Balancing Risks: The framing of human genetics in online news media

Jennifer Molina
JRM116@student.canterbury.ac.nz

February 2004

This project was completed as part of a summer studentship at the Social Science Research Centre, University of Canterbury, Christchurch, New Zealand between Nov 2003 and Feb 2004

Supervised by:
Rosemary Du Plessis and Dr Anne Scott,
School of Sociology and Anthropology, University of Canterbury
rosemary.duplessis@canterbury.ac.nz  a.scott@canterbury.ac.nz

The work reported in this document is part of a larger interdisciplinary research programme: Constructive Conversations/ Korero Whakaaetanga: Biotechnologies, dialogue and informed decision-making. This programme is funded by the Foundation for Research Science and Technology and based at University of Canterbury. The research focuses on the social, cultural, ethical and spiritual implications of new health biotechnologies. The focus in the first year of this project has been on genetic testing. Visit the website for this project: www.conversations.canterbury.ac.nz
Abstract

Over the last three years, media coverage of advances in genetic testing, genetic screening and gene therapy has taken a sharp turn from an optimistic belief in progress to a more critical stance, at times approaching a fierce anxiety about the social and ethical implications of “playing god”. While science journalism has generally been criticised for its sensationalism, advances in human genetics are appearing in the media more often, and instead of being focused on the sensational aspects of this technology, many are framed in terms of the ethical and social dilemmas they pose. The ideal of “journalistic objectivity”, however, encourages reporters to write stories which acknowledge the arguments of both the proponents of human genetics and those who assume a ‘watchdog’ role. Human genetics is a topic too complicated for such a “one-side-versus-the-other” approach, however, and the resulting stories often lack the thorough understanding of the complexities of the science that is necessary for critical analysis. This paper explores the framing of human genetics in online media coverage between 2000 and 2003. It incorporates analysis of eighty-six articles on genetic testing, genetic screening, gene therapy and human genetics in general accessed over two months between November and December 2003. Trends in these articles are related to recent academic literature on science journalism.
CONTENTS

1. Introduction p.4
2. Human Genetics and scientific journalism p.8
3. ‘Codes’, gene ‘fishing’ and health ‘horoscopes’ – media metaphors p.17
4. Genetic testing – issues of choice, privacy and the right to know p.19
5. Genetic screening – a focus on populations p.20
6. Gene therapy – doing something about it p. 21
7. Conclusion p.23
8. Online Articles Analysed p.25
9. References p.31
1. **INTRODUCTION**

**Online news media and human genetics**

Over the last three years, media coverage of advances in genetic testing, genetic screening and gene therapy has taken a sharp turn from an optimistic belief in progress to a more critical stance, at times approaching a fierce anxiety about the social and ethical implications of “playing god”. While science journalism has generally been criticised for its sensationalism, advances in human genetics are appearing in the media more often, and instead of being focused on the sensational aspects of this technology, many are framed in terms of the ethical and social dilemmas they pose. The ideal of “journalistic objectivity”, however, encourages reporters to write stories which acknowledge the arguments of both the proponents of human genetics and those who assume a ‘watchdog’ role. Human genetics is a topic too complicated for such a “one-side-versus-the-other” approach, however, and the resulting stories often lack the thorough understanding of the complexities of the science that is necessary for critical analysis.

This paper explores the framing of human genetics in online media coverage between 2000 and 2003. It incorporates analysis of eighty-six articles on genetic testing, genetic screening, gene therapy and human genetics in general. These articles were accessed online over two months between November and December 2003. Trends in these articles are related to recent academic literature on science journalism. The paper begins with a discussion of human genetics and scientific journalism and then focuses on four major themes of particular interest to the researcher - the metaphors used in discussion of human genetics, genetic testing, genetic screening and gene therapy.

**Research strategy**

In order to have a “globally” representative sample of online media for this analysis of media reportage on human genetics generally and genetic testing, genetic screening and gene therapy in particular, I chose sites from the United States, United Kingdom, Australia and New Zealand. I did a keyword search on The Guardian UK, BBC News Online, New York Times on the Web, Yahoo! News, USA Today online, ABC Online and the NZ Herald for articles containing the following words: human genetics, genetic testing, genetic screening and gene therapy. I limited my search to articles written between 2000 and 2003. I also investigated the alternative media sites Independent.co.uk and MotherJones.com to make a comparison between the frames used in mainstream media sources.

---

1 Nisbet and Lewenstein (2001, p.4) have defined frames as, “structure[s] that organize central ideas in an issue, incorporate certain symbolic devices and metaphors.” Frames are always selective, as some issues are highlighted by relevant stakeholders to advance certain truth claims and policy positions, while other issues are ignored (Petersen 2002 p.75-76; Conrad 1997, p.141). My interest is in how this process of selection occurs in online news articles that examine developments in human genetics, and more specifically genetic testing, genetic screening and gene therapy.
with those used by alternative media sources. Finally, I used the search engine Google to identify other online media sources containing articles on human genetics. Findings included: bionews.org.uk, bmj.com, msnbc.com, theage.com.au, expnews (epolitix.com) and The UK Royal Society’s ‘news and media releases’ page. Overall I analysed eighty-six articles: forty-one on genetic testing, twenty-two on genetic screening, twelve on gene therapy and eleven on human genetics in general.

Science journalism and reports on human genetics – an overview

Turney (1998) provides an illuminating history of media framings of biological research and the life sciences, beginning in the 1800s. His examination of newspaper articles reveals changing public perceptions of biological advances, the emergence of a science/media fusion and a struggle between optimism and pessimism. An analysis of today’s media framing of genetic testing, genetic screening and gene therapy is not complete without acknowledging how the media emerged as a central force in the advancement of these technologies. As a result of the advent of the steam press, “scientists began trying harder to influence or control the public image of science in the media outside their own hands – attempts which have gone on ever since” (Turney 1998, p.46).

The media has not always been an instrument for the advancement of science. To the contrary, the media has often been chastised for what Lewis Wolpert calls “genetic pornography”, for many geneticists consider that contemporary mass media portray their work in a negative light (Turney 1998, p.3). Either way, science journalism plays an important role because it “can reinforce the authority of science in society [by providing] scientists with unique opportunities to defend and augment their authoritative position in society” (Zehr 1999, p.8). Journalistic practice does not stand alone in its role as mediator between scientists and the public. It has been assisted and shaped by events such as a conference held by The Foundation for American Communications where scientists, academics, ethicists and other ‘experts’ advised journalists on how to write about genetics (Murray 2001, p.15). It is important to consider how such involvement influences science reporting.

As Priest (1999, p.107) points out, “journalism is not written on a blank slate but inscribed as one component in a complex information environment.” Science journalism is historically and culturally situated, and has varied greatly over time. The 1960s was a period of scientific and technological ‘breakthroughs’ and ‘revolutions,’ but this changed in the 1970s as wonder about the marvels of science gave way to concern about the risks. Journalists temporarily shifted their attention to consequences, becoming “critical investigators”, but by the 1980s the enthusiasm of the 1960s re-emerged, and the old clichés about ‘breakthroughs’ reappeared (Nelkin 1987, p.10, 97; Nisbet & Lewenstein 2001, p.5-6). Nisbet and Lewenstein (2001, p.2) indicate, “coverage shifted from a heavy positive emphasis on economic prospect and progress in 1995 and 1996, to an increase in discussion of ethics, public accountability, and controversy in 1997, 1998, and
It is typical of coverage on biotechnology that there is a “swing from claims of miracles to visions of apocalypse...from optimism to doubt” (Nelkin 1987, p.40; Craig 2000, p.161). This was certainly what I found in the articles analysed here, as I will demonstrate throughout the paper.

Pressure on writers from editors and the need for ‘breaking’ news is an important factor in the constant shifts in coverage of scientific issues. Competition, deadlines, budgets, and the need to cover complex subjects within limited space and time, all detract from ‘in-depth’ reporting on human genetics (Nelkin 1987, p.111). It tends to be only when a ‘breakthrough’ or ‘disaster’ occurs that reporting is generated, as editors encourage journalists to recognize and highlight controversy and explore hypothetical risks and public responses to them (Kitzinger & Reilly 1997, p.326; Dunwoody 1999, p.70).

Most writers on science journalism argue that coverage of human genetics has been overwhelmingly positive. Editorial expectations dictate that stories must be interesting to entice readers, hence, “even if only a few maverick scientists speculate about the point when genomics scientists will be able to ‘build organisms from scratch’, it is precisely such speculations which are gladly taken up by the mass media and disseminated to a broad public” (Gottweis 2002, p.212). The media is generally criticised for its emphasis on the potentials of genetics and its lack of acknowledgement of the consequences that go along with such optimism. Coverage in the U.S. news, especially, tends to be fairly homogenous in its optimism, representing the point of view of large institutions (Priest 2001, p.2-3). Research has shown, however, that coverage of biotechnology tends to be more negative in places such as Europe, where public knowledge about biotechnology is much higher (Priest 2001, p.2).

The challenges of uncertain science
Stocking (1999, p.30) claims it is reasonable to speculate that individual journalists’ knowledge levels, and their appreciation of the value of science, will have some influence on how scientific uncertainty is reported. This is certainly pertinent to the framing of human genetics in online media, as several of the articles were written by the same author. These journalists had titles such as ‘science correspondent’, ‘science editor’, ‘science reporter’, ‘chief political

---

2 See Ward 2002, p.188 for a full discussion.
correspondent, ‘health correspondent’, ‘health reporter’, ‘health editor’, ‘medical writer’, and even ‘acclaimed author’. Most of these writers were from the United Kingdom, where there is more opportunity to move into a specialist position as a scientific journalist than there is in Australia and New Zealand. There has also been a greater emphasis on policy development relating to genetic testing in the United Kingdom between 2000 and 2003.

United States news organisations were chosen by Craig (2000 p.161) in his analysis of media content because, “given the training of their staff members and the financial resources available to these organizations, they could be expected to provide a benchmark for the current state of ethics coverage.” Although these science reporters are specialists at their newspapers, they are generalists when it comes to science cover, so “they frequently call upon experts to help them understand the details, context, and meaning of new scientific discoveries” (Conrad 1999, p.288). The most obvious evidence I found of this in the articles I analysed was the abundance of quotes from ‘experts’. By experts I refer to scientists and other people with professional expertise in the field of human genetics. Although a few articles used no direct quotes, some articles included up to seven comments from experts and four from those in ‘watchdog’ organisations or people who were involved in the regulation of human genetics. Other commentators were lawyers, philosophers, sociologists, industry and the general public. In fact, many of the articles were written as a continuous stream of quotes, and generally included comment from people in a variety of different positions/professional locations. In terms of expressing the views of ‘the public’, however, journalists tended to ‘speak on behalf of’ or make assumptions about views in the community, rather than include community voices.

11 Matt Ridley: Ridley, M. April 3, 2003, “We’ve never had it so good – and it’s all thanks to science” in Guardian.
Dolly the sheep, cloning and the news media
The cloning of Dolly the sheep in 1997 drastically changed reporting on genetics.\(^\text{12}\) It was the beginning of attention to ethics, regulation and public opinion associated with genetics, which until then had been very rare. These transformational effects on media coverage of biotechnology continued into coverage in 1998 and 1999 which included higher levels of controversy. Dolly touched a social nerve, “creating a novel news frame in which the opinions of ethicists acted as counterpoint to those of scientists. But broader institutional interests also helped shape this debate, which in the end served primarily to maintain the existing distribution of power rather than subvert it” (Priest 2001b, p.97; Priest 2001a, p.59).

So, although ethics was brought onto the science journalism agenda, the stories were framed “largely in terms of risk and imminent threat, providing little in-depth exploration of the nature and extent of these risks and threats” (Petersen 2002, p.85-86). This pattern of coverage resonates with the findings of my study. The majority of the news reports I examined considered ethical issues, but few articles provide any in-depth discussion.\(^\text{13}\) Furthermore, as Petersen (2002, p.86) points out, “although the ethical, legal and social implications of cloning constitute the focus of a number of substantive articles, the power and authority of science, and its potential to alter the natural – whether for ‘good’ or ‘evil’ purposes – is never in doubt.”

Media coverage of Dolly also reveals how certain issues are the focus of reportage because they exhibit certain characteristics. Neresini (2000, p.379) states:

Dolly has at least two characteristics that are ideal for activating the interest of the media... First, cloning contains that irresistible mix of attraction and fear that makes it so suitable for the mass media. Cloning inspires our collective imagination by linking to deeply rooted images, many derived from science fiction... Secondly, Dolly has an identifiable personality, with a name and an image, and there is nothing better to satisfy the needs of the media to construct stories full of fancy to attract the attention of the general public.

2. HUMAN GENETICS AND SCIENTIFIC JOURNALISM

Framing debates about science
Although the online media now acknowledges, and indeed often frames human genetics stories in terms of social, ethical and legal issues, the reporting still follows the familiar patterns of science journalism. The issues are still largely framed in terms of risk, a simplistic balancing of optimism and caution, and reliance on quotes from experts and well-known journals such as Science,


\(^\text{13}\) 82% of the articles use the word ‘ethics’ at least once but only four articles attempted to explain what constitutes ethics and highlight the important issues.
Nature, The University of Maryland’s Journal of Health Care Law & Policy, British Medical Journal, Journal of the American College of Cardiology and The Journal of the American Medical Association. Aside from risk, the main frames used are sets of various antitheses: individual choice versus collective responsibility, cost versus benefits, fears and anxieties versus scientific reasoning, experts versus community voices, and progress versus potential negative consequences. Fear is another important topic that often emerges from this analysis of articles on human genetics, often to be discredited by the reasoning and assurance of experts, peer reviews and papers in scientific journals.

A striking feature of writing on human genetics is homogeneity. Because journalists are bound by similar cultural biases and professional constraints, and to some extent share common assumptions about science and technology, their writing on scientific issues and events takes place within what Todd Gitlin calls a frame: “a persistent pattern of cognition, interpretation and presentation, of selection, emphasis, and exclusion. This frame organises the world for journalists, helping them to process large amounts of information, to select what is news and to present it in an efficient form. Their metaphors, descriptive devices, and catch phrases are expressions of this frame” (cited in Nelkin 1987, p.9).

The frames used by journalists generally maintain a positive image of genetic research through various techniques, such as “the strategic use of titles, quotations from researchers, references to credible sources such as peer-reviewed scientific journals, the inclusion of the human interest element, and the choice of particular words, metaphors and analogies” (Petersen 2001, p.1266). The ways in which the articles I analysed used such techniques will be discussed in detail later in this paper.

Ethical issues and public dialogue
The online articles I analysed reveal a definite awareness of the importance of ethical issues and public dialogue. One article in BBC News about £1.8m awarded to Scotland’s top medical school in order to ‘push it to the forefront of global genetic research,’ emphasises the benefits of such research while legitimating this viewpoint through an attention to ethics. The article quotes Prof. David Porteous: “It not only brings together the medical and scientific experts in genetics, but places ethical, legal and social questions firmly at the heart of the research.” The article goes on to say, “meanwhile, the legal and ethical issues raised by the genetic research are to be explored by the University of Edinburgh’s School of Law.” The use of a quote by an authoritative figure reveals the journalist’s acknowledgement that the public requires accountability, yet this is the extent of the discussion in the article, we are not told what, exactly, the ‘ethical’ issues are. Likewise, an article from The Guardian about the UK Government’s plans to widen genetic screening for inherited learning disorders states, “A subgroup of the national screening committee...says such screening

would be introduced only as part of an ethically approved research project."\textsuperscript{15} Like the \textit{BBC News} article, there is an \textit{attention} to ethics, but no in-depth discussion of the specific ethical issues raised by this use of genetic technology.

Contrary to Priest’s findings that coverage in the United States tends to be homogenous in its optimism, I found a recent example from a US source that attends to the importance of ethics and public dialogue. One \textit{Yahoo! News} article states, “the nascent business of nutritional genomics raises serious concerns that should be addressed...a team of Canadian ethicists said yesterday.”\textsuperscript{16} The article also quotes Dr. Peter Singer, the director of the joint centre for bioethics at the University of Toronto saying, “What we mostly want to do here is make sure that the science and the ethics of this promising new field go hand-in-hand.” The public is then given a website address where they can express their views and concerns, which will be considered by the centre when making recommendations for the ethical operation of this field. Significantly this US online media source refers to a Canadian attempt to integrate science and ethical analysis.

**Striving for ‘balance’?**

All of the articles I analysed addressed ethical, legal and social issues, but to varying degrees. Some lean towards optimism about scientific progress and the potential of these technologies, while others frame the issues in a more cautious way. Often the ethical issues do not receive as much detailed discussion as the potential benefits. Some journalists strive for ‘balance’, but nevertheless frame the issues in ways that favour one side of the argument over the other.

---

\textbf{A Case Study: Controversy Over the Genetic Screening of Newborns}

The possibility of pre- and post-natal screening for inherited genetic disorders featured in fourteen of the articles analysed. Generally the journalists acknowledged both sides of the story, but more often than not it was obvious which ‘side’ of the debate they favoured. McKinney’s article, for instance, although given the very balanced title, “Pros and Cons Seen with Broader Newborn Screening,” begins and ends with attention to cons, and includes more paragraphs on the cons than the pros.\textsuperscript{17}

Not only is it the greater volume of pros or cons appearing in a story that suggest support for one side of the argument, but also the way journalists choose to structure their sentences. For example, in her article “Instant Screening of Newborns Urged,” besides the obvious representation of a position in the title, Tanner states: “The expanded testing can cause more false-positive findings, but overall it led to less stress for the babies’ parents, the government-funded study found.”\textsuperscript{18} Greater weight is given to the reassurance offered at the end of the

\textsuperscript{15} Meikle, J. September 3, 2003, “NHS urged to widen genetic screening” in \textit{Guardian}.  
\textsuperscript{16} Branswell, H. November 3, 2003, “Public urged to debate ethics of matching diet to genetic makeup” in \textit{Yahoo! News}.  
\textsuperscript{17} McKinney, M. November 18, 2003, “Pros and Cons Seen with Broader Newborn Screening” in \textit{Yahoo! News}.  
\textsuperscript{18} Tanner, L. November 18, 2003, “Instant Screening of Newborns Urged’ in \textit{Yahoo! News}.  

10
sentence and only three of the fourteen paragraphs in the article reviewed critical positions on genetic screening for newborns. McKinnel also gives weight to advocacy of pre and post natal screening by citing evidence about the way “The March of Dimes” supports the expanded screening method, whereas the cons merely stand alone with no authoritative voice to support them. It appears as though the cons were only included to create the appearance of balance, and to be ultimately outweighed by positive responses to genetic screening.

There are also inconsistencies in the ‘evidence’ journalists’ use. McKinnel’s reference to the March of Dimes, for instance, is used by Edelson in his article, “Debate Surrounds Screening Newborns for Genetic Disorders,” where he claims the organisation, “takes a cautious approach.” This is intriguing as two journalists, who obviously have divergent views on the merits of such testing, use the same source quite differently. A focus on articles on genetic screening of newborns suggests that, while appearing to pursue journalistic balance and objectivity, some journalists include contrary viewpoints to sustain the appearance of balance, rather than an even handed discussion of the issues.

Journalists aim to operate within a “norm of objectivity” (Zehr 1999, p.10). Dunwoody (1999, p.71) states:

The big problem for journalism is that it has neither the time nor the expertise to determine if a source is telling the truth. When sources offer conflicting truth claims, reporters pull out of their toolboxes two strategies to counteract their inability to establish validity. One strategy is objectivity… The other strategy is balance.

Nelkin (1987, p.91) believes that journalists no longer see that real objectivity is possible, but since they are expected to approach that ideal they attempt to balance diverse points of view, “by presenting all sides fairly, and by maintaining a clear distinction between news reporting and editorial opinion.” Conrad (1999, p.289) also points out that, “given the limits of news stories, reporters believe there is normally room for only two sides of a story, and thus they don’t attempt to refract the full range of viewpoints or the nuanced contentions that may exist around a particular finding.”

**News stories, public narratives and cultural practices**

The culturally specific nature of coverage is also important, and came through quite strongly in the articles I analysed. Lewenstein (1995, p.347) claims, “media coverage is shaped by structural relationships within communities (including political relationships) as well as by the media’s need to present ‘stories’ that have ‘conflict’ embedded in them.” There is a reliance on imagery and metaphors circulating in the broader culture, hence stories on human genetics reflect social biases and assumptions (Petersen 2001, p.1257). Doyle (1994, p.53) also points out that science stories “are bound up with other historical, political, and theological narratives that are deeply ingrained in our cultural practices.”

---

From the articles analysed, it seems that the cultural practices constraining reporting on human genetics in the last three years rest on the assumption that science and progress are in people’s best interest. There is no questioning of whether these advances are necessary, or indeed wanted, rather it is assumed that people want to rid the world of disease and live longer. Along with this is a prevalent individualism, the assumption that individuals are responsible for their own health and the potential risks associated with new technologies. Revill, for instance, in her article about the proposed UK Biobank, quotes Dr. John Newton, the chief executive of Biobank: “The new genetics provides a stunning opportunity to move ahead in our understanding of variability in human health.”

Although there is an attention to the risks involved, the idea that this project is an opportunity is never questioned, reinforcing how such dominant cultural beliefs are echoed and reinforced in reporting on new science. Revill ends the article by asking, “Will Britain leap towards its new role in the post-genome era, or will the concerns over confidentiality lead to another scientific failure? It will probably boil down to the public’s confidence in scientists – and at the present time that remains very much under question.”

Likewise, Radford’s article, “DNA pioneer urges gene free-for-all,” uses this quote from Prof. James Watson, the man who deciphered the double helix of DNA, which reinforces and naturalises the dominant belief in progress: “Enhancement means making better…I’d like to have been born brighter. Our whole civilisation has been giving people the right to try and improve things. Occasionally you get very conservative governments who want to stop all improvement. I think it is human nature, the drive to make things better.” Such quotes legitimate the dominant discourse that praises scientific progress for ‘the good of humanity’ rather than questioning who benefits from such advances.

Reporting risk

Kitzinger and Reilly (1997, p.320) write about ‘risk reporting’ and the media’s tendency to highlight some risks while ignoring others. This relates to Ulrich Beck’s notion of ‘risk society’—that we are a society obsessed with risk (Beck, 1992). Media reporting sometimes eschews risk in favour of offering assurance. There seems to be a current cultural preoccupation with risk, and most of the articles I analysed used the word risk in a variety of contexts, either framing the issues in terms of what is being done to minimise risks, or optimism about the potential to reduce the risk of inheriting a genetic disease, or caution about the

---

22 For example: “the population itself is not at risk...The issue will be covered in Amendments to the Human Assisted Reproductive Technology Bill, which is expected to be passed next year.” Walsh, R. (15 November 2003), “Ethics of sex choice probed” in The New Zealand Herald Online.
23 For example: “For the first time in history, we have the scientific knowledge to unravel the genetic risk factors responsible for common killers.” BBC News (8 August 2003), “Genetic research funding boost”.

12
risks of a science as powerful and unknown as human genetics. These risk issues are discussed in the articles with relation to privacy of genetic information, potential discrimination on the basis of genetic factors, and the consequences of knowing an undesirable and irreversible “fate”. Risks for industry are also highlighted in some articles, for instance, Conaway states, “many insurance companies, especially in the private sector, say that, since they are in the business of managing risk, both the insurer and the insured ought to have access to the same risk information.”

Quoting the ‘experts’

In terms of people and journals quoted in the articles, the experts were almost always doctors or professionals with long titles and extensive explanations of their qualifications and interests. The Nobel Prize winners are also a favourite source and such qualifications give the quote a strong legitimacy. Sir Paul Nurse was a Nobel Prize winner often quoted. Another favourite was Dr. Peter Singer, the director of the Joint Centre for Bioethics at the University of Toronto. He is quoted in two articles on the matching of diets with genetic makeup. In Sekhri’s article, he is quoted, “In the future, we may choose a breakfast cereal based on our genes.” Whereas Branswell, in the same online site, writing one day prior to Sekhri, quotes, “What we mostly want to do here is make sure that the science and the ethics of this promising new field unfolds hand-in-hand.” Expert quotes can be used to legitimate the point of view a journalist wants to illustrate.

The use of quotes from ‘expert’ sources is a two-way game. Journalists’ reliance on institutional information “colours” the news according to the interests of those sources, creating “the opportunity for institutional interests to frame the issue in ways that played upon ambient cultural predilections” (Priest 2001b, p.110). Not only do scientists and genome researchers package information for journalists in order to promote their work, “political leaders…seek to establish their competence by demonstrating responsiveness to emerging issues” (Priest 2001b, p.107). One article in 2000 was dedicated to showing then president Bill Clinton’s responsiveness to the issue of the potential misuse of genetic tests. Likewise, in Britain, Tony Blair revealed his responsiveness to the social

---

25 Nobel laureate Sir Paul Nurse spoke last week of the need for public debate on the issues surrounding genetic testing…the leading UK scientist spoke of possible future uses of new genetic technology, and warned of potential genetic discrimination by insurers and employers.” BioNews (10 March 2003), “Call for debate on genetic tests.”
28 Petersen 2001 p.1257; Dunwoody 1999, p.75; Nelkin 1987, p.174
29 In one of the most detailed speeches on medical research issues given by a US president, Mr. Clinton barred American federal government agencies from discriminating against employees on the basis of genetic tests...included in his recent state of the union address that ‘we must see that science serves humanity, not the other way around’.” Kettle, M. (9 February 2000), “Clinton puts ban on misuse of gene tests” in The Guardian.
implications of human genetics in an article on how the NHS will safeguard against the formation of a ‘genetic underclass’.

Editors are also more likely to accept sources that are visible in culture, such as officials (Stocking 1999, p.28). Conrad (1999, p.286) found the mean number of experts quoted was 2.8 per story. He states that “sources require journalists to get their views or ideas into the news, while journalists require sources for direction, clarification, context, perspective, and commentary.” Scientific journals are also referred to as being “the periodical waters where science journalists regularly troll for news stories” (Conrad 1999, p.286). Evans (1995, p.168) argues that journalistic ethos requires a combination of widely recognized journals and a “top guy in the field” for an article to be credible. Petersen (2001, p.1257) points out that journalists find science intimidating so editors insist on “sources that have obvious credibility.” Journals are often referred to in the articles analysed. *New Scientist* is referred to for information on cystic fibrosis tests. Some statistics from the journal *Science* are included to illustrate the fears of genetic discrimination in the workplace, and a study in the journal *Nature* is referred to in an article on genetic testing to name a few. One article, however, was critical of the ‘truth’ quality of information from journals because of peer review, stating, “Peer review is the safety net that guards science – research submitted to a journal is checked by peers to guarantee it is credible before publication.”

Sometimes the quotes from experts display a critical stance on the social and ethical implications of human genetics giving more weight to that side of the argument. It could be argued that this is only because, “one-sided messages about biotech’s fruitful promise – however accurate – are unlikely these days to be persuasive” (Priest 2001, p.95). As Zehr (1999, p.9) points out, “these uncertainty claims often appear objective and authoritative in public science because it appears that scientists are frankly and openly admitting incomplete knowledge.” Several of the quotes analysed could give this impression,
particularly one in Ellingsen’s article. Dr. Peacock, a ‘genetic pioneer,’ is said to “believe in the promise of gene technology…but knows that tinkering with the blueprint for life is a decision that should not be left to the scientists alone.”

Representing critical voices
The watchdogs, pressure groups and critical voices were limited almost exclusively to Dr. Helen Wallace from Genewatch UK whose qualifications and experience receive little attention, but whose comments are generally used to support claims for caution and regulation regarding human genetics. In Barnett’s article, “Gene test to help you beat death sparks row on ethics”, Dr. Wallace’s quotes are used to argue for the regulation of DIY genetic test kits. A handful of other watchdog groups are also mentioned throughout the articles, but only sporadically. Priest (2001, p.6) points out that, “other voices...may be reported to create the appearance of a “balanced” story, yet they are subtly positioned as representing fringe (if not lunatic) perspectives. They are included only to be delegitimized.” It could be argued, however, that the use of ‘critical’ voices in reporting on human genetics, like the use of ‘expert’ voices, serves the same purpose of legitimating a particular argument rather than achieving journalistic ‘balance’ per se.

Ethics and objectivity
The reason ethics has received such little press has to do with the difficulty of covering it “objectively” as required by journalistic standards (Priest 2001b, p.106; Kitzinger 1997, p.324). Priest (2001a, p.65) states:

In our culture, ethical reasoning (especially outside of religious contexts) is not seen as having the force of scientific reasoning; ethical conclusions are classified as judgment or opinion, rather than as factual or explanatory, and it is typically access to facts—specialized knowledge—that justifies claims to expertise in our society. So it is not surprising that media frames sometimes tended to treat ethicists’ comments as coequal with those of scientists (that is, as expert opinion) and sometimes did not.

Craig (2000, p.161) used ‘ethical theory’ to examine ethics in media coverage of genetic testing and found that many of the frames used, while not categorized as ethics per se, related to costs and benefits, which are the core concerns of

---

utilitarian ethics. So, although journalists might have difficulty tackling ethical issues head-on, they often refer to them indirectly, particularly through the frame of ‘cost’. This is exemplified in one ABC Online article, where a quote by Professor Ursula Kees explains that a new test for genes related to cancer is “simple and inexpensive,” followed by a paragraph stating the information from such a test is “crucial when deciding what treatments to pursue.”

Similarly, Pollack states that the cost of a proposed genetic test for breast cancer is, “expected to be $3,000 or more. Just how useful the test would be was a matter of debate here.”

Another reason ethics is often neglected is explained by Hubbard & Wald (1993, p. 4), who believe ethics does not measure up to the need for novelty in journalism. Instead, most current reporting on genetics contains “a mix of interesting facts, unsupported conjectures, and wild exaggerations of the importance of genes in our lives” (ibid.) No matter how exaggerated genetic research may be, “the press reports it with a straight face,” because genes are newsworthy (Hubbard & Wald 1993, p. 6).

This need for “newsworthiness” is enhanced if the issue is linked to a larger issue that has already been established as being of major public concern, such as the crisis in health care funding (Petersen 2001, p.1263). In one of the articles by Meek, for instance, the impact of genetic testing on private insurance is linked to criticisms of the UK government’s failure to properly address the issue of tobacco-related deaths. By drawing on a well-established issue, Meek can make a more legitimate critique of the UK government’s ability to respond to pressing health issues.

Novelty and news
Reporting on human genetics is a constant search for novelty, as science writers, “look for unique, esoteric, and cutting-edge research projects to enhance the novelty of their articles” (Zehr 1999, p.10). Priest (1999, p.97), points out that, “the genetic science most likely to be defined as news is what Latour called emergent science, science whose truth has not yet been settled by consensus, either scientific or public.” New and definitive findings and controversy especially draw media attention (Kitzinger & Reilly 1997, p.344). One such example of this is the ABC Online article, “Genome scientist admits switching samples” which reveals, “The former head of the United States company which raced to sequence the human genome, has revealed that he switched cell samples so that the final sequence was mostly his own genetic blueprint.”

---

41 “Sir Paul attacked the government for what he saw as its failure to deal with tobacco, which still causes 100-120,000 premature deaths a year.” Meek, J. (5 August 2002), “Cancer gene tests ‘will destroy private health’ in The Guardian.
42 ABC Online (11 May 2002), “Genome scientist admits switching samples.”
draw readers’ attention and are likely to be published, even if they have little relevance to the important issues of human genetics.

Interestingly, scientists are very aware of this tendency, exemplified by the fact that more than 75 percent of scientists believe that the mass media are more interested in sensationalism than the truth, claiming that media coverage concentrates too much on trendy discoveries rather than basic research and development (Nisbet & Lewenstein 2001, p.3).

3. ‘CODES’, GENE ‘FISHING’ AND HEALTH ‘HOROSCOPES’ – MEDIA METAPHORS

Nelkin (1987, p.10) argues that, “explaining and popularizing unfamiliar, complex, and frequently technical material can often be done most effectively through analogy and imagery.” Hence, metaphors and a whole host of other rhetorical devices are used by journalists in reporting on human genetics in online news media, especially in articles relating to gene therapy—the most elusive topic.

Common metaphors include “the genetic code...that tends to stutter with a four-letter repeat,”43 and unlocking, unravelling and unfolding secrets, mysteries and benefits.44 Such common metaphors and imagery of secrets, blueprints and code have become so accepted they often become read as literal. As Petersen (2001, p.1262) points out, as a result of such widespread use, “the metaphorical and literal have become blurred, so that it is difficult to recognise the ways in which the metaphors invite certain interpretations and not others.”

Metaphors in the articles analysed included “the ‘nuggets’ in the goldmine of information”,45 “trying to corral a horse after it has escaped the barn”,46 planting a shade tree for the next generation”,47 “a treasury of personal and medical information”,48 “hunting”,49 ‘fishing’ in the genome pool and “allowing commercial companies to go ‘gene fishing”,50 and “blueprints for life” or “book of life” (Condit 1999).51

44 For example: “Now researchers in Queensland are much closer to unlocking the mystery” in ABC Online (18 November 2003), “Scientists seek to take guesswork out of predicting twins.”; “DNA from 146 Icelandic families has unlocked remarkable benefits” in ABC Online (11 June 2002), “Icelandic DNA provides vital clues to human genetic code.”
45 ABC Online (11 June 2002), “Icelandic DNA provides vital clues to human genetic code.”
48 Ibid.
51 “Awareness was fast growing of the impact of the human genome project, the unravelling of the
Other rhetorical devices included the use of alliteration in “buzzwords” and catchy phrases, such as “museum of middle-aged mankind”, “tailormade treatments”, “genetic jeopardy”, and “health horoscopes”. “Postcode prescribing” is used to describe a phenomenon in Britain where expensive drugs are rationed according to where people live. Alliteration makes such phrases more accessible to the general public who might find it difficult to remember complex scientific terminology. It also makes the articles more pleasant and ‘light’ to read.

Petersen (2001, p.1257) argues that “the choice of metaphors is always strategic and scientists as well as journalists have always been keenly aware of the impact of metaphors on the public’s understanding of science.” Friend (2003) uses this imagery in his critique of geneticists’ ignorance of ethical issues regarding “the subject of designing babies” He argues that: “The goal is to stimulate debate about the difficult bioethical issues that scientists, like errant paperboys, seem to be tossing at the public’s doorstep.” Friend uses other powerful imagery in his discussion of genetics, stating, “Embryos are never created equal. Think of your own genetic makeup as the hand of cards you were dealt at conception. With each conception in the family comes a new shuffling of the deck and a new hand.”

Likewise, an article in BioNews critiquing the lack of regulation on genetic tests includes this quote: “there is more government oversight of the colouring used in M&Ms than there is for genetic tests.” It is also easier to use catchy terms such as “gay gene” rather than saying, more accurately, “a marker for a gene associated with homosexuality” (Conrad 1997, p.147). Such shortcuts, while they may simplify difficult scientific concepts so that more people can understand them, can oversimplify complex issues, and overgeneticize the issues they describe (Conrad 1997, p.149-150). Also, “the use of anthropomorphic terms such as ‘rogue genes’ and ‘killer diseases,’ which attribute malevolent intent to genes and diseases, reinforce the heroic image of genetic researchers, and bolsters their status as guardians of the public’s health” (Petersen 2001, p.1264).

---

3. This term is used several times in the articles along with “personalised prescriptions.”
8. The 'card' metaphor is also used in Barnett, A. (19 January 2003), “Gene test to help you beat death sparks row on ethics” in The Observer.
4. GENETIC TESTING – ISSUES OF CHOICE, PRIVACY AND THE RIGHT TO KNOW

The majority of articles analysed for this project focused on genetic testing. These were framed in a variety of ways, such as the tension between an individual’s ‘right to know’ and their family’s right ‘not to know’. There was also discussion of the possibility of discrimination and invasion of privacy if genetic information was used in the context of education, employment, insurance and crime. Often mentioned was the possibility of surveillance of the population through knowledge about their genetic inheritance. The anxieties caused by inconclusive results, false-positives and false-negatives, and the consequences of increased pre-natal testing (such as tests for cystic fibrosis and the resulting increase in abortions) were also common frames.

It is the threat to individuality, to a person’s ‘right to know’ their genetic information, which especially in the United States, ignites discussion in the media about genetic testing. Priest (2001, p.4) states, “biotech becomes news when it directly threatens what we hold sacred: the individual human being as an independent biological and economic unit.” We live in an intensely individualistic culture, and although genes are understood as behaving in a deterministic way, “individual human beings are still seen to have the ability to make choices, and the right to make those choices is very highly regarded in American social and political culture” (Priest 2001b, p.12, 80). This is evident in Ratcliff’s article about the regulation of DIY genetic testing kits, where she states, “CA [Consumers’ Association] recognises the civil liberties argument that an individual should have the right to know personal genetic information about themselves without restriction from the state... Consumers must be properly informed of the risks and implications of taking a test to ensure that they are able to make informed decisions about whether to go through with it.”

One article actually tackled the issue of individualism directly, by including a quote from Dr. Helen Wallace of GeneWatch UK, relating to genetic testing in the workplace, where she argues, “An acceptance of that sort of testing removes the impetus from the employer to improve work conditions, and opens up a whole new front for discrimination.” The ability to make informed decisions places more responsibility on the individual and less on society, a view rarely discussed in reporting on human genetics. Because this appeared in one of the alternative media sites, it could be an indication that such sites have less editorial constraints and can delve into some of these issues that the mainstream media either avoids or lacks the resources necessary to deal with. In The Guardian, a paper known for its ‘leftist’ leanings, individualism is also criticised.

---

61 Whitfield, P. (20 September 2003), “A testing time for your finances: Genetic fingerprinting may soon decide your career, insurance and pension prospects” in Independent.co.uk.
Petersen (2002, p.81) expands on this, and concluded from his research on genetics in the media that:

Few articles acknowledge the importance of non-genetic factors, particularly social environment, to the formation of identity, and how science itself, through its power to alter the body might be implicated in the forging of new identities. Rather, media attention focused almost exclusively on the dangers of the technology for ‘individuality,’ ‘the integrity of families’ and society more generally, and concerns about its regulation.

Nelkin and Lindee (cited in Condit 1999, p.170) have argued that, “the images and narratives of the gene in popular culture reflect and convey a message we will call genetic essentialism ...[which] reduces the self to a molecular entity, equating human beings, in all their social, historical, and moral complexity, with their genes.” The degree to which articles reveal a genetic determinism varies, however, as “some articles describe genetics as exerting “influence” while others describe genes as exercising “control.” The former is clearly less deterministic than the latter” (Condit 1999, p.176). Condit (1999, p. 150, 171) identified the “blueprint” metaphor as one of the significant carriers of an essentialist, discriminatory and deterministic mindset. Interestingly, in the article, “Blueprint for life,” Friend almost deconstructs the blueprint metaphor in his discussion of new reproductive technologies, by pointing out that, “environment plays a strong role in shaping a person’s life,” only to re-inscribe it by stating, “But genes set the stage.”63 Although there is increased awareness of the social causes of disease, genes are still given the highest priority.

One article, however, looks at genetic essentialism critically, with a quote by Dr. Weisbrot, president of the Australia Law Reform Commission (ALRC), stating, “We need to have intelligent application of genetic technology and warn people against the dangers of genetic essentialism: the idea that a person is their genes.”64 The author also included a relatively in-depth discussion of ethics addressing the issue of a person’s “right to know” their genetic information.

5. GENETIC SCREENING – A FOCUS ON POPULATIONS

The articles on genetic screening were generally framed in terms of fears about discrimination based on genetic makeup and the possible evolution of a ‘genetic underclass’ is frequently mentioned. Risk, choice, surveillance and costs versus benefits were all common frames. Genetic screening is different from genetic testing because it involves testing populations rather than individuals (Hubbard & Wald 1993, p.33). Because of this, the articles on genetic screening tend to focus on social impacts more than those about genetic testing. Evans (1995, p.173) indicates that social science is usually excluded from science reporting “unless it

64 Salleh, A. (15 November 2001), “Genetic testing inquiry takes off” in ABC Science Online.
can be linked to such symbolic complexes as Government, Family, or Education." I found this to be the case in the articles I analysed, since each issue regarding genetic screening was, by its very nature, closely tied to issues of government regulation (especially for pre- and post-natal screening for inherited disorders), and family, in terms of conflicts between an individual’s ‘right to know’ and their family’s right ‘not to know.’

Another recurring theme in the articles I reviewed on genetic screening was that of “international competition.” Politicians, especially, are often quoted urging the public that it is essential to stay on top of the game. For instance, John Reid (the new health secretary in Britain) is quoted in *The Guardian*: “Our vision is for the NHS to lead the world in taking maximum advantage of the safe, effective and ethical application of the new genetic knowledge and technologies for all patients as soon as they become available.”

Nelkin (1987, p.7) claims that a focus on competition and a “race” for breakthroughs has always been a common feature of science writing. International competition and national pride came out in a sort of ‘gene race’ rhetoric with quotes from politicians urging the public that advances in human genetics were necessary to ‘stay in front’ and ‘lead the world’.

The biggest uproar and criticism in media coverage of genetic screening seems to arise around issues of screening for “behavioural characteristics.” Nelkin (1987, p.27) notes that it is theories of behaviour that bear on controversial social stereotypes which draw the attention of the media. Radford’s article, “Warning on linking genes and human behaviour,” states that behavioural genetics “raises the danger that genes might be used as glib explanations for complicated human responses.” Wade, in a *New York Times* article, states, “Altering the genes that shape human behaviour is not to be undertaken lightly.” Kitzinger & Reilly (1997, p.326-7) indicate, “It could be that the idea of a gene for behaviour challenges key aspects of Western thinking such as the notion of ‘free will’ and is seen to threaten fundamental rights and duties.”

6. GENE THERAPY – DOING SOMETHING ABOUT IT

“We have always been prisoners of the body, victims of morbidity and mortality, and we desire the power that biology might give us to relieve these burdens, [hence] medical and biological stories have long accounted for a large proportion of the press reporting of science” (Turney 1998, p.37).

---

65 Press Association (24 June 2003), “Reid pledges £50m to put NHS at forefront of gene therapy” in *The Guardian*.
The articles on gene therapy are largely framed in terms of the implications of “playing god” and overstepping boundaries, so-called ‘Frankenstein science,’ changing the foundations of parent-child relationships and the quest for an elusive human ‘perfection’. These fears and anxieties are balanced, however, by geneticists’ promises of enhanced medical benefits now and for future generations by ‘weeding’ out inherited diseases and tailoring drugs to suit individual genotypes through the ‘magic’ of pharmacogenetics.

There were fewer articles on gene therapy (only twelve of the eighty-six) than human genetics in general, genetic testing and genetic screening, and this could be a reflection of not only a lack of demonstrable progress, but the difficulty of reporting on such an uncertain and controversial area. In the articles on gene therapy, there was a definite underlying fear of a eugenics revival.\(^{68}\) Many were “tempered by warnings...as yesterday’s technological frontiers come back to haunt the present” (Nelkin 1987, p.53).\(^{69}\) The focus is generally on social inequality that could arise from a ‘designer baby’ revolution.

One of the main discourses identified by Kitzinger (1997, p.322-323), which is often used as a frame in articles on gene therapy, is the ‘great promise’ discourse. Such discourse focuses on the supposed benefits and advantages of new therapies. An article from *The Guardian*, in June 2003, written after the release of the UK white paper states, “The three-year plan...includes safeguards to prevent the emergence of a genetic ‘underclass’.”\(^{70}\) It then states, “Urgent test times will also be cut to just three days.” It goes back and forth between an optimistic forecast and the need for caution when considering applications of human genetics.

Hubbard & Wald (1993, p.112) found that even though there was no certainty about when and if genetic treatments would be successful, the *Times* was already hailing them as the wave of the future. This focus on potential benefits is further reinforced by the fact that words such as risk, threat, peril and danger rarely appeared in the headlines (Kitzinger & Reilly 1997, p.324). ‘Risk’ only appeared twice and ‘danger’ once in the headlines of the eighty-six articles analysed.

Another pattern of inconsistency in coverage is that gene discoveries remain prominent in the headlines, whereas disconfirmations are seldom reported (Conrad 1997, p.145). This corresponds to my findings where nearly twenty of the articles had ‘confirmation’ headlines, whereas less than ten had


\(^{69}\) Paul (1994, p.142) also notes the prevalence of anxieties in contemporary discourse on human genetics, especially gene therapy, at the prospect of a ‘eugenics revival’. Whitford, B. and agencies (24 June 2003), “NHS to safeguard against ‘genetic underclass’” in *The Guardian*.\(^{70}\)
disconfirmation headlines. The remainder of the headlines did not focus on this issue.

In independent media such as MotherJones.com, however, there is much more attention to historical context. Rifkin's article, for example, places the issue of gene therapy within the context of a ‘new’ eugenics, giving detailed descriptions of progress to date in somatic and gene therapy, outlining the evolution of the human genome project, and referring to a 1992 poll on the use of gene therapy to improve babies' physical characteristics.\(^7\)

**CONCLUSION**

To conclude, I would like to draw on the observations of Petersen (2001, p.1264), who points out:

> Although concerns about the ethical implications of genetic research in general, and cloning research in particular, are frequently expressed in articles…the validity of particular research projects is rarely questioned… There is little debate about the value of particular lines of genetic research, about whether research can deliver what is promised, and whether funds used for research would be better spent in other ways. Furthermore, few articles make reference to, or comment…on, the content of earlier news reports, or refute earlier reported findings.

After analysing these articles in relation to the literature on media coverage of biotechnology, a range of conclusions can be reached. Firstly, it appears that journalists are still bound by certain professional constraints: lack of time, editorial opinion, lack of specialist knowledge on a new and controversial science, the need for ‘newsworthiness’ and the desire for reporting that is balanced and objective. Within these constraints, however, it seems that coverage on human genetics is remarkably varied. There is a clear shift towards attention to ethical issues and the need for ‘public dialogue’.

The frames used in these stories generally centred on the ‘balancing’ of optimism for scientific progress (and along with that the national identity and pride that comes from being at the ‘forefront’ of a new and potentially lucrative science), against the ethical issues and concerns raised by regulators, watchdogs, pressure groups and other critical voices in society. Many journalists emphasised the potential benefits of human genetics for preventative medicine and personalised treatments, while others highlighted the risks and social, ethical and political concerns associated with such a mystifying and controversial science.

It appears that human genetics is reported more frequently and in more ‘depth’ in the United States and the United Kingdom, where policy and regulation is more advanced and topical, than in New Zealand. The articles in this analysis reveal that reporting on human genetics has shifted from mostly optimistic and

sensational coverage throughout the 1990s, to an attention to ethical issues, regardless of the difficulty in reporting ethics 'objectively,' between 2000 and 2003. Opinions are beginning to crystallise around the issues of human genetics, and this is reflected in online news media where journalists are taking new and varied approaches to covering the risks and uncertainties of science.
ONLINE ARTICLES ANALYSED:


BBC News (30 April 2003), “Gene test blunders abortion risk”.

BBC News (8 August 2003), “Genetic research funding boost”.


Hinsliff, G. (1 December 2002), “Clampdown on DIY gene test kits” in The Observer, available:

Hinsliff, G. (17 August 2003), “Fears over genetic profiles for all” in *The Observer*, available: [http://observer.guardian.co.uk/politics/story/0,6903,1020381,00.html](http://observer.guardian.co.uk/politics/story/0,6903,1020381,00.html) (accessed on 19 November 2003).


MacLeod, S. (26 November 2003), “Third parties increasingly access material from blood bank DNA” in *The New Zealand Herald Online*, no longer available online.


Meek, J. (18 November 2003), “Pros and Cons with Broader Newborn Screening” in *Yahoo! News*, no longer available online.


Meek, J. (31 October 2002), “Decode was meant to save lives...now it’s destroying them” in *The Guardian*, available: [http://www.guardian.co.uk/print/0,3858,4536024-103680,00.html](http://www.guardian.co.uk/print/0,3858,4536024-103680,00.html) (accessed on 16 November 2003).


Rowell, A. (19 August 2003), “Safe science is not always good science: The Royal Society must not be allowed to stifle the GM debate” in Guardian Unlimited, available: http://www.guardian.co.uk/gmdebate/Story/0,2763,1021573,00.html (accessed 19 November


Whitfield, P. (20 September 2003), “A testing time for your finances: Genetic fingerprinting may soon decide your career, insurance and pension prospects” in *Independent.co.uk*, available:


Hardcopies of all these articles are stored in the Social Science Research Centre, University of Canterbury, PB 4800, Christchurch, New Zealand.
REFERENCES


