2001: Mad cows, Cloning of a human embryo, Human genome (complete sequence), biological weapons (Anthrax).

2002: AIDS (International Conference in Barcelona), sexuality and reproductive issues, ecstasy.

2003: SARS epidemy, sexuality and reproductive issues (abortion, assisted reproduction law...).

The majority of the news about genetics was published in the "Society" section of the newspapers and sometimes in specific Science supplements and

the source of information used by the journalists is very often a person with expertise in the genetics field. The ethical aspects of cloning, gene therapy, embryo research, genetic manipulation/transgenics and human genome produced letters to the editor, opinion articles and editorials.

In a two-year follow-up of the topic Cloning we have shown that at the beginning and just after the announcement of “Dolly” the news covering Cloning were informative but changed to the ethical aspects turning to opinion news.

D. de Semir, T. Adrover (1999). "Cloning seen by spanish newspapers. Use of Quiral databse for case studies". Libro II (p.678) de Comunicaciones y Pósters del *I Congreso sobre Comunicación Social de la Ciencia (Granada)*.

A qualitative study (not shown) of the total amount of news and the news concerning genetics has revealed that the Quantity of news is not always linked to a Quality of them. Instead of publishing more news it would be better to publish less news but with more quality.

### Figures and tables

**Table 1.** The percentages of news about genetics with respect to the total of news are shown in brackets.

<b>Year</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>Total</b>
<b>N°of news</b>	5984	8706	11135	11945	11200	15037	12882	
<b>N°of news about genetics</b>	263 (4.4%)	526 (6%)	527 (4.7%)	743 (6.2%)	750 (6.7%)	700 (4.6%)	1023 (8%)	
<b>ABC</b>	1484	2360	2014	2314	2409	3824	3151	<b>17556</b>
<b>El País</b>	1194	1780	1900	1917	2458	3445	2573	<b>15267</b>
<b>El Mundo</b>	1386	1983	1930	1964	2289	2813	2889	<b>15254</b>
<b>El Periódico</b>	962	1298	1389	1886	2066	2703	1974	<b>12278</b>
<b>La Vanguardia</b>	958	1285	1502	1464	1977	2252	2295	<b>11733</b>

## **Parallel Session 4: Cultural Identity Implications in Genomics Research and Communication**

### **CULTURAL COMPETENCE IN GENETICS EDUCATION**

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#### **Abstract**

There is increasing awareness of the importance of genetic information in determining family members' current and future health. The Centre for Genetics Education, in close collaboration with providers of genetic counselling services, aims to provide accessible and relevant genetics knowledge to members of the public. In order to do so, resources are developed in a variety of formats to convey information and engage the public in a discussion of genetics and its implications. The challenge of communicating genetics information in Australia requires attention to cultural diversity and the way in which it affects the dissemination of scientific knowledge.

**Key Words:** Culture, Genetics, Communication.

Genetic counselling is a multidisciplinary approach to providing diagnosis, risk assessment, education and support to individuals and families affected by genetic conditions. It is also a process that delves into the foundations of a family. For effective communication in genetic counselling, it is essential to understand how individuals translate genetic information within the context of their own belief systems. The fundamental tool used during the first stage of genetic counselling is the documentation of a detailed family health history (pedigree). This inevitably involves addressing issues such as hereditary, kinship and personal beliefs about characteristics of certain family members. Cultural diversity plays a major role in determining people's beliefs and opinions about such issues.

The completion of the Human Genome Project in 2003 brings with it the promise of health benefits and an improved understanding of genetic conditions. Accompanying these benefits comes the impact of the knowledge and the choices regarding the utilisation of genetic technologies. Addressing these issues is optimally done within a genetic counselling context. Issues of informed consent and communication of the consequences of gaining personal genetic information has never been more crucial. The ability of providers of genetic counselling services in Australia to address these issues is challenged by a culturally diverse population. If the new technology is to be used responsibly, and made accessible

to all Australians, it is vital that genetic counselling service providers attain cultural competence and practice within a model that embraces, rather than excludes cultural diversity.

The impact of cultural beliefs on the uptake of genetic counselling and the ensuing technologies has been studied internationally<sup>1,2</sup> and to a lesser degree in Australia<sup>3</sup>. It has been documented that health providers can categorise individuals from specific cultural backgrounds and may make assumptions about their needs and opinions<sup>3,4</sup>. This can lead to incorrect perceptions and may jeopardise optimal communication between provider and client.

Genetics education has historically been enmeshed in the genetic counselling process<sup>5</sup>. As genetic counselling is primarily a communication process, it is affected by the skills of the practitioner in conveying complex principles at an appropriate level to the client. The challenges faced when communicating across cultures impacts on the genetic counselling process.

#### Why is culture so important in genetics?

*A person's background, in terms of their ethnicity or cultural practices, can be a predictor of their genetic health.*

During genetic counselling, information is collected from clients regarding their ancestry in order to predict the potential gene mutations present in their DNA. This can be a powerful tool in risk assessment, particularly where consanguinity is the reason for seeking genetic counselling.

*Gathering what may be deemed "basic" family health history information can be challenged by cultural beliefs.*

When collecting a family history, simply extracting from a client the details regarding their siblings or other kinship relationships may not be as "basic" as it seems. The documentation of a family health history in genetic counselling is governed by an understanding of biological inheritance within an Anglo-Celtic-Saxon concept of the family tree. Particularly in cultures where child rearing is viewed as a community role, rather than exclusively that of the biological parents, the definition of a sibling by the genetic counsellor may be in conflict with the understanding and beliefs of the client.

*New technologies may target certain population groups as being at risk of ethno-specific genetic conditions.*

In the case of the genetic condition hypercholesterolaemia, the Lebanese population has been identified as being at increased risk. This condition is one of the growing number where pharmacogenetics will be used in targeting pharmaceuticals to the genotype of affected individuals. The challenge of informing this community about the issues related to genotyping such as informed

consent, insurability and privacy must not be overlooked as the promise of better treatment arrives.

Genetic counselling practitioners in Australia often use educational tools and resources to assist in communicating complex issues to their clients. These tools may be in written form, either produced by the practitioner, obtained from the Centre for Genetics Education or other sources. It is important to know whether these educational tools, when used as resources to aid the genetic counselling process, do meet the needs of a culturally diverse population. The production of culturally inappropriate resources may result in the limitation of access to quality genetic counselling and enabling informed choice about the utilisation of new genetic technologies by a large proportion of Australians.

Genetics education resources must therefore reflect a diverse population and be validated by the community it serves.

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**Parallel Session 4: Cultural identity implications in genomics research and communication**

**GENETICS AND BEHAVIOR IN THE NEWS:  
THE FATE OF GENETIC OPTIMISM**

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**Abstract**

**Context:** Research on genetics and behavior has grown in past two decades, which is reflected in an increase in news coverage. The news media is a major source of public understanding of genetics.

**Method:** We examined U.S. print news coverage of genetics and behavior in major from 1970-95.

**Results:** The dominant frame of “genetic optimism” was identified: a gene exists, it will be found, it will be good. Despite disconfirmations, genetic optimism persisted in the US reporting.

**Conclusions:** The genetic optimism frame can distort, misrepresent and reify the impact of genes on behavior, and under represents criticism. Genetic optimism may vary by news culture and time.

**Key words:** genetics, news, public conceptions

**Text**

Over the past two decades the pace and specificity of discoveries associating genetics with behavior has accelerated, which is reflected in the increase in news coverage about genetics and behavior. The news media is a major source of public understanding of genetics and a strong influence on public discourse (Nelkin and Lindee, 1995; Conrad, 1997; Van Dijck, 1998; Condit, 1999).

**Method and Sample**

This paper is drawn from a larger study, which examines the presentation of three cases of genetics and behavior in the news from 1965-1994: homosexuality, mental illness, and alcoholism. The data include all articles published in 5 major American newspapers (Boston Globe [BG], Los Angeles Times [LAT], New

York Times [NYT], Washington Post [WP], and Wall Street Journal [WSJ]) and three news magazines (Newsweek, Time, and US News and World Report.) for this period.

My analysis of genetics and behavior in the news I examined what “frames” were used in presenting the news. Journalists do not simply report the “facts”, but rather present the news in the context of a particular frame. Journalists develop specific media frameworks, which enable them to process, report and present large amounts of information quickly and routinely (Gitlin, 1980:7).

### Rise of Genetic Optimism

This paper builds upon earlier papers (Conrad and Markens, 2001; Conrad, 2000; Conrad, 2002) and provides a brief history of “genetic optimism.” Using mental illness as the example genetic optimism has three components.

A gene exists. The idea of specific identifiable genes reflects research claims of molecular biology. The news articles frequently reported discoveries of genetic markers or linkage as if the science discovered the existence of a “genetic flaw” or “faulty gene”. Genetic markers are usually particular genetic constellations, rarely specific genes.

It will be found. Even when reporters recognized that genetic markers were not specific identified genes, they displayed confidence that the gene existed and would be found. In the light of the new genetic technology, genes would be identified.

It will be good. The assumption is that finding genes for mental illness will be good for sufferers, their families and society. Most of the stories promised the possibility of accurate genetic diagnoses or new treatments for the disorder could be developed soon; some suggested that a genetic revolution in treatment was just around the corner. Others believed that genetic explanations would remove blame from families and guilt from sufferers.

The genetic optimism frame was reflected in virtually all major stories on genetics and mental illness from the 1980s through 1995.

### Homosexuality, “the Gay Gene” and the News

Dean Hamer’s 1993 article in Science claiming the discovery of a marker on the Xq28 chromosome, became front page news world-wide and soon was touted “the gay gene.”

I compared the American and British press reporting of Hamer’s study. The American press framed Hamer’s work in “cautiously optimistic” terms: the science was good and it was likely to have some positive effects on gays. The British press, however, framed the stories as “the perils of the gay gene,” emphasizing potential difficulties: new genetic discrimination of gays, genetic

screening, aborting “gay fetuses”, possible genetic therapy (see Conrad and Markens, 2001). The assumption of genetic optimism frame underlied the American reporting, but not the British. Hamer’s work remains contentious, but even if it were valid, it would not constitute a “gay gene” as was commonly depicted in the press.

### The Fate of Genetic Optimism

With one interesting exception, genetic optimism was pervasive in the US reporting of genetics and behavior in the news. In the late 1960s and early 1970s and early 1990s (The Bell Curve) there were widespread news stories of studies associating race, genetics and IQ. In both cases, however, the reporting was overwhelmingly critical of genetic explanations. There was no genetic optimism here at all. Why? Perhaps because race was a hot button in the US, because it was (bad) social science and not molecular biology, or because stories were written by news rather than science reporters.

The case of alcoholism parallels mental illness and homosexuality. The title of our paper reflects its content: “Has the gene for alcoholism been discovered three times since 1980?” (Conrad and Weinberg, 1996)..

In my study period, when a new genetic discovery related to a significant social issue is discovered, it is typically presented with great fanfare and optimism. If the study cannot be replicated or is disconfirmed, and there were many (e.g., D2Dopamine receptor and alcoholism, several genes for mental illness, the “novelty seeking” gene), this was ignored or there was a small mention in the back pages. Big news when genes are found, no news when they are lost, creating a misleading public perception about the advances of genetics.

### Conclusion

While the scientific accuracy of the gene stories is high, the genetic optimism frame distorts some of the findings, misrepresents and reifies the impact of genes on behavior, and leaves no space for critics or an examination of potential negative impacts. A comparison of American and British press suggests that genetic optimism can vary by news culture. Genetic optimism presents an overly sanguine picture of the state of genetics; as we enter the genetic age it is important to balance the extraneous “hype and hope.”

### References

References are available from author: [conrad@brandeis.edu](mailto:conrad@brandeis.edu)