

The Human Genome Project and the media. Case study: the relation between genetics and the media

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Terms such as gmo, genetic tests and pharmacogenomics, which were once used only by experts, belong today to everyday language. The new vocabulary of molecular biology shows an increase in the interest of society in scientific problems, and in particular the recent cultural supremacy of molecular biology. For all of us, the gene symbolizes progress and power, the hope of fighting incurable diseases, and the fear of terrifying genetic manipulations. These aspects become real events and characters in the Human Genome Project.

But this great international project has also shown that the relation between science and society is changing. This event can actually be seen as a metaphor of science leaving academic laboratories to settle new areas of society. From economics to sociology, from epistemological discourse to bioethical debate, from medicine to basic research, in all these fields genome becomes the main topic of discussion and food for thought. Public attention to this international project has grown constantly throughout its development, and it peaked when science came into contact with the press.

Today mass media represents one of the most important opportunities for public debate in modern society. Newspapers, radio and television are one of the greatest means of communication between political power and citizens (Gaskett G. and Bauer M.

W. 2001). They do not simply constitute a bidirectional information flow within society, but they also show the problems public opinion is more interested in. The analysis of the ways media deals with current topics can give an idea of how most people perceive and evaluate various issues. Means of communication, together with politics, law and personal opinions expressed in more or less private conversations, belong to the so-called “public sphere” of a country (ibidem).

This research evaluates the ways mass media has dealt with the Human Genome Project in the attempt to define the public image of this great scientific project in different countries. To that end, both quantitative and qualitative analyses have been carried out on five newspapers ¹ in four different countries: United States, France, England and Italy. The purpose was to determine:

- the extent of media coverage of the Human Genome Project during its development, and its impact on the media;
- which issues have been discussed and which of them have been illustrated positively or negatively;
- how the two above-mentioned aspects have changed during the years of the Human Genome Project;
- the differences in the communication of this event by the media of various countries (Italy, France, England and the United States).

Considering Bauer’s definition, the following newspapers have been analysed: the *Corriere della Sera* and *la Repubblica* for Italy, *Le Monde* for France, *The Independent* for Great Britain and *The New York Times* for the United States.

Data has been collected both using electronic databases, available on-line and on CD-ROM, and filing the periodicals on microfilms. Unfortunately, data availability was different from newspaper to newspaper. Some of them have digitised information only from a certain date — for instance, the file of the *Corriere della Sera* starts from January 1992 — or such information is available only on payment — this is the case of *The New*

¹ The definition is by Martin Bauer and it explains the reason of choosing such an analysis. He writes that among all mass media some dailies and magazines are considered to function as a source of information not only for the public, for politicians, manufacturers and operators of different sectors, but also for other media. Analysing the *opinion-leading* press, we can have both a reasonable and reliable evaluation of the way society elaborates the significance of important issues, and an inside look at how this information flows in time (Bauer M.W. and Gaskell G. 2001).

York Times before 1996. Others have no digital file (*The Independent*). The following chart shows the availability of digitised information of the five newspapers:

Newspaper	Years	Support
<i>Corriere della Sera</i>	1992-2001	on-line file
<i>La Repubblica</i>	1990-2000	CD-ROM
<i>Le Monde</i>	1990-2001	on-line file
<i>The Independent</i>	1994-2000	CD-ROM
<i>The New York Times</i>	1996-2001	on-line file

Digital files have been used for an early quantitative evaluation of media coverage of the Human Genome Project. Later two sample periods have been chosen from obtained data. Then a different analysis, both qualitative and quantitative, according to Bauer and Gaskell (Bauer M.W. and Gaskell G. 2001), has been carried out on the two sample periods.

Quantity analysis

The Human Genome Project: a media event?

Different studies have shown that the media has been increasingly interested in biotechnologies since the seventies (Lewenstein B.V. and Nisbet M.C. 2002; Bauer M. W. 2001; Gaskett G. and Bauer M.W. 2001). Similarly, subjects relating to genetics and to biomedicine, such as the Human Genome Project, have drawn the attention of the public and they have acquired increasing relevance in newspapers. As early as 1995, an analysis carried out by the University of Tennessee showed that news from the Associated Press Agency relating to the Human Genome Project was increasing.

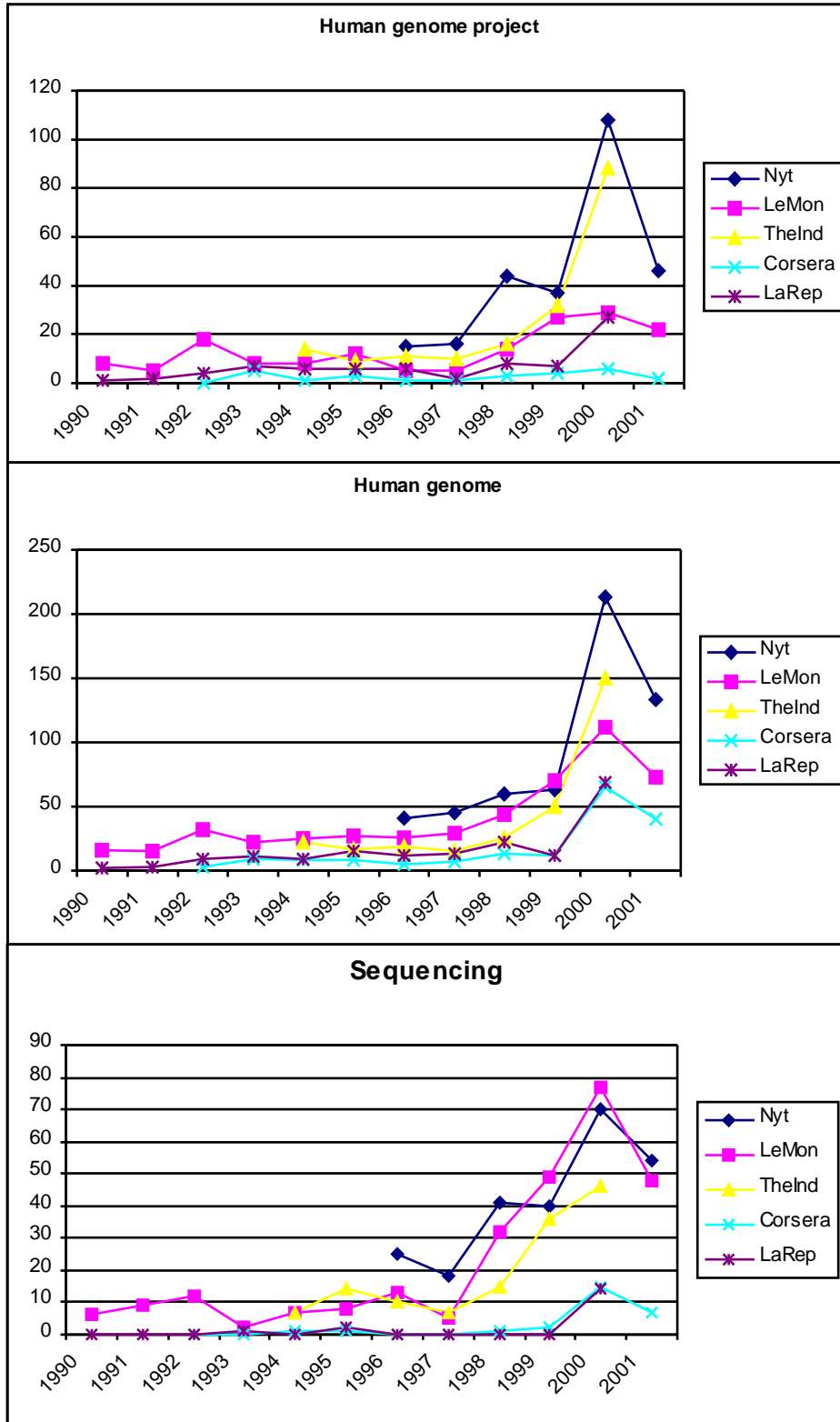
Year	Number of articles
1984-85 (June-July)	0
1985-86	8
1986-87	24
1987-88	21
1988-89	23
1989-90	14
1990-91	34
1991-92	39
1992-93	43
1993-94	40
	—
Total	246

(Riechert Bonnie P. 1995).

The quantitative analysis carried out on the five newspapers has shown an increase in the number of articles on subjects relating to the Human Genome Project, a result similar to that obtained by Riechert. This quantitative evaluation was carried out from 1990 — when the Human Genome Project was launched — to 2001 — when the sequence was published. Various keywords have been used to emphasize different characteristics of media coverage of this subject.

The most specific expression “Human Genome Project” has been used in articles where the international project was the main subject or where it was expressly mentioned in the text. On the contrary, the expression “human genome” has been employed for subjects relating to human genetics, but not in the context of the project.

Finally, the word “sequencing” represents an attempt to collect information as to how a more specific language spread in use throughout the years. The following charts show the results of this research. Each chart refers to a different keyword and illustrates the number of articles per year.



The charts show a clear difference in the number of articles published by the five newspapers in the course of the same years. The *New York Times* is undoubtedly the daily which has given more attention to the Human Genome Project. For instance, in 1996 — the first year with data availability for all five newspapers — 41 articles about human genome appeared in *The New York Times*, as against 5 in the *Corriere della Sera*. In 2000, when coverage of the event peaked in all five newspapers, *The New York Times* published 108 articles relating to the Human Genome Project, while *The Independent* published 88, *Le Monde* 29, *la Repubblica* 27 and the *Corriere della Sera* 6.

Another result of the charts is undoubtedly the negative inflection in the number of articles appeared in 2001. This could be quite strange, since the two sequences were published in February 2001. In 2000, however, the completion of the sequence had already been announced and a press conference with the protagonists of the event had been held in the White House (Davies K. 2001; Marshall E. 2001). The above-mentioned result has an explanation: the event (i.e. the press conference) expressly prepared by the media hit the headlines more than the event itself (the publication of the sequence).

As far as the language is concerned, *Le Monde* and *The Independent* use more specific terminology.

Examining the general trend of the previous charts and the figures of the following ones, it is clear that, apart from 2000, the most interesting year with regard to the media attention for the Human Genome Project was 1998. Actually, compared with 1997, 1998 doubled the number of articles on the international project. *The New York Times* passed from 16 to 44; *Le Monde* from 5 to 14; *The Independent* from 10 to 16; *la Repubblica* from 2 to 8 and the *Corriere della Sera* from 1 to 3. However, it is essential to remember that Craig Venter founded Celera Genomics exactly in May 1998, challenging the public sector on human genome sequencing (Davies K. 2001).

QUANTITY ANALYSIS CHARTS

Keyword: Human Genome Project

	Nyt	LeMon	TheInd	LaRep	Corsera
1990		8		1	
1991		5		2	
1992		18		4	0
1993		8		7	5
1994		8	14	6	1
1995		12	9	6	3
1996	15	5	11	6	1
1997	16	5	10	2	1
1998	44	14	16	8	3
1999	37	27	32	7	4
2000	108	29	88	27	6
2001	46	22			2
Tot	266	161	180	76	26

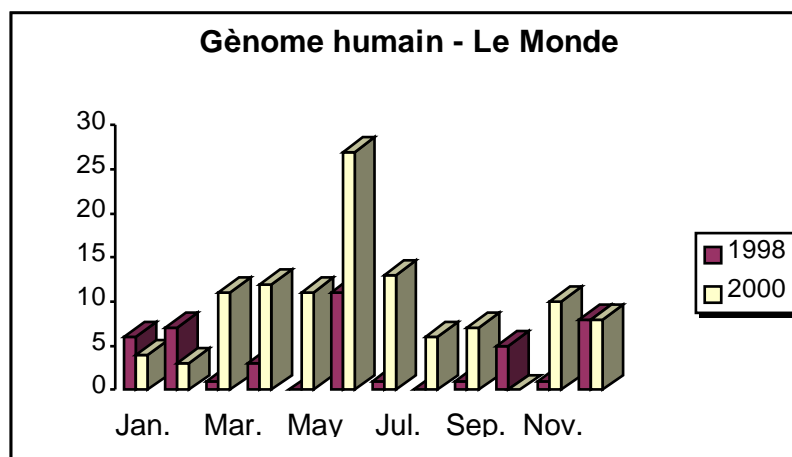
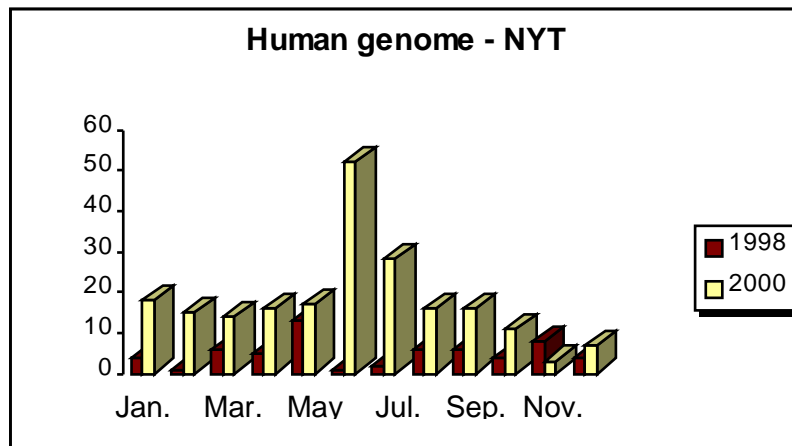
Keyword: human genome

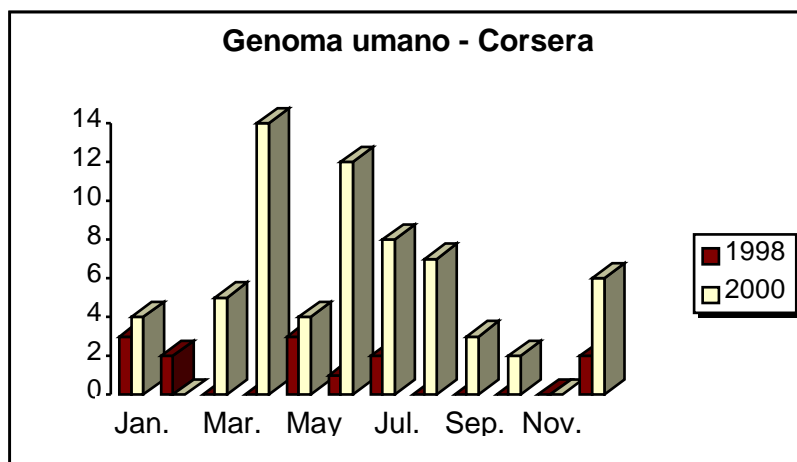
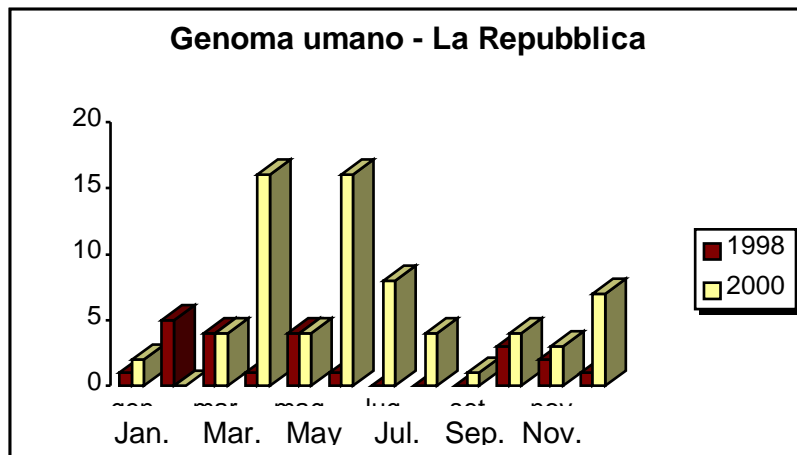
	Nyt	LeMon	TheInd	LaRep	Corsera
1990		16		2	
1991		15		3	
1992		32		9	3
1993		22		11	9
1994		25	22	9	8
1995		27	17	15	8
1996	41	26	19	12	5
1997	45	29	15	13	7
1998	60	44	26	22	13
1999	63	70	50	12	12
2000	213	112	150	69	65
2001	133	73			40
Tot	555	491	299	177	170

Keyword: sequencing

	Nyt	LeMon	TheInd	LaRep	Corsera
1990		6		0	
1991		9		0	
1992		12		0	0
1993		2		1	0
1994		7	7	0	1
1995		8	14	2	1
1996	25	13	10	0	0
1997	18	5	7	0	0
1998	41	32	15	0	1
1999	40	49	36	0	2
2000	70	77	46	14	15
2001	54	48			7
Tot	248	268	135	17	27

The monthly distribution of articles in 1998 and in 2000 also proved interesting. In 1998 most articles about human genome appeared undoubtedly in May and June — the keyword “human genome” has been chosen for monthly distribution in order to analyse more articles. However, *Le Monde* published all articles early in June, whereas the other four newspapers mostly in May. As far as 2000 is concerned, the number of articles peaked in all newspapers in June, as a consequence of the concerted press conference in the White House (White House 2000). Several articles on prospects and on possible consequences of this international project appeared also in July 2000. The two Italian newspapers *la Repubblica* and the *Corriere della Sera* published several articles also in April, when Venter declared, he had completed the first draft of the human DNA sequence.





N.B. Monthly distribution data is not available for The Independent..

Quality analysis

Sample

The above-mentioned quantity analysis refers to all ten years of the Human Genome Project. A more accurate analysis has, however, been carried out on a shorter period of time. Considering the years and months in which the media showed greater attention to the Human Genome Project and relating them with events taking place during the so-called “genome rush”, four months have been chosen as a representative sample: May and June 1998 and June and July 2000. 155 articles have been catalogued and analysed altogether. The following chart shows sample distribution according to year and newspaper.

Number of analysed articles						
Newspaper	Nyt	LeMon	TheInd	LaRep	Corsera	Tot
1998	10	10	3	5	3	31
2000	38	26	32	16	12	124
Tot	48	36	35	21	15	155

Later, all sample articles have been analysed and catalogued according to purpose-specific parameters. These parameters have been chosen in order to obtain two different types of information. The first evaluation, though not exhaustive, had to determine the importance given by each newspaper to the Human Genome Project and to define the ways the subject had been dealt with. To this end, each article was catalogued according to length, typology, section occupied in the newspaper, and author. Then, after reading all the articles carefully, their subjects and valence were defined. The following chart shows parameters used to catalogue sample articles.

Date	Macroframe	TOPICS (Microframe)	
Title	Science	Discovery; research history	1
Author		Scientific description; methodologies	2
Author's typology		Genetic determinism	3
Section		Research developments	4
Typology		Scientific research rules; research freedom	5
Length	Business	Public research vs private research	6
Subject		Financing	7
Valence		Profits; commercial exploitation	8
Frame		Market; exchange	9
Agents	Medicine	Genetic diseases and cancer	10
Metaphors		Therapies, diagnoses, medicines; pharmacogenomics	11
		Genetic analyses; genetic characterization	12
	Legal/ethical	Patents; properties	13
		Genetic data control; data access	14
		Legal and ethical implications; genetic manipulation	15

Results

Relevance

An early evaluation of the importance given by the five newspapers to the Human Genome Project shows an increase in the number of articles published by all newspapers from 1998 to 2000. The difference regards mainly newspaper sections where articles are written. In 1998 articles about the human genome occupied chiefly news and science sections, whereas in 2000 they covered nearly every section. However the two Italian newspapers constitute an exception, since they preponderantly talk about the Genome Project only in news pages — thus in relation to a specific event — or at the most in culture pages.

No article appeared in the business section of *The New York Times* in 1998, whereas there were 7 in 2000. No article was in the local news in 1998, whereas there were 2 in 2000: this shows that the human genome has acquired great relevance, also in less specific sections. The American newspaper usually prefers quite long and exhaustive articles, with remarks by a scientist or an expert, whereas the Italian ones opt for interviews with questions and answers. The American newspaper also publishes numerous letters in *Letters and Opinions & Editorials*, two sections for comments by experts and readers. These sections also contain remarks by scientists who write to the newspaper to comment on a particularly relevant fact or simply to reply to a previously published letter. Similarly *The Independent* has sections for letters and comments. Moreover its section *Monitor: all the news of the world reports* letters published by other newspapers. Among 40 articles published by *The Independent* in June and in July 2000, 16 were letters. This data shows that both the American and the English newspaper give importance to readers' opinions and that their pages constitute an occasion for public discussion.



On the contrary, *Le Monde* prefers articles of medium length. In 1998 most sample articles appeared in the *Aujourd'hui* science section, whereas in 2000 the human genome occupied nearly every section, in particular *Horizon*, a space where news is analysed and commented on. Compared with *The New York Times*, which prefers exhaustive articles, *Le Monde* seems to deal with the Human Genome Project in articles on current affairs, since most articles are published in news pages.

Generally speaking, the two Italian newspapers, the *Corriere della Sera* and *la Repubblica*, have dealt with the Human Genome Project very little. Their articles are mainly interviews to Italian scientists or news items. Unlike *The Independent* and *The New York Times*, the two Italian newspapers have given very little space to this subject in sections for comments and letters. For instance, *la Repubblica* published only one reader's remark and one comment on the Human Genome Project in the two sample periods, whereas the *Corriere della Sera* reported no such article at all. The two Italian dailies generally make less room for their readers than the other newspapers, also in relation to the number of pages. Both newspapers prefer articles of medium length. Moreover, the Human Genome Project — above all in the *Corriere della Sera* — appears almost only in news items, and not in finance, culture or society pages.

Le Monde.fr **The New York Times**

A difference between the five newspapers lies in the way they have individually followed the event. The *New York Times* and *Le Monde* have scientific journalists who have followed the Human Genome Project since its very early years. Nicholas Wade for *The New York Times* and Catherine Vincent and Jean-Yves for *Le Monde* have written most articles on this topic. Furthermore, Andrew Pollak has often contributed to the American newspaper, as he reported on the Human Genome Project in business and finance sections. The Italian newspapers have some journalists dealing with the human genome — such as Margherita De Bac for the *Corriere della Sera* and Giovanni Maria Pace and Vittorio Zucconi for *la Repubblica* —, however they are not as specialized as their American and French colleagues. In general, journalists are experts on genomics — or in any case on biology and medicine — and they write in different newspaper sections according to need. In the Italian newspapers, on the contrary, the Human Genome Project is dealt with by different journalists according to the section it occupies.

Themes and frames

Content analysis gives an idea of how the different newspapers have dealt with the Human Genome Project. 15 recurring themes (see chart “Quality analysis: sample”) have been defined to analyse all articles. The main themes of each article have been identified with each been attributed a valence, thus determining the author’s position — whether positive, negative or neutral. Subsequently, all themes have been classified in four main categories or frames: science, business, medicine and legal/ethical. The interesting aspects of the analysis have been the comparison of the different newspapers and the change in themes discussed by the same newspaper from 1998 to 2000.

A constant characteristic of all newspapers is the presence of themes relating to the medicine frame, although they are not the main ones. Furthermore, this frame has always a positive valence for all newspapers.

In the months of May and June 1998, when Craig Venter announced his challenge to the public sector, the most discussed macroframes in all newspapers were science and business. On May 12 1998, The *New York Times* talked of a “competition for human genome sequencing”. On June 23 1998, it reported details of the Venter and Celera Genomics affair with great precision, comparing different sequencing strategies and describing financial intrigues between research institutes and commercial businesses. Although calling Craig Venter the “Bill Gates of genetics” and reporting the indignation of the academic world, competition between public and private structures was also seen as an incentive to do better and more thoroughly. In fact, when the Wellcome Trust decided to double financing for the Human Genome Project, The *New York Times* carried the headline “International Gene Project Gets Lift” reporting that the Congress was deciding to improve the aims of human genome research.

After Craig Venter had announced his challenge to public sector scientists, on June 3 *Le Monde* dedicated a full page to the news. It headlined the article “Public research against private interests” and it added the comment of two French scientists specializing in genomics, the director of the sequencing centre and the person in charge of the French Scientific Research Council for the Human Genome Project. The tone of the article was extremely objective. In the same days, however, researchers of the Pasteur Institute in Paris obtained another great scientific result, i.e. the sequencing of tubercle bacillus. *Le Monde* dedicated a lot of space to this event and on June 26 1998 it published several articles focusing on scientific issues. The principal valence in French

articles was undoubtedly neutral and objective, except for themes relating to the medicine frame, which are all markedly positive.

The attitude of *The Independent* proved to be different. On May 17 1998, it described Venter as the “buccaneer of genetics” who aimed to “know the secrets of life and become rich”. Confrontation between public and private research, commercial exploitation of results of the Human Genome Project and patents are presented in a thoroughly negative way. On May 7 1998, *The Independent* reported briefly that an American company had obtained the patent on the sequence of the meningitis bacterium. In a few lines the British newspaper made an ironic remark about “how commercial businesses want to patent every life form in order to make money”. In general, *The Independent* presents themes relating to business and legal/ethical frames in a negative way, whereas the scientific ones are presented in a thoroughly neutral way.

The two Italian newspapers did not publish many articles about the human genome in May and June 1998. Neither the *Corriere della Sera* nor *la Repubblica* have reported on the foundation of Celera Genomics by Craig Venter. Only Giovanni Maria Pace wrote of “a private business which promises to decode the three billion pairs of bases of our genetic inheritance by 2002” in an article about future medicine and medical ethics in *la Repubblica* on June 4 1998. On the contrary, on May 15 1998 both the *Corriere della Sera* and *la Repubblica* published the news of the discovery of the “genius gene”, which was not reported by the other three newspapers.

However it is important to underline that in that period the Italian newspapers were focused on the enactment of the European directive on the subject of biotechnologies, intended to control genetic engineering research and embryo experiments. On May 12 1998, *la Repubblica* published a comment by Stefano Rodotà on the possibility of “patenting all living beings” and on its implications for scientific research. Moreover, on May 13 1998 it reported Monsignor Elio Sgeccia’s remarks about “the absence of restraints on genome experiments”.

The *Corriere della Sera* is not interested in the Venter and Celera Genomics affair at all and it has given little space also to the enactment of the European directive on the subject of biotechnologies. Only on May 19 1998 it reported on a mysterious agreement between Renato Dulbecco and Luigi Berlinguer, the then minister for scientific research: such an arrangement should have decreed “Italy’s resumption of the Human Genome Project, which had been interrupted because of lack of funds”. Italy’s lack of funds for genome research was also discussed in an article in the *Corriere della*

Sera on May 29 1998. This feature reported that scientists of the Italian Research Council had discovered the genes of Omenn's Syndrome, a disease causing immune system disorders. In general, the *Corriere della Sera* dealt with research financing very often, both in May and June 1998 and in June and July 2000. *La Repubblica* discussed this subject in June and July 2000, again upon Italy's exclusion from the international project because of lack of funds. In general, Italian sample articles discuss themes relating to science quite often. However, these subjects have a positive connotation in the *Corriere della Sera*, since they are linked to promising prospects of biomedical sciences, whereas they have a negative valence in *la Repubblica*, where they are connected to various issues — patents, commercial exploitation of living beings and the spectre of eugenetics.

The analysis of articles published in June and July 2000 shows great many differences in the importance given to each theme. The *New York Times* is the only one not to change the way it deals with the human genome when passing from one period to the other. In general, it discusses all themes, whereas in 1998 it focused mainly on scientific description, on relations between public and private research and on financing. Moreover, the valence, which is clearly positive in the first sample period, becomes more neutral in the second.

As far as *Le Monde* is concerned, it discusses different themes from May and June 1998 to June and July 2000. The first period focuses on the science frame, especially on scientific description and discovery history, whereas the second deals mainly with patents, commercial exploitation of genetic research results and legal/ethical implications. The valence of each theme also changes. Scientific themes are almost always discussed in a neutral way. On the contrary, commercial exploitation and legal/ethical implications are no longer described neutrally, but in clearly negative terms. Actually, France was concerned with patent debate in this second sample period. The French government, and, in particular, its Minister of Justice, Elisabeth Guigou, disputed the European directive of June 6 1998 relating to the patentability of genetic sequences. They claimed that France could not implement such a directive because it went counter to national legislation. In 1994 the French bioethical commission had prohibited the marketing of the human body and single body parts ², as reported by *Le Monde* at pages

² In 1975 molecular biologists met in Asilomar to discuss the potential risks of new techniques of recombinant DNA. They defined protocols to make experiments safer. In a short time, these draft principles were formalized in guidelines issued by the National Institutes of Health and later adopted as self-regulation by all research laboratories using recombinant DNA (Lungagnani V. 2002, pp.6 ff.). On the contrary, the elaboration of guidelines by the scientific community brought to no laws by the American government and European Community alike. In the nineties, this deficiency in European legislation led to the elaboration of laws considering biological technologies a dangerous activity a priori. In the United States this legislative vacuum was covered by the activity of three federal agencies,

9 and 15 on June 16 2000. This unconstitutional aspect has been immediately stressed by opinion movements, namely Greenpeace. On June 27 2000, *Le Monde* reported that the French were against profiting from commercial exploitation of the human genome, considered to be the common inheritance of humankind.

As far as *The Independent* is concerned, frames relating to business and to legal/ethical implications have a negative connotation in both sample periods. This newspaper has, among other things, published many articles about legal/ethical implications of the Human Genome Project. It has also discussed themes relating to the science frame many times: they have a positive valence in 1998, whereas their connotation is positive, negative or neutral in 2000.

In the 2000 sample period, the two Italian newspapers deal mainly with scientific issues. The *Corriere della Sera* is mostly interested in the medicine frame, whereas *la Repubblica* discusses mainly legal/ethical implications. The *Corriere della Sera* deals with the Human Genome Project very little, focusing on Italy's exclusion from the international project. "Even if Italy has made several genetic discoveries, its funds are a hundred times lower than in the United States and in Great Britain": this is a comment by Paolo Vezzoni, director of the Institute for biomedical technologies of the Italian Research Council in Milan, published by the *Corriere della Sera* together with scientists' and politicians' declarations during the White House press conference. Patents and commercial exploitation of genetic resources are discussed very seldom, even if they are considered a positive stimulus to economics and research. On the contrary, *la Repubblica* discusses all topics with the same frequency. As against 1998, there is an increase in interest in research developments and financing. This newspaper also emphasizes Italy's exclusion from the international project. It reported "Genome: Italy is out" on June 26 2000 and "And we have no money" on June 27 2000. Genetic data control, as far as privacy is concerned, and legal/ethical issues are discussed quite often and they have almost always a negative valence, as with topics concerning hypothetical commercial exploitation of genetic sequences.

specifically instructed to control all possible applications of new biological technologies: the Food and Drug Administration (FDA), the Environmental Protection Agency (EPA) and the United States Department of Agriculture (USDA). In the eighties, within the ambit of OECD (Organization for Economic Cooperation and Development) activity, Europe approved US guidelines, which were meant to foster the marketing of the first biotechnological achievements — i.e. recombinant human insulin and genetically modified seeds. However the European Community had no central watchdog such as the US Federal agencies. Therefore its member countries adopted different emergency regulations on the subject of biotechnologies. Today the harmonization process of such rules has yet to be concluded.

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